

# ME/CFS/FM/Lyme Collaborative Research Update Open Medicine Foundation (OMF)



## Open Medicine Institute continuing ME/CFS Research Pilots with \$612,000

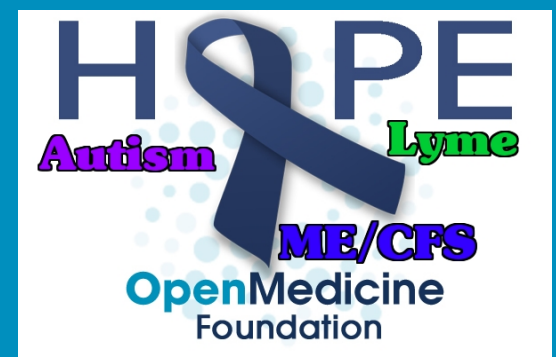
**Open Medicine Foundation & Institute** is thrilled to announce receipt of \$612,000 towards a series of investigative research projects which will take us one step further in our quest to find a cure for neuro-immune illnesses.

Compelling areas include an in-depth study of 20 ME/CFS patients:

- **Whole genome sequencing**
- **A virome survey of oral viral flora**
- **A gene expression study** to examine 30,000 human genes for changes in gene expression patterns correlated with improvement/response to treatment
- **Two proteomic/metabolomic pilot studies:**
  - One looking at over 250,000 protein features per sample. Resulting in a protein profile to compare a baseline ME/CFS patient with responders and non-responders.
  - The second analysis will examine 30,000 smaller molecule profiles representing toxins and metabolites in the same set of samples. This will further our understanding of what a patient's profile looks like on a molecular level pre and post-treatment.
- **Natural killer cells, B-cells, and T-cells** will be looked at for functional performance, activation markers when compared between ill and recovered patients
- **Other Immunology studies** will include single cell measurements, acetylation and other cellular parameters
- **Breath testing for GI flora** gas production with dietary changes to start looking at the effect of the gut microbiota on the disease, recovery and treatment
- **Measurement of mitochondrial** and related biochemical pathways that play a role in oxidative stress and energy production, adrenal and thyroid pathways that regulate metabolic function along with full panels of

**November 2013**  
Happy Thanksgiving

**Special Funding  
Announcement**



*We give thanks to our families,  
friends, supporters and donors that  
give us HOPE in our quest to find a  
cure!*

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

**Click to see:  
[The OMI-MERIT Initiative  
Top 10 ME/CFS PROJECTS:](#)**

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

pituitary, gonadal, adrenal and other hormones.

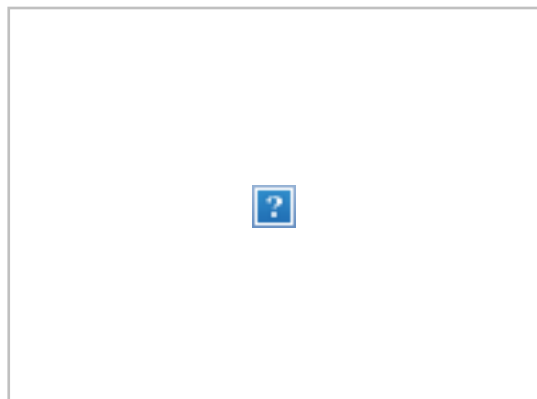
- **Brain/Cognitive Data** will be collected using unique on-line programs including reaction time, short-term memory, latency, and additional cognitive assessments. These data will be correlated with clinical and molecular endpoints
- **Quantified-Self (self measurement)** projects will rely on wearable devices logging data of activity, heart rate, sleep patterns, blood pressure, heart rate variability (a measure of stress) and others

Leading this research effort will be Andreas Kogelnik, MD, PhD of the Open Medicine Institute. OMF Executive Director, Linda Tannenbaum, announced that funding for these critical projects has come from two anonymous donors that have generously stepped forward to accelerate ME/CFS research to the next level. In addition, over \$12,000 has been received from generous on-line giving from individuals. The impact these donors are making provides immeasurable hope for the patient community.



## RESEARCH UPDATE

1. **DNA Genetics Study:** The ME/CFS DNA Genetics Study, is fully underway. This study includes whole genome sequencing and analysis, DNA methylation investigation and Human Leukocyte Antigen (HLA) sequencing in approximately 1000 individuals. Ron Davis, PhD, of the Stanford Genome Technology Center is the key collaborator on the study.



2. **Moringa oleifera Pilot:** The manufacturer of the Moringa product altered the original formula so this project has been put on hold.

## Current OMI-MERIT\* Projects

\*Click [here](#) to see complete details of OMI-MERIT Initiative

-Natural & OTC Substances

Visit our website for details:  
[www.openmedicinefoundation.org](http://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.

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### Quick Links

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- Neuro Registry & Biobank-**Pilot Funded**
- Protein Panels-**Pilot Funded**
- Other Mono & Combo Therapy-**Crowdfund planned to fund a Pilot**
- Immunologic Biomarker Exploration-**Pilot Funded**
- DNA Genetics- **Fully Funded**
- Mass Spec/ Environmental-**Pilot Funded**
- Viral Testing-**Partially Funded**
- Advanced Biomarker Study-**Pilot Funded**



Check out OMI research projects underway  
with your funding support.

**[www.openmedicineinstitute.org](http://www.openmedicineinstitute.org)**

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## Turn Your Online Shopping Into Donations for Research

An Easy & Free Way YOU can help

Every time you shop using iGive, a portion of the money you spend benefits Open Medicine Foundation. It's a free service, and you'll never pay more when you reach a store through iGive. To get started, create your free iGive account at: [www.iGive.com/OpenMedicineFoundation](http://www.iGive.com/OpenMedicineFoundation).

Once you set your account up, tell a friend to do the same by going to the tell-a-friend page. <http://www.igive.com/html/tellafriend.cfm>.

Together we can raise money for Open Medicine Foundation without spending anything we wouldn't already be spending. Holiday shopping online could not be easier and at the same time support urgent research.

**Isn't that a gift in itself? Together WE can make a difference!**



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## The Half Marathon Challenge

Linda (ED of OMF) and Don Tannenbaum, founders of the Neuro-Immune Disease Alliance (NIDA) raised over \$25,000 for OMF in a half marathon last month. The HOPE is for others to get their friends and



family to walk, run, bike, eat, cook, smile **FOR A CURE** and help raise funds for research! That is how we will get it done! Create your special event and designate OMF as the beneficiary.

**You are helping to create HOPE.**



## International Collaboration Crowdfund Project Ahead

Watch for Dec 3rd Newsletter

The Swedish Women for ME funded Linda Tannenbaum to visit RME patient support groups in Boras, Gottenburg, and Stockholm to share the HOPE of current research and to meet with researchers in Sweden. An International Crowdfund for an International Research Project specific to symptom relief for patients will be announced in the next newsletter. Truly a priority while we look for a cure.

*Beautiful Stockholm in Autumn!*



## Collaborating to keep you informed

Special Collaborative Agreements for cross promotion, sharing information, resources and ideas regarding research and translational medicine to help patients with Neuro-Endocrine-Immune Illnesses are growing and encouraged. OMF has special agreements with PANDORA Org., ProHealth, Health Rising and ME/cvs Vereniging Nederland and looks forward to creating many more collaborative agreements. We all want to help patients, give HOPE and join in the quest to find a cure.

Click on their logos below for knowledge, support and a tremendous amount of helpful information.



Check out our new website  
[www.openmedicinefoundation.org](http://www.openmedicinefoundation.org)

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 and support scientific meetings for continued global collaboration.

*The Open Medicine Foundation is investing in wellness for neuro-immune diseases. With the DNA Genetics study almost completed and the exciting pilot studies ahead, we look forward to seeing where this leads us in our quest to find a cure! Discovery continues!*

Best,  
Linda Tannenbaum  
Executive Director  
Open Medicine Foundation  
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Tax ID: 26-4712664

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# Please Donate Now to keep the research momentum going

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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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