

ME/CFS e-Newsletter

Collaborative Research Update

Open Medicine Foundation (OMF)

Global effort to find answers!

In 2013 already, over \$128,000 received for ME/CFS research; \$1.7 million pledged.

OMI-MERIT Research is underway.

Visit our website and review the research projects that are taking off with your support.

www.openmedicinefoundation.org



Rituximab Clinical Trial Effort Receives First \$100,000 towards New Potential ME/CFS Treatment!

We are thrilled to announce that the Open Medicine Foundation (OMF) has received its first donation towards a comprehensive scientific strategy to attack ME/CFS. A very generous patient from the Open Medicine Clinic has donated \$100,000 to initiate the proposed large-scale, international, multi-center Clinical Trial with rituximab for ME/CFS. His optimism is helping launch the fund raising for this clinical trial so that people around the world can realize the potential benefit from this and other potential therapies.

This donation leads the way for others to donate (\$50 or \$100 or whatever they can) to help jump start research to help find needed diagnostic tools and treatments for this debilitating, devastating, life-altering disease.

With \$50-\$100 from 100,000 patients, friends, family and foundations towards the \$7.65 million initial goal for this trial, then this study can begin immediately. With 200,000 such gifts we could start a comprehensive list of projects with direct diagnostic or treatment effects!

Donors have already pledged over \$1.7 million towards various OMI-MERIT

January 2013

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Donate Now to Accelerate Research for ME/CFS

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
- Natural & OTC Substances

Visit our website for details:
www.openmedicinefoundation.org

Actions to date resulting from First ME/CFS Roundtable sponsored by OMF

Held June 2012, New York City

On the way to crack ME/CFS

OMI-MERIT

**"Open Medicine Institute-
Myalgic Encephalomyelitis Roundtable
in Immunology & Treatment"**

In June 2012 top researchers and clinicians from all around the world gathered in New York City for a discrete brainstorm roundtable. The goal was to set a scientific agenda that would maximize benefits for diagnosis and treatment of ME/CFS. The participants openly discussed the current state of ME/CFS research, new ideas and collaborations that will fast track research to find effective diagnostic tools and treatments. The 3-day brainstorm meeting had an immediate result – the OMI-MERIT Initiative: a top 10 list of priority projects.

[Click here to see the top 10 list](#)

Scientists and clinicians from USA, Italy, Britain, Germany, Sweden and Norway were present at the meeting in New York City. Since June, researchers and clinicians from Australia, Japan, Canada and New Zealand have also joined in support of the OMI-MERIT project.

The meeting was Chaired by Dr. Andreas Kogelnik with the OMI team and all the participants worked together through a dynamic discussion to make the meeting a success, leading to the first comprehensive clinical and scientific strategic plan for fighting ME/CFS. To ensure that this plan is successful, OMI is coordinating an international network of researchers and clinicians to fast track answers for ME/CFS. OMI is also leading parallel charges across other neuroimmune illnesses like Lyme, MS, & Autism. The OMI emphasizes 1) worldwide collaboration; 2) involvement of thought leaders in research – especially in genomics and immunology – from academia, clinical practice, and industry; 3) advanced use of newly developed information technology (for patients) and coordinated data sharing systems (among researchers, providers, and health care institutions) developed by OMI specialists. Tools such as OpenMedNet, which is already in use for several ongoing studies, will be generally available for public use by patients through mobile apps and the Web by March of 2013.

Here's what the experts are saying:

"This field is too complex for any of us to stand alone, if we want to find answers we need to work closely together with ME/CFS patients and the community at large and apply the best science, technology and people that are available. That is the key to the OMI-MERIT projects."

- Dr. Andy Kogelnik

"The launching of the OMI-MERIT initiative brings great hope and challenges to the worldwide ME/CFS community of patients, clinicians and researchers. This truly translational program will certainly expedite efforts at defining sub groups of patients and stimulate effective diagnostic and therapeutic protocols."

- Dr. Daniel Peterson

"I have always felt that international research collaborations is an essential part of the process of understanding of the underlying disease process in ME/CFS. Bringing together such an outstanding international mix of established ME/CFS

researchers, along with others who could bring new thinking to the table and challenge existing ideas, was no mean feat. We managed to reach a consensus on a list of key research priorities and clinical trials to assess specific drug treatments that have now been announced. Let us now focus on raising funds to put these proposals into action!"

-Dr. Charles Shepherd.

CLICK HERE
TO DONATE

Open Medicine Foundation

Patient advocates advancing medicine

ME/CFS goals:

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

Dear ME/CFS Community,

We're pleased you've expressed an interest in receiving our newsletter and are delighted to be sending you this inaugural issue. As you know, I believe wholeheartedly in the focus of the Open Medicine Institute (OMI) and am glad to be supporting its significant ME/CFS research as Executive Director of the Open Medicine Foundation. OMI is moving ahead with planning, trial design and technology advances designed to conquer this devastating disease - and do so as quickly as possible. We are looking forward to keeping in touch with you and updating you on our progress (and accepting gratefully, any donations).

Here's to a healthful New Year that leads to answers for the ME/CFS community!

Best,

Linda Tannenbaum

Executive Director

Open Medicine Foundation

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Donate Now
\$13.5 million needed

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

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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 on the ME/CFS horizon.

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