# Vitamin B12 & Folate Placebo-Controlled Study to begin



# Vitamin B12 & Folate ME/CFS Study Funded



We are very excited to announce that the MTHFR, B12 & Folate placebo-controlled clinical trial is moving head thanks to the generousity of our many donors. Thank you all for making this possible!

This study will show if ME/CFS patients benefit significantly when taking B12 & Folate, shown anecdotally to reduce fatigue and cognitive issues in many ME/CFS patients that have a MTHFR gene mutation.

This is the first-ever placebo-controlled clinical trial to be done on B12 and Folate for ME/CFS patients and we hope to be able to do the same for Autism, Lyme and Fibromyalgia patients in the future.

Dr. Andreas Kogelnik and Dr. David Kaufman of the Open Medicine Institute will lead the study.



#### **Quick Links**

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# **Exciting Research Continues at Open Medicine Institute (OMI)**



- Multi-Site Clinical Assessment of ME/CFS now in year 3
  - Open Medicine Institute is the coordinator for 5 of the 7 sites of the CDC's clinical assessment project of ME/CFS.
- OpenMedNet, OMI's Enhanced Data
   Platform to collect BIG DATA from thousands of patients has completed its enhancement project and is on track for release any day now.
- 3. **DNA ME/CFS Genetics study** This study includes whole genome sequencing and analysis, DNA methylation investigation and HLA testing on approximately 1000 patients; it will be completed within the next few months.
- 4. In-depth study of 20 ME/CFS patients has begun:
  - Whole genome sequencing
  - A virome survey of oral viral flora
  - A gene expression study
  - Proteomic/metabolomic pilot studies
  - Study of Natural killer cells, B-cells, and Tcells
  - Single cell measurements, acetylation and other cellular parameters
  - Breath testing for GI flora
  - Mitochondrial and related pathways that play a role in oxidative stress and energy production
  - Brain/Cognitive Data unique on-line measurement program
  - Quantified-Self (self measurement) projects using wearable devices

National Press Club, Washington D.C.



On January 24th 2014 White House Chronical host Llewellyn King, Open Medicine Institute's director, Andreas Kogelnik, MD, PhD, and Blue Ribbon Foundation's founder, Ryan Prior spoke at the National Press Club in Washington D.C. about Myalgic Encephalomyelitis/Chronic fatigue syndrome (ME/CFS).

Mr. King and Dr. Kogelnik also appeared in a segment about ME/CFS on Sirius XM Radio POTUS 124 (Politics of the United States) in Washington, D.C. on January 24th, 2014.

# PANDORA org.net



-Lots of great news from our partners at PANDORA Org: Congratulations on winning \$5000 in gas cards from the CITGO Fueling Good contest. -Lori Chapo-Kroger, will give a

1-hour course on ME/CFS and fibromyalgia at the Mercy Health St. Mary's Hospital, Michigan.

- -PANDORA Org will present at a mental health fair on March 11 at the University of Alabama Huntsville School of Medicine.
- -PANDORA Org president Lori Chapo-Kroger and contracted communications specialist Tina Tidmore will be giving an oral presentation on Expanding Access to Knowledgeable Care of NEIDs An Alabama Case Study during the IACFS Conference being held March 20-23 in San Francisco.

### **Collaborating with**

#### **Global Information:**

Take a look at the ME Global Chronicle which can be downloaded from http://let-me.be and view over 34 YouTube interviews by *Team Science to Patients* at www.me-cvsvereniging.nl.

## **OpenMedicine Foundation**

Tax ID: 26-4712664
Patient advocates advancing medicine.

#### **Our Mission:**

- To communicate, engage and inform the ME/CFS 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 grateful to our generous donors and the patient community for helping to move research forward. I am particularly excited about the MTHFR/B12/Folate study because it may prove to help many patients while we are all in search of a cure.

Best,
Linda Tannenbaum
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### **Stay Informed**

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#### **Please Donate Now**

Research studies start as they are funded.



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

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