

To: Secretary of Health and Human Services Sylvia Burwell
National Institutes of Health Director Francis Collins

Building an ME/CFS Research Initiative at NIH that Works: a Community Approach

The ME/CFS community is united in its goal of NIH funding commensurate with the burden and costs of our disease, and on par with research funding for diseases like Multiple Sclerosis. The recent reports by the Institute of Medicine and NIH Pathways to Prevention Program validate the “urgent need” to research ME/CFS. They are a call to action.

We understand NIH is evaluating next steps in addressing the gaps in ME/CFS science. We believe the following elements are essential and immediate next steps for NIH to build an ME/CFS initiative that catalyzes recent advances and works for the long term to return more than one million Americans to health. They are consistent with the blueprint outlined in the Pathways to Prevention report and recommendations from the Secretary’s Chronic Fatigue Syndrome Advisory Committee.

Essential, Immediate Steps for NIH to Build an ME/CFS Research Initiative that Works:

1. Assign ME/CFS to a strong, well-funded Institute like NINDS, to enable strategic planning and structural accountability.
2. Fund a mix of intramural and extramural research (as NIH does for Multiple Sclerosis and scores of other diseases), including a focus on identifying diagnostic biomarkers.
3. Form and fund translational networks and centers of excellence, utilizing clinical experts in the field to build on recent collaborations and findings.
4. Design and fund clinical trials for drug development, so ME/CFS patients can have our AZT; government can catalyze private investment by the pharmaceutical industry; and scientists can study the responders.
5. Present a plan to ramp up funding to a per-patient level on par with Multiple Sclerosis over the next two to three years.

MS is a strong example that embodies the promise of scientific research at NIH. 30 years ago, MS – with similar symptoms – was stigmatized as ME/CFS is now. Today MS is treatable with one of 13 FDA-approved medications because of NIH-led science. This gives us great confidence in the power of the NIH.

With a strong investment in NIH research, ME/CFS patients are within reach of diagnostic tests and FDA-approved treatments. In 2012, President Obama asked NIH to elevate ME/CFS research, and the IOM and P2P reports provide the roadmap and scientific imperative. Together, let’s build an ME/CFS research initiative that works for patients' health and scientific advancement.

Courtney and Robert Miller (25-year patient)
obtained Pres. Obama's promise to elevate ME/CFS



Exchange between Courtney Miller and President Obama at April 21, 2011 town hall meeting in Reno, Nevada



Solve ME/CFS Initiative

Solve ME/CFS Initiative, Los Angeles, CA, national association



Health Rising, online patient community



Simmaron Research

Scientifically Redefining ME/CFS

Simmaron Research, Incline Village, NV

Massachusetts CFIDS/ME & FM Association

Massachusetts CFIDS/ME & FM Association
Quincy, MA

Education, Support and Advocacy since 1985



Open Medicine Foundation, Mountain View, CA



New Jersey ME/CFS Association, Florham, NJ



ProHealth, online patient community

Myalgic Encephalomyelitis Action Network, online patient community



Workwell Foundation, Ripon, CA

