

November 13, 2015

Francis Collins, M.D., Ph.D.
Director, National Institutes of Health

Walter Koroshetz, M.D.
Director, National Institute for Neurological Diseases and Stroke

Dear Drs. Collins and Koroshetz,

We sincerely want to thank you for your leadership roles in elevating NIH's approach to ME/CFS research. Your October 29th announcement and your public statements will go a long way in the Institutes and the scientific community to renew scientific and medical research into our disease, and we are hopeful and grateful.

We welcome your decisions to initiate a deep study of patients at the NIH Clinical Center, to assign leadership of the disease to Dr. Koroshetz and NINDS, and to upgrade and transform the Trans-NIH Working Group to Institute and Center directors. We believe these are important steps to building a research initiative with the potential to discover diagnostics, treatments and prevention of ME/CFS. Patients urgently need these advancements.

Thank you for extending your hand to members of our community. We are eager to work together to bring our ideas and experience to make the most of these initiatives. Please engage us. There is much research to do and progress to be made, and we have high hopes that NIH can change the course of our disease as it has done for so many.

We look forward to hearing more details regarding these important endeavors and to productive collaboration in solving our debilitating disease. So much needs to be done to achieve parity with other serious diseases. We also expect that in the near future we will see a significant increase in NIH funding commensurate with the disease burden to patients, families, and the United States' economy.

With appreciation,

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

Open Medicine Foundation
Agoura Hills, CA

New Jersey ME/CFS Association
Florham Park, NJ

SOLVE ME/CFS Initiative. National organization.
Los Angeles, CA

Simmaron Research
Incline Village, NV