

Congress of the United States
House of Representatives
Washington, D.C. 20515

Anna G. Eshoo
Eighteenth District
California

October 4, 2016

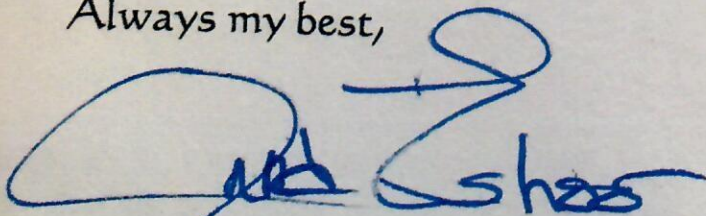
Janet L. Dafoe, Ph.D.

Dear Janet,

As you know, my colleagues and I wrote to Dr. Francis Collins, Director of the National Institutes of Health, urging him to devote more resources to ME/CFS. I recently received a reply from him and a copy is enclosed for you.

I'm encouraged by this timely, complete and detailed response which gives me hope. I look forward to hearing about progress being made to learn the cause and cure of this debilitating condition.

Always my best,



Anna G. Eshoo
Member of Congress

Enclosure



September 29, 2016

The Honorable Anna Eshoo
U.S. House of Representatives
Washington, D.C. 20515

Dear Representative Eshoo:

Thank you for your letter of September 9, 2016, concerning the National Institutes of Health's (NIH) plans to advance research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). We want to assure you that the NIH is committed to furthering research on this debilitating disease, and I am pleased to provide an overview of current initiatives and activities.

The complexity of ME/CFS and the need for an inter-disciplinary approach to better understand and develop treatments for this disease necessitate a trans-NIH approach that involves coordination among multiple NIH components. Because of this, the Trans-NIH ME/CFS Working Group is not housed within any Institute. While the National Institute of Neurological Disorders and Stroke (NINDS) helps organize and manage the Working Group under the leadership of NINDS Director Dr. Walter J. Koroshetz, it is a team effort among 23 Institutes, Centers, and Offices. The Working Group facilitates this coordination and meets regularly to discuss the best ways to foster ME/CFS research. As a first step toward encouraging ME/CFS research in the extramural community, the NIH has already funded seven supplements to existing awards focused on understanding the causes and mechanisms of ME/CFS. Awarded supplements will enable existing projects to expand the collection and analysis of ME/CFS patient samples to aid in biomarker identification and help identify potential therapeutic targets.

The NIH is preparing two Requests for Applications (RFAs) which will support ME/CFS collaborative research centers and a Data Management Coordinating Center. These RFAs will be released once they are finalized.

In order to make progress in ME/CFS research, collaboration among the NIH, the extramural community, and the ME/CFS community is essential, and we value the extensive comments generated by the RFI. The responses, which include input from individuals, patient advocacy organizations, researchers, and healthcare professionals can be viewed online via this site: <https://www.nih.gov/mecfs/announcements>. The Working Group is preparing a summary of the responses and will use the input to help guide future ME/CFS research and research training.

Plans are also proceeding for a clinical research study on ME/CFS that will be conducted at the NIH Clinical Center. This intramural study will explore the clinical and biological characteristics of ME/CFS following a probable infection to improve understanding of the disease's cause and progression. We are finalizing the protocol and the informed consent forms, and healthy volunteers are being recruited to participate.

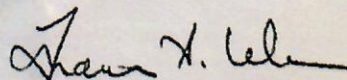
The goal is to admit the first set of healthy volunteers next month. Once techniques have been refined in studies of healthy volunteers, the protocol team will begin to bring individuals with ME/CFS to the NIH campus.

The NIH recently formed an ME/CFS Scientific Interest Group to provide a forum for researchers to discuss and disseminate clinical and scientific information about the disease. The Group seeks to foster new research collaborations across the NIH campus and is open to all intramural and extramural investigators interested in learning more about ME/CFS. The Scientific Interest Group is led by NINDS Clinical Director Dr. Avi Nath, who is also the principal investigator of the upcoming NIH intramural study on ME/CFS. The ME/CFS Scientific Interest Group has started a bimonthly seminar series with internal and outside experts and may include additional lectures, seminars, panel discussions, and other opportunities to facilitate discussion and collaboration.

We are hopeful that these new initiatives will support the efforts of the scientific experts who are working on this very challenging disorder, lead to an increase in the number of investigators who receive NIH grants to study ME/CFS in the future, and encourage rapid scientific progress and the development of new ways to diagnose and treat ME/CFS.

I am sending identical letters to your co-signatories.

Sincerely yours,



Francis S. Collins, M.D., Ph.D.
Director