**THE WHITE HOUSE**

WASHINGTON

July 26, 2012

Mrs. Courtney Miller
Reno, Nevada

Dear Mrs. Miller,

At a town hall meeting in Reno, Nevada last April, you asked me about the level of funding for research at the National Institutes of Health (NIH) devoted to Chronic Fatigue Syndrome (CFS). I told you I would ask NIH for a report on what they are doing to address CFS. I understand that my Deputy Chief of Staff for Policy, Nancy-Ann DeParle, spoke with you last week about this, and I wanted to follow-up with you personally.

I asked Dr. Francis S. Collins, M.D., Ph.D., the Director of NIH, for a status report on what NIH is doing to find a cure for CFS. He reports that NIH has spent $6.3 million on research on CFS in FY 2011, which is an increase of $1.5 million (31 percent) from the level of spending on this disease when I took office. This research, he explained, is promoted and facilitated through the coordinated efforts of the Trans-NIH Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Working Group.

The National Institute of Allergy and Infectious Diseases (NIAID); the National Cancer Institute (NCI); the National Heart, Lung, and Blood Institute (NHLBI); and the National Institute of Neurological Disorders and Stroke (NINDS) supported 36 research projects on CFS in FY 2011. As part of these projects, NIAID is supporting a multisite study of unprecedented scale designed to address whether a murine retrovirus is associated with CFS. NCI supports intramural and extramural research on viruses linked to both cancer and CFS. NHLBI supports research projects examining circulatory dysfunction, orthostatic intolerance, and the autonomic nervous system as they relate to CFS and NINDS supports extramural research on the effects of CFS on the central nervous system.

In addition, Dr. Collins reports that NIH hosted a State of Knowledge Workshop on ME/CFS last April that Nancy-Ann told me your husband Robert attended. The workshop brought together a broad group of attendees and investigators from various scientific disciplines and identified gaps in knowledge and new opportunities for biomedical research on CFS.

I understand that NIH will continue to encourage research on CFS through two Program Announcements of the same title (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Etiology, Diagnosis, Pathophysiology, and Treatment). NIH expects these research programs will enhance our knowledge of the disease process and provide evidence-based solutions to improve the diagnosis, treatment, and quality of life of all persons with ME/CFS. Dr. Collins also advises that the Department of Health and Human Services (HHS) has launched an Ad Hoc Workgroup on CFS and is working to develop a Department-wide strategy to address the disease. This effort is being led by Howard Koh, M.D., Assistant Secretary for Health at HHS.

Finally, I should also note that – as I am sure you know – we are engaged in a debate in Washington about the appropriate level of funding for research at NIH and other important government services such as funding for education and clean energy. If the House Republican budget were to be enacted, the Office of Management and Budget (OMB) estimates that the number of new grants from NIH for promising research projects would shrink by more than 1,600 in 2014 and by over 16,000 over a decade, potentially curtailing or slowing research to find a cure for Alzheimer's disease, cancer, and CFS. I will continue to fight to cut the deficit and build a stronger economy through balanced deficit reduction that asks all Americans to shoulder their responsibility and pay their fair share of taxes, cuts spending, and invests in areas critical to job creation, innovation, and growth. But you should know that this is an area of considerable disagreement between my Administration and many Republicans in Congress.

I have asked Nancy-Ann to stay in touch with Dr. Collins at NIH and Dr. Koh at HHS about my interest in their efforts on CFS. And I have asked her to update you from time to time. She reports that you are extremely knowledgeable about developments in the research on CFS, so I hope you will keep in touch with us as well.

Sincerely,