September 9, 2016

Dr. Francis Collins, Director  
National Institutes of Health  
1 Center Drive, Room B1-118  
Bethesda, MD 20892

Dear Dr. Collins,

We write to thank you for your attention to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and encourage you to continue to strengthen the National Institutes of Health’s (NIH) efforts in ME/CFS biomedical research.

As you know, ME/CFS is a complex, debilitating, and chronic disease afflicting 1 to 2.5 million Americans. It costs individuals, the U.S. health care system, and our economy an estimated $17-$24 billion annually. Yet, as the Institute of Medicine noted in its report, “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness,” there has been “remarkably little research funding” to date to discover its cause or possible treatments.

A number of us sent you a letter in March of 2014 to express support for ME/CFS research and are heartened by your commitment to advance diagnosis, treatment, and a cure for ME/CFS through a reinvigorated Trans-NIH ME/CFS Working Group (Working Group) housed within the National Institute of Neurological Disorders and Stroke (NINDS), and new intramural and extramural research programs that will bring new investigators into the field.

We encourage the Working Group to consider in a timely manner the input received through its recent Request for Information (RFI) regarding emerging needs, opportunities, and strategies for ME/CFS research and research training. We also ask that you provide us with the current status of this planning effort and the specific intramural and extramural activities planned for the rest of FY 2016, 2017, and 2018.

Thank you for your attention to these critical issues. We look forward to your response.

Sincerely,

Zoe Lofgren  
Member of Congress

Anna G. Eshoo  
Member of Congress
Karen Bass  
Member of Congress

Joyce Beatty  
Member of Congress

Suzanne Bonamici  
Member of Congress

Robert A. Brady  
Member of Congress

Julia Brownley  
Member of Congress

Vern Buchanan  
Member of Congress

Katherine M. Clark  
Member of Congress

Steve Cohen  
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Elijah E. Cummings  
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Peter A. DeFazio  
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Suzan K. DelBene  
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Mark DeSaulnier  
Member of Congress

Robert J. Dold  
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Elizabeth H. Esty  
Member of Congress

Sam Farr  
Member of Congress

John Garamendi  
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Raúl M. Grijalva  
Member of Congress

Luis V. Gutiérrez  
Member of Congress

Steve Israel  
Member of Congress

Joseph P. Kennedy III  
Member of Congress

Ron Kind  
Member of Congress

Steve Knight  
Member of Congress

John Lewis  
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Daniel W. Lipinski  
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Frank C. Guinta  
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Michael M. Honda  
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Walter B. Jones  
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Derek Kilmer  
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Peter T. King  
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Barbara Lee  
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Ted Lieu  
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Doris Matsui  
Member of Congress
Jim McDermott  
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David B. McKinley  
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Patrick Meehan  
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Chellie Pingree  
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Kathleen M. Rice  
Member of Congress

Austin Scott  
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Louise Mcintoch Slaughter  
Member of Congress

Christopher H. Smith  
Member of Congress

James P. McGovern  
Member of Congress

Martha McSally  
Member of Congress

Eleanor Holmes Norton  
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Mark Pocan  
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Adam B. Schiff  
Member of Congress

J. James Sensenbrenner, Jr.  
Member of Congress

Adam Smith  
Member of Congress

Jackie Speier  
Member of Congress
Eric Swalwell  
Member of Congress

Chris Van Hollen  
Member of Congress

Mike Thompson  
Member of Congress

Bonnie Watson Coleman  
Member of Congress

Peter Welch  
Member of Congress