

Congress of the United States
Washington, DC 20515

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.

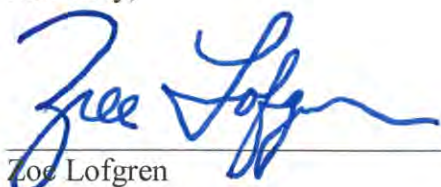
As you know, ME/CFS is a complex, debilitating, and chronic disease afflicting 1 to 2.5 million Americans. It costs individuals, the U.S. health care system, and our economy an estimated \$17-\$24 billion annually. Yet, as the Institute of Medicine noted in its report, "Beyond Myalgic Encephalomyelitis/Chronic 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,



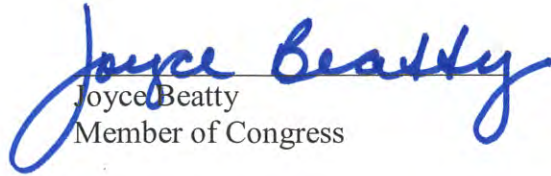
Zoe Lofgren
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Anna G. Eshoo
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Karen Bass
Member of Congress



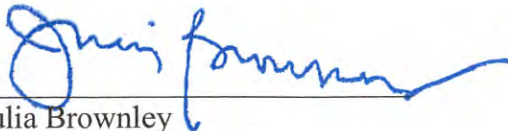
Joyce Beatty
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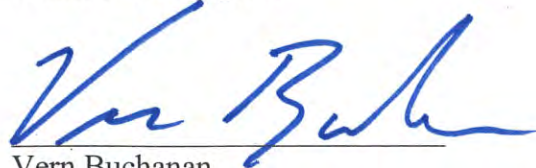
Suzanne Bonamici
Member of Congress



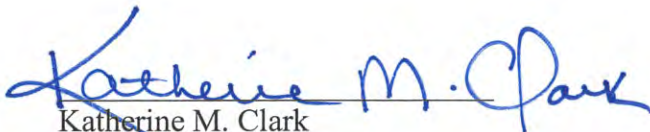
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Vern Buchanan
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Elijah E. Cummings
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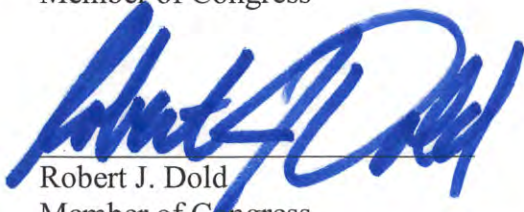
Peter A. DeFazio
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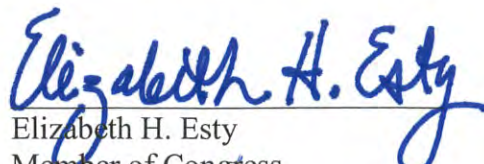
Suzan K. DelBene
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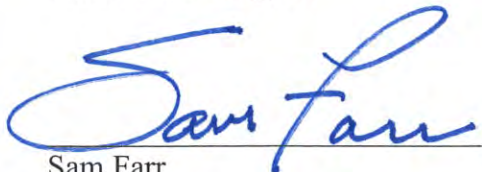
Mark DeSaulnier
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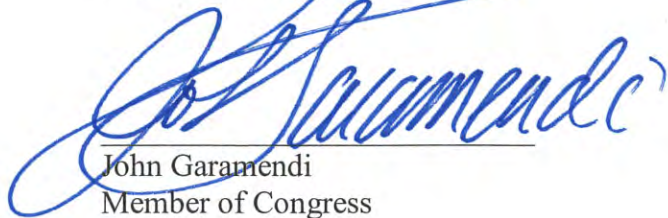
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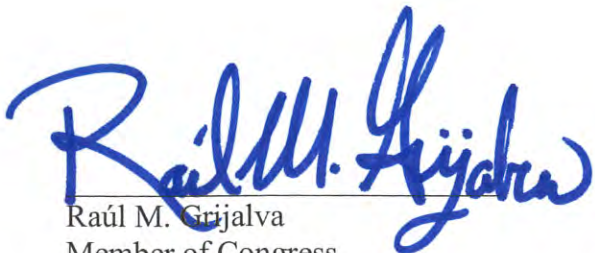
Elizabeth H. Esty
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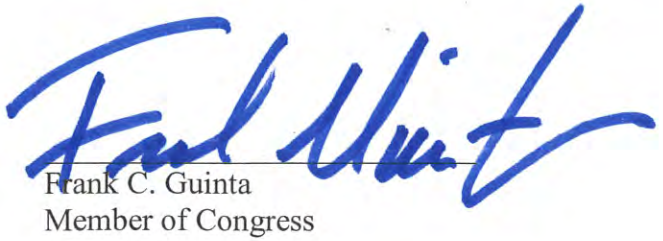


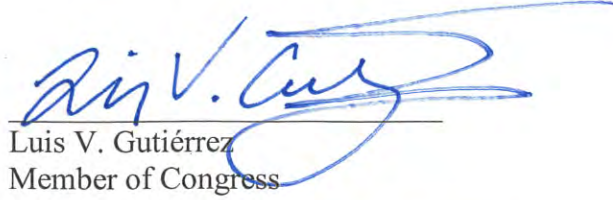
Sam Farr
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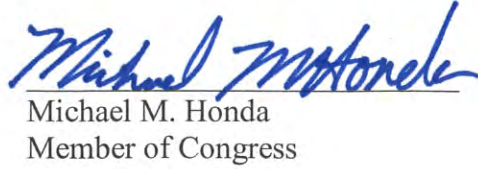


John Garamendi
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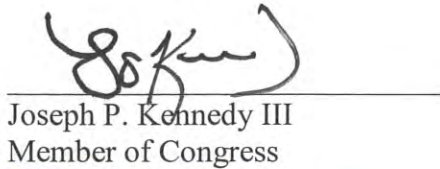

Frank C. Guinta
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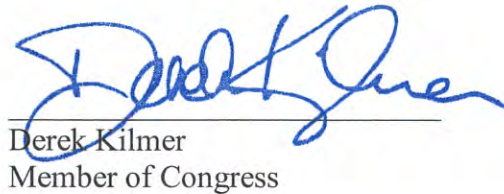

Luis V. Gutiérrez
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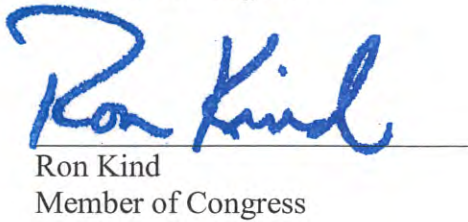

Michael M. Honda
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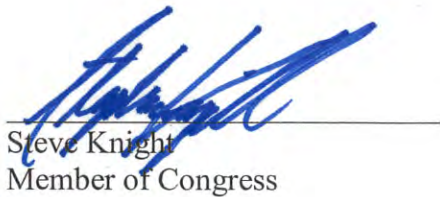

Walter B. Jones
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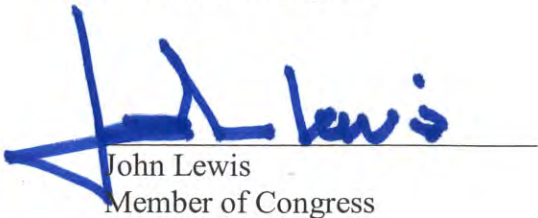

Derek Kilmer
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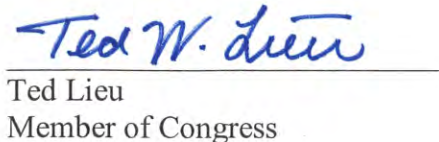

Ron Kind
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Member of Congress

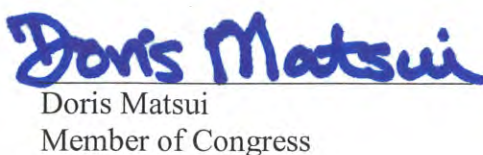

Steve Knight
Member of Congress

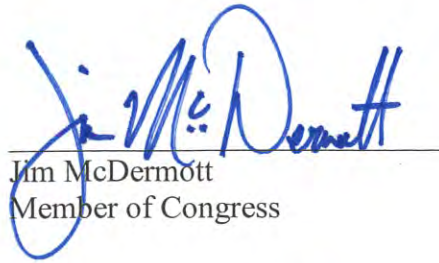

Barbara Lee
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John Lewis
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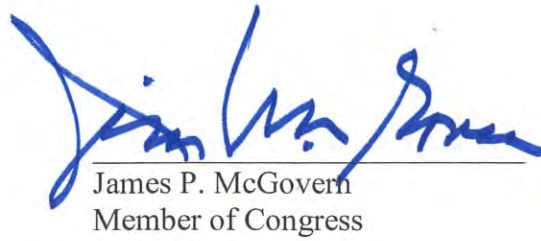

Ted Lieu
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Daniel W. Lipinski
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Doris Matsui
Member of Congress



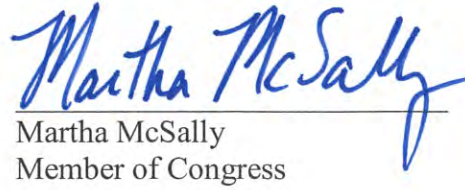
Jim McDermott
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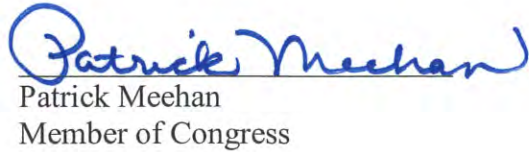
James P. McGovern
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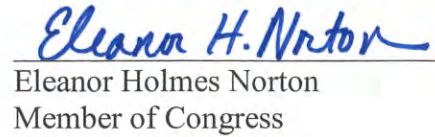
David B. McKinley
Member of Congress



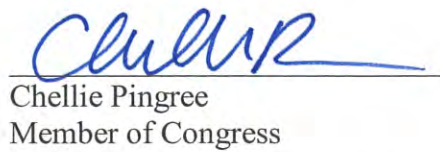
Martha McSally
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Patrick Meehan
Member of Congress



Eleanor Holmes Norton
Member of Congress



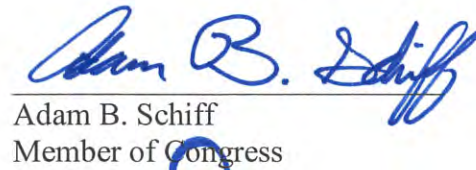
Chellie Pingree
Member of Congress



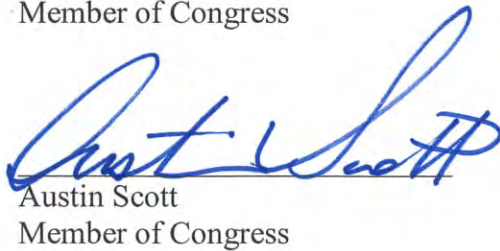
Mark Pocan
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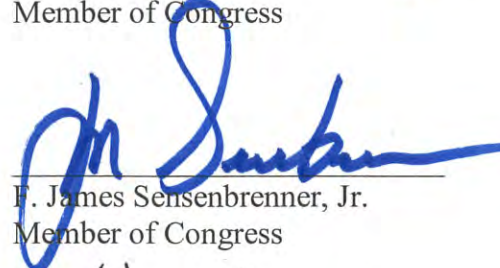
Kathleen M. Rice
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Adam B. Schiff
Member of Congress



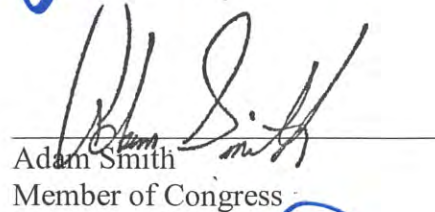
Austin Scott
Member of Congress



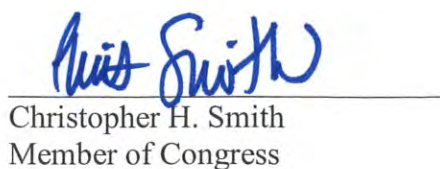
F. James Sensenbrenner, Jr.
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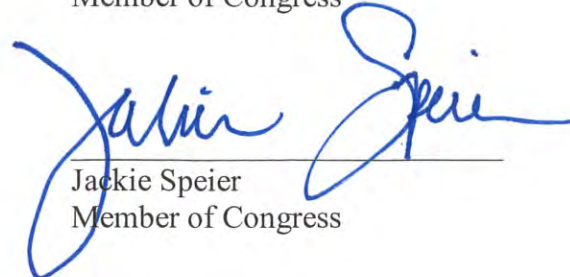
Louise McIntosh Slaughter
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Adam Smith
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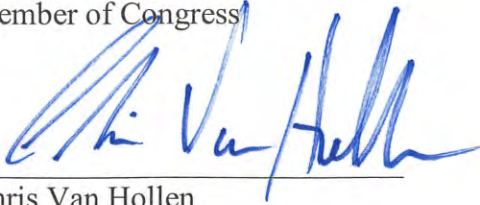
Christopher H. Smith
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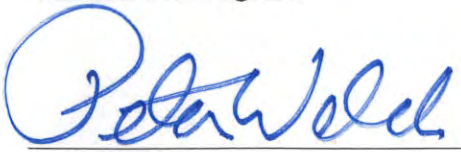
Jackie Speier
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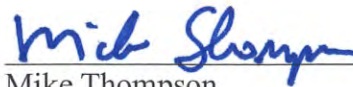
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