

## Proposed FY17 Appropriations Language

This document contains a draft of the Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS) language that the US Action Working Group would like to see included in the FY17 appropriations bill or accompanying report.

### 1. Health and Human Services Overall

**General Department Management:** *Chronic Fatigue Syndrome [CFS] also called ME/CFS --* The Committee endorses the Department's continued support of the CFS Advisory Committee and urges accelerated progress on its recommendations to strengthen research, education, training, care, and services to better address the needs of as many as 2.5 million Americans living with ME/CFS. Further, to address the critical gaps in medical care highlighted by the recent Institute of Medicine Report, the Committee urges HHS to find creative ways to fund regional Centers of Excellence that include both a research component and direct clinical care component

### 2. National Institutes of Health

**Office of the Director:** *Chronic Fatigue Syndrome [CFS] also called ME/CFS -* The Committee is pleased to see the 2015 reports from the National Academy of Science's Institute of Medicine and the NIH's Pathways to Prevention along with the recent advancements in science and renewed interests of researchers. The Committee urges the NIH to collaborate with disease researchers, clinicians, and patients and their advocates to address the historical lack of research and to capitalize on these opportunities to make progress on this poorly understood disease. Specifically, the Committee recommends that the NIH make funding commensurate with disease burden and use that funding to jumpstart the field through a set of intramural and extramural investments that include Requests for Applications (RFAs) for biomarkers and treatment trials, set-aside funding for investigator initiated studies (including for hypothesis generation), regional Centers of Excellence, and support for a network of researchers to develop a research strategy with defined milestones and to reach consensus on a research case definition and research standards.

### 3. Centers for Disease Control and Prevention

**CDC:** The Committee recommends a restoration of the CDC budget and an increase to a total of \$10M to be used to support the completion of CDC's Multi-Site study and to provide a much-needed medical education campaign. The Committee applauds the CDC's efforts to collaborate with disease experts in its Multi-Site study. However, the Committee is disturbed that, in spite of previous CDC medical education efforts, the IOM noted that patients continue to experience disbelief, mistreatment, and neglect at the hands of their doctors.<sup>1</sup> The Committee is pleased to hear that the National Academy of Science's Institute of Medicine has clarified the disease definition and that the Institute of Medicine and the CFS Advisory Committee have made recommendations to educate the medical community.<sup>2</sup> We urge CDC to leverage those recommendations to provide new clinical guidelines and to execute a broad-based medical education campaign. To address the critical lack of access to clinical care, the Committee also urges the CDC to work with the NIH and other agencies within the Department to find creative ways to fund a clinical care component to regional Centers of Excellence.

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<sup>1</sup> Institute of Medicine of the National Academies. “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.” Institute of Medicine of the National Academies. Final report May 2015. <http://www.iom.edu/Reports/2015/ME-CFS.aspx> Page 16, 29.

Also see

National Institute of Health. Office of Disease Prevention. “Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. December 9-10, 2014. Executive Summary.” National Institute of Health. Office of Disease Prevention. Final Report June 16, 2015.

<http://prevention.nih.gov/docs/programs/mecfs/ODP-P2P-MECFS-FinalReport.pdf> Page 4.

<sup>2</sup> U.S. Department of Health and Human Services CFS Advisory Committee. Advisory Committee Meeting Recommendations. August 18-19, 2015. <http://www.hhs.gov/advcomcfs/recommendations/2015-08-18-19-recommendations.pdf>

HHS’s response to these recommendations: <http://www.hhs.gov/advcomcfs/recommendations/08182015-agency-responses.html>