

Enclosure: Proposed Language for FY 2020 Labor, Health and Human Services, Education, and Related Agencies Appropriations Committee Report

Office of Secretary: General Department Management: Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS).--

The Committee is very concerned that the Secretary of Health abruptly disbanded the Chronic Fatigue Syndrome Advisory Committee (CFSAC) without any alternative plans to carry out its functions and current projects. There remains an urgent need for U.S. inter-agency coordination and collaboration with stakeholders to adequately address the needs of the ME/CFS health crisis. Previously, this Committee encouraged HHS to utilize CFSAC to accelerate progress on ME/CFS research, education, training, and clinical care. This Committee also previously expressed concern about the ME/CFS clinical care crisis and the lack of FDA approved treatments. In the absence of CFSAC, the Committee requests that HHS submit a plan outlining how it intends to address the crisis in ME/CFS clinical care, accelerate drug development for ME/CFS, and collaborate across HHS, with other agencies, and with ME/CFS stakeholders.

Multi-institute Research Issues: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).--

The Committee commends the NIH on its new ME/CFS efforts, including its plans for a 2019 conference on accelerating research into ME/CFS and its formation of the National Advisory Neurological Disorders and Stroke (NANDS) Council Working Group. However, the NIH itself has acknowledged that 10 to 20 times more funding is required to make progress in the field. The Committee is concerned that the level of funding for ME/CFS research is still very low considering the burden of disease. The Committee believes that current efforts will take too long to produce effective outcomes that will enhance the health and reduce the disability of millions of Americans living with ME/CFS. The Committee urges the NIH to collaborate with disease experts and the patient community to identify additional opportunities to expedite progress. Specifically, the Committee recommends that the NIH significantly increase ME/CFS investments such as (a) new ME/CFS disease specific funding announcements, including those with set-aside funds, to deliver needed diagnostics and treatments as quickly as possible, (b) an initiative to reach consensus on the ME/CFS case definition, and (c) mechanisms to incentivize researchers to enter the field.

Centers for Disease Control: Chronic Disease Prevention and Health Promotion: Chronic Fatigue Syndrome [ME/CFS]

The Committee recommends \$9,900,000 for Chronic Fatigue Syndrome to be utilized for existing and new projects. This is \$4,500,000 more than the fiscal year 2019 budget request and is expected to be a sustained increase, reflecting the Committee's concern about the lack of accurate information about ME/CFS prevalence, risk, and natural history, as well as inaccessible clinical care for ME/CFS patients. In addition to ongoing projects, the Committee expects \$2,750,000 of this increase to be utilized for a critically-needed national epidemiological study to collect baseline data on the number and types of people (sex, age, race) who have ME/CFS. The CDC is directed to ensure that disease experts and the patient community are involved in study design and to use patient selection criteria that are consistent with the National Institutes of Health Collaborative Research Centers. The Committee also expects the CDC to utilize \$1,000,000 of this increase to expand its current ME/CFS medical education efforts, particularly the dissemination of the CDC's recently updated online medical guidance for ME/CFS, in partnership with disease experts and medical associations. \$300,000 of the increased funding will also be used to support disease experts in the development of an Extension for Community Health Outcomes (ECHO) program for ME/CFS as the Committee is committed to addressing the critical shortage of expert ME/CFS physicians. The Committee also recommends the remaining \$450,000 increase to accelerate the publication of the results of the ongoing Multi-site Clinical Assessment of ME/CFS.