

**Congress of the United States**  
**Washington, DC 20515**

March 28, 2019

The Honorable Rosa DeLauro  
Chair  
Appropriations Subcommittee on Labor,  
Health and Human Services, and Education  
2358-B Rayburn House Office Building  
Washington, DC 20515

The Honorable Tom Cole  
Ranking Member  
Appropriations Subcommittee on Labor,  
Health and Human Services, and Education  
2358-B Rayburn House Office Building  
Washington, DC 20515

Dear Chairwoman DeLauro and Ranking Member Cole:

As you begin work on the Fiscal Year 2020 Labor, Health and Human Services, and Education Appropriations bill, we respectfully request that you provide increased funding at \$9.9 million for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Programs at the Centers for Disease Control and Prevention (CDC), and to include the attached report language to complement this work.

ME/CFS is a chronic, complex, multi-system disease characterized by profound fatigue, cognitive impairment, sleep disorders, autonomic dysfunction, chronic pain, and other symptoms often exacerbated by exertion of any sort. The Institute of Medicine estimated in a 2015 report that between 836,000 and 2.5 million people in the United States suffer from ME/CFS.<sup>1</sup> The CDC has labeled ME/CFS as “America’s hidden health crisis,” as a vast majority, about 90 percent, of people with ME/CFS remain undiagnosed.<sup>2</sup>

It costs individuals, the U.S. health care system, and our economy an estimated \$17-\$24 billion annually, as 25 percent of patients are bedbound or housebound at some time in their lives and an estimated 69 percent are unable to work.

Requested funds include level funding for existing CDC programs, such as the Behavioral Risk Factor Surveillance System state tracking survey, the Common Data Elements project, medical education efforts, and the multi-site clinical assessment of ME/CFS. An additional \$4.5 million is requested for new programs, such as a nationwide epidemiological study, medical education programs, and Project ECHO.

#### **Nationwide ME/CFS Epidemiological Study**

Current data on the demographic groups and number of people affected by ME/CFS is limited, localized, and outdated. There is a lack of accurate information about ME/CFS prevalence, risk, and natural history, making it difficult to mount an appropriate government response to the ME/CFS health crisis. As such, \$2.75 million of the increased funds should be used to conduct a nationwide ME/CFS epidemiological study, the results of which would be reported to Congress within four years.

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<sup>1</sup> “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness,” Institute of Medicine of the National Academies, May 2015, <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>.

<sup>2</sup> Ibid.

## **ME/CFS Medical Education**

It is understood that ME/CFS is significantly undiagnosed and therefore underreported. The CDC recently updated its ME/CFS online clinical guidance and released a new ME/CFS Continuing Medical Education credit program. \$1 million of the additional funds should be used to disseminate updated and appropriate clinical guidance, particularly in rural areas and medically underserved populations, to equip medical providers with the skills and knowledge necessary to recognize and treat ME/CFS patients. A sustained, multi-year dissemination effort is necessary to encourage collaboration between the CDC, ME/CFS experts, medical associations, stakeholders, and state and local partners, which is critical to ensuring the inclusion of all communities.

## **Project Extension for Community Health Outcomes (ECHO)**

Project ECHO is a telehealth initiative that brings evidence-based health care to frontline providers in underserved areas through specialist mentoring. \$300,000 will fund the development of an ME/CFS curriculum and outreach to the medical community, enabling specialists to share their expertise with primary care providers.

Additionally, we urge the inclusion of the attached Report Language urging the Department of Health and Human Services (HHS), National Institutes of Health (NIH), and the CDC to take the following steps:

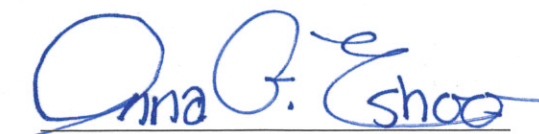
- Encourage HHS to submit a plan outlining how it intends to foster interagency and stakeholder collaboration and engagement to address the ME/CFS clinical care crisis and to accelerate drug development following the sunset of the Chronic Fatigue Syndrome Advisory Committee (CFSAC).
- Urge the NIH to collaborate with disease experts and the patient community to increase investments in research and to provide incentives for researchers to enter the ME/CFS field.
- Fully fund the CDC's ongoing ME/CFS projects and new programs vital to building on current efforts.

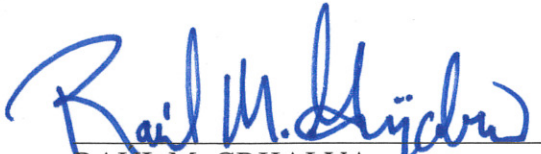
Much needed funding, focused research, and improved medical education will strengthen support for and improve the lives of ME/CFS patients across the country.

Again, we urge you to support \$9.9 million in ME/CFS funding in the FY20 appropriations bill to fund the appropriate research and to develop strategies for effective treatment and prevention. We appreciate your leadership on this issue and thank you for your consideration of this request.

Sincerely,

  
ZOE LOFGREN  
Member of Congress

  
ANNA G. ESHOO  
Member of Congress

  
RAUL M. GRIJALVA

  
MARK DESAULNIER

  
JAMES P. MCGOVERN

  
HARLEY ROUDA

  
STEPHEN F. LYNCH

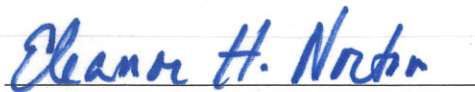
  
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CHELLIE PINGREE

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KAREN BASS

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ANGIE CRAIG

Jack Bergman

JACK BERGMAN

Tom O'Halleran

TOM O'HALLERAN



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AYANNA PRESSLEY



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BRIAN HIGGINS



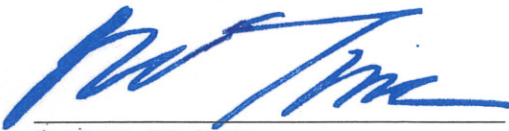
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LISA BLUNT ROCHESTER



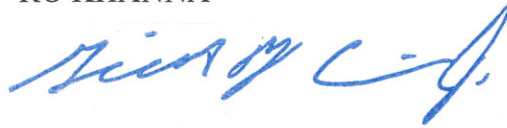
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RO KHANNA



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GILBERT R. CISNEROS, JR.



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WILLIAM R. KEATING



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PETER WELCH

## **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 concerned about the Secretary's decision to abruptly disband 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 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 has acknowledged that 10 to 20 times more funding is required to make necessary 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 and Prevention**

#### **Chronic Disease Prevention and Health Promotion: Myalgic Encephalomyelitis/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 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 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. 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.