

April XX, 2019

Chairman Roy Blunt
Senate Appropriations Subcommittee on
Labor, HHS, Education
Washington, DC 20510

Ranking Member Patty Murray
Senate Appropriations Subcommittee on
Labor, HHS, Education
Washington, DC 20510

Dear Chairman Blunt and Ranking Member Murray,

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.¹ 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.²

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Current data on the demographic groups and number of people affected by ME/CFS is limited, localized, and outdated.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

¹ “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>.

² Ibid.

nationwide ME/CFS epidemiological study, the results of which would be reported to Congress within four years.

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,

