

Congress of the United States
Washington, DC 20515

February 15, 2019

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Dear Secretary Azar:

We write to bring to your attention concerns from the Colorado Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) community regarding the expiration of the Chronic Fatigue Syndrome Advisory Committee (CFSAC).

In 2015, the National Academy of Medicine published a report, which estimated up to 2.5 million Americans suffer from ME/CFS, with most them going undiagnosed.¹ This chronic illness is a multisystem condition for which there is no known cause, treatment or cure. Individuals living with this debilitating disease are often unable to attend school or work. As a result, ME/CFS costs the economy an estimated \$18 to \$24 billion per year.²

On September 16, 2018, the discretionary CFSAC under the Department of Health and Human Services (HHS) disbanded after its charter expired and was not renewed. The CFSAC was established in September of 2002 to provide recommendations to HHS on issues related to ME/CFS. We would like to share the attached letter from Colorado's ME/CFS community raising their concerns regarding the disbanding of the CFSAC and the need for access to effective, comprehensive care to help treat this condition.

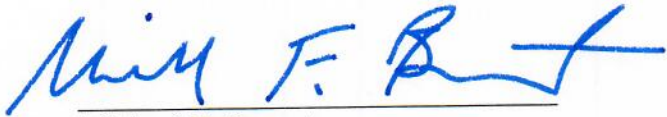
We appreciate the department's efforts to address the needs of patients with ME/CFS and encourage you to work with the patient community moving forward on future research, potential treatments and education initiatives.

Thank you for careful and full consideration of the attached letter.

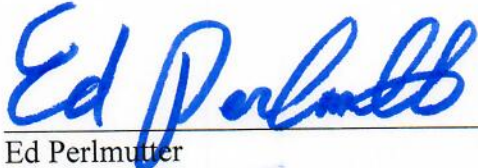
Sincerely,

¹ <https://www.cdc.gov/me-cfs/index.html>

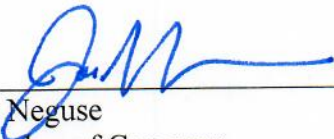
² *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*, National Academies Press. (Feb. 2015), <https://www.ncbi.nlm.nih.gov/pubmed/25695122>.



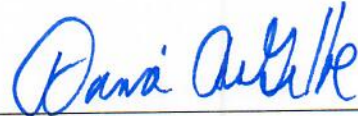
Michael F. Bennet
United States Senator



Ed Perlmutter
Member of Congress



Joe Neguse
Member of Congress



Diana DeGette
Member of Congress



Jason Crow
Member of Congress

2/15/2019

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Azar:

We write regarding efforts throughout the U.S. Department of Health and Human Services (HHS) to better understand and improve health outcomes for Americans living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). The Colorado ME/CFS community has concerns about the effects that the end of the Chronic Fatigue Syndrome Advisory Committee (CFSAC) in September, the slow pace and scale of HHS' work on ME/CFS, and the apparent lack of a comprehensive ME/CFS strategy will have on their health and prospects for recovery, as well as their pocketbook. It is estimated that ME/CFS impacts up to 42,000 Coloradans and costs the Colorado economy \$280 to \$400 million a year.

ME/CFS is a chronic, multisystem condition for which there is no known cause, treatment, or cure. Individuals living with this debilitating disease are often unable to attend school or work. While we are encouraged to see the initiatives underway at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) to help improve the quality of life for individuals living with ME/CFS, we believe more must be done to help the quality of life of Coloradans living with ME/CFS, particularly since ME/CFS patients have a lower quality of life than any other disease measured.¹

Currently there are no ME/CFS specialists in Colorado. Major medical and educational institutions in the state do not have any ME/CFS curriculum or educational materials. Those fortunate enough to receive an ME/CFS diagnosis in Colorado usually see several doctors before they have one that will believe them, be supportive, and will not recommend inappropriate and harmful clinical guidance.

MEAction of Colorado has members who have educated their own doctors to get a diagnosis, had their medical diagnosis of ME revoked by unbelieving medical offices leaving them unable to afford treatments, and have avoided helpful treatments because they couldn't afford them due to difficulties with diagnosis and insurance.

The CFSAC's Medical Education Working Group was developing recommendations for programs and materials that agencies would utilize to educate health care providers about ME/CFS and to address the increased risk of suicide in this patient population. In a state without

¹ *The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)*, Danish Center for Healthcare Improvements, <http://paperity.org/p/73597499/the-health-related-quality-of-life-for-patients-with-myalgic-encephalomyelitis-chronic>

any ME/CFS specialists, their work was vital to Coloradans with ME/CFS. Notwithstanding this urgent need, HHS disbanded the CSFAC without any plan to complete the unfinished work.

By disbanding the CFSAC, HHS created a void in both intra-departmental and inter-agency collaboration and removed a platform for streamlined stakeholder engagement. Vital ongoing projects such as the health care provider recommendations--so critical in a state with a total ME/CFS educational vacuum--were halted mid-stream. This is particularly unfortunate considering outside stakeholders, including Members of Congress, no longer have access to a one-stop-shop, both for learning about all federal initiatives to address ME/CFS and for providing input on federal plans and recommendations. We understand that the CDC has twice-a-year stakeholder engagement and outreach calls, but for a disease that affects tens of thousands of people in Colorado, this is not nearly enough engagement.

To help us better understand how HHS will fill the CFSAC vacuum and build upon its ME/CFS efforts, please answer the following questions:

1. In the absence of CFSAC, what are HHS' plans for engaging stakeholders in its activities and fostering communication and collaboration between stakeholders and the agencies that participated in CFSAC? How will the projects that were underway at the time of CFSAC's dissolution be completed?
2. Please describe HHS' strategic plan to expedite the delivery of diagnostics, treatments, and approved drugs. How is the department working with outside stakeholders, including engaging with medical associations, to address the lack of clinical expertise in ME/CFS?
3. Please describe how the NIH will further enhance extramural research on ME/CFS? How will NIH help incentivize researchers to enter the field?
4. Does the CDC have a strategy and timeline for conducting national epidemiological research to better understand ME/CFS prevalence, risk factors, natural history, and prognosis? What is the CDC's strategy for educating medical providers and the public on ME/CFS? Please describe any additional resources or authorities the CDC may require to actualize these strategies.

Thank you for your attention to our request. We look forward to working with the department to build upon your existing efforts to improve the quality of life for the ME/CFS community.

Sincerely,

MEAction Colorado Co-chairs

Diane E. Edes, Parent of Person with ME, Westminster

John Kelty, Husband of Person with ME, Elizabeth

Hannah Rice, Person with ME, Boulder

Solve ME/CFS Initiative Board of Directors

Diane Reimer Bean, Parent of Person with ME, Centennial

MEAction Colorado Activists

Destiny Brown, Person with ME, Ft. Collins
Susan E. Cunningham, Person with ME, Denver
Julie Kelty, Person with ME, Elizabeth
Jane Mattingly, Person with ME, Arvada
Jillene Moore, Person with ME, Loveland
Tina Palomino, Person with ME, Greeley
Tom Strobel, Life partner of Person with ME, Denver
Daniel Taron, Brother of Person with ME, Denver

CC: Dr. Francis Collins, Director, National Institutes of Health
Dr. Robert Redfield, Director, Centers for Disease Control and Prevention