

November 7, 2018

Secretary of Health Alex Azar  
U. S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Dear Secretary Azar,

We are writing as current and former members of the Chronic Fatigue Syndrome Advisory Committee (CFSAC), as biomedical researchers and clinicians with expertise in the disease Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and as ME/CFS patient organizations to voice our concerns with HHS's decision to disband the CFSAC. We are calling for CFSAC to be immediately reinstated.

The 2015 report by the National Academy of Medicine (NAM) stated that ME/CFS "is a serious, chronic, complex, and multisystem disease that frequently and dramatically limits the activities of affected patients." NAM noted that ME/CFS affects 1-2.5M Americans of all genders, ages, races, and ethnic groups. It results in more functional impairment than a number of other chronic diseases with many patients unable to work and costs the economy \$17-24B annually in direct medical expenditures and lost productivity. NAM found, "remarkably little research funding," a "paucity of research" outside the fields of psychiatry and psychology, and a healthcare profession who have been persuaded that ME/CFS is a psychological problem. Further, NAM also notes a lack of diagnostics and FDA-approved treatments and a medical community that views the disease negatively, expresses hostility and disbelief to patients, and recommends treatments that can exacerbate their symptoms. This situation has persisted for the last three decades.

During its 15-year tenure, CFSAC repeatedly recommended that HHS address these issues. CFSAC's concerns were reiterated in HHS's own reports and in the NAM report. But the vast majority of those recommendations were not enacted by HHS and little changed.

Following the 2015 NAM report, co-sponsored by HHS and the Social Security Administration, and NIH's 2015 Pathways to Prevention report, the situation is just beginning to improve. NIH has begun to invest in research programs. The CDC has updated its website with more accurate information. A few major academic centers have begun to research the disease.

But funding still remains far below that of other similarly disabling diseases. The breadth and volume of research being conducted lags far behind that necessary to deliver urgently needed diagnostics and treatments. Little is known about the natural history of the disease and nothing about how to prevent it. There exist only a dozen or so clinical experts nationwide, a number of whom are reaching retirement age while other medical

providers still either doubt the disease is real or lack the knowledge to provide appropriate patient-care. Patients struggle to get even the most basic treatment.

These outstanding needs – “research on diagnosis, treatment and management of ME/CFS”, “inform...health care professionals”, “partnerships to improve the quality of life of ME/CFS patients” – comprise the Duties outlined in CFSAC’s Charter. CFSAC’s work is not done. The very recent progress is still precarious, tentative, and has not yet made a difference in patient care or outcomes.

In the last two years, CFSAC has begun to establish productive, collaborative partnerships across the ME/CFS community, HHS agencies, and other Departments including the Social Security Administration, and the recently added Department of Defense and the Veterans’ Administration. While not a member, the Department of Education was also an active participant. CFSAC’s current workgroups had been focused on medical education, engaging pharmaceutical companies to stimulate treatment trials, and promoting awareness and education in schools. These efforts were all cut short when CFSAC was dissolved.

There is no other entity in the U.S. capable of advancing such broad-based engagement and collaborations across such diverse areas of need. Given CFSAC’s unique role and the magnitude and urgency of persisting needs, we believe it is shortsighted to dissolve CFSAC at this critical time.

We respectfully request CFSAC’s immediate reinstatement with the full constituency that existed when it was disbanded. We look forward to your response.

Respectfully,

**Current CFSAC members (As of September 2018)**

Dr. Faith Newton, (CFSAC Chair)  
Professor of Education  
Delaware State University  
Dover, Delaware

Lucinda Bateman, MD  
Medical Director  
Bateman Horne Center  
Salt Lake City, Utah

Alisa Erika Koch, MD, PhD

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Amrit Shahzad, MBBS, MBA

Ben HsuBorger  
CFSAC Liaison Member for MEAction

Courtney Miller  
CFSAC Liaison Member for Simmaron Research

Terri L. Wilder, MSW  
CFSAC Liaison Member for MEAction

Leah Williams, PhD  
CFSAC Liaison Member for Massachusetts ME/CFS & FM Association

#### **Former CFSAC Members**

Dane Cook  
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University of Wisconsin – Madison  
Department of Kinesiology  
Madison, Wisconsin

Kenneth J. Friedman, PhD  
Associate Professor of Physiology and Pharmacology (retired)  
New Jersey Medical School  
University of Medicine and Dentistry of New Jersey  
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Carol Head  
CFSAC Liaison Member for Solve ME/CFS Initiative  
President, Solve ME/CFS Initiative  
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Nancy Klimas MD  
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Director, Miami VA Medical Center GWI and CFS/ME Program  
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Steven P. Krafchick MPH, JD  
Treasurer, International Association for Chronic Fatigue Syndrome/Myalgic  
Encephalomyelitis  
Private Law Practice  
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James M. Oleske, MD, MPH  
François-Xavier Bagnoud Distinguished Professor of Pediatrics  
Senator of RBHS Research Centers, Bureaus, and Institutes  
Director, Division of Pediatrics Allergy, Immunology & Infectious Diseases  
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Scientific Director  
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Staci Stevens, MA  
Exercise Physiologist  
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#### **Other Researchers and Clinicians**

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Thomas J. Long School of Pharmacy & Health Sciences  
Department of Physical Therapy  
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Clinician in Private Practice (retired)  
Associate Clinical Professor  
Yale Child Study Center (retired)  
New Haven, Connecticut  
Associate Clinical Professor  
University of Connecticut Department of Psychiatry (retired)  
Storrs, Connecticut  
Lecturer, Harvard Medical School (retired)  
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### **ME/CFS Patient Organizations**

American ME and CFS Society  
Massachusetts

Massachusetts ME/CFS & FM Association  
Massachusetts

#MEAction  
California

Minnesota ME/CFS Alliance  
Minnesota

Open Medicine Foundation  
California

Pandora Org.  
Michigan

Simmaron Research Foundation  
Nevada

Solve ME/CFS Initiative  
California

Wisconsin ME and CFS Association  
Wisconsin

CC:  
Assistant Secretary for Health Brett P. Giroir, M.D.