

Congress of the United States

Washington, D.C. 20515

July 15, 2008

The Honorable Michael O. Leavitt
Secretary of Health and Human Services
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

Dear Secretary Leavitt:

We are writing to urge you to renew the charter and fully fund the Department of Health and Human Services (DHHS) Chronic Fatigue Syndrome Advisory Committee (CFSAC). The charter is set to expire on September 5, 2008.

The CFSAC was established to provide evidence-based advice and recommendations to you and the Assistant Secretary of Health on a broad range of topics including: the current state of Chronic Fatigue Syndrome (CFS) research, opportunities for future research, current and proposed diagnostic and treatment methods, and the development and implementation of programs to educate the public, health care professionals and researchers about CFS advances.

Chronic Fatigue Syndrome (CFS), also known as chronic fatigue and immune dysfunction syndrome (CFIDS), is a complex and severely debilitating chronic illness that affects up to 4 million Americans, according to the latest CDC estimate. CFS is now recognized by most authorities, including CDC and NIH, as a severe and complex illness. Unrelenting exhaustion, widespread muscle and joint pain, cognitive impairments (particularly problems with memory and concentration), unrefreshing sleep, sore throat, headache, and a constellation of other symptoms are debilitating enough to dismantle careers and destroy active lifestyles. Its hallmark has come to be identified as "post-exertional relapse," a return of all symptoms that follows even modest physical or mental activity and can last for days or weeks.

Due to the multi-symptom nature of the illness, CFS is often challenging for health care providers to diagnose and treat – and equally challenging for patients and families to endure. Nearly 25 years after the first documented outbreak of CFS, scientists are still searching for the causes of CFS and have yet to develop a diagnostic test or identify widely effective treatment.

Alarming, less than 20 percent of CFS patients have been diagnosed, yet early detection and symptom management have been shown to improve the patient's long-term outlook. The high prevalence of CFS, its low rate of diagnosis and the annual economic toll of up to \$25 billion demonstrates the need for increased public and policy-maker awareness and a more potent research effort.

Meetings of the CFSAC provide a vital opportunity for experts selected by the Department to listen to and exchange information with representatives of DHHS agencies, including the National Institutes of Health, Centers for Disease Control and Prevention, Health Resources and Services Administration, Agency for Healthcare Research & Quality, Food and Drug Administration and Social Security Administration. The CFSAC meetings also provide opportunities for patients and advocates to express support for or concerns about CFS programs through public testimony. Thus, the CFSAC allows for greater transparency and accountability for CFS programs, helping to ensure the most effective policies and utilization of federal

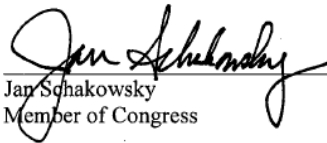
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resources dedicated to CFS. For example, at present the CFSAC has presented your office with a host of recommendations designed to improve the performance of the CFS program at CDC. We await a response to these recommendations.

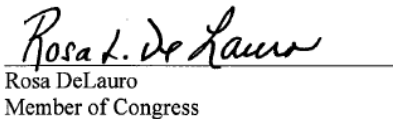
The CFSAC serves as an important forum for obtaining information, providing input and monitoring progress on federal activities pertaining to CFS. We believe that it is essential the CFSAC continue its work to keep the momentum moving forward. Therefore, we urge you to renew the CFSAC charter before its September 5, 2008 expiration and to fully support its important work.

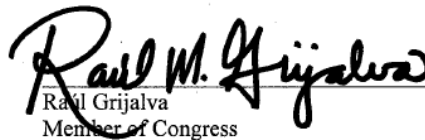
We appreciate your consideration of our views and look forward to receiving your response.

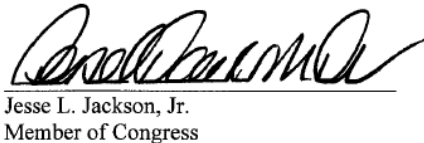
Sincerely,


Jan Schakowsky
Member of Congress

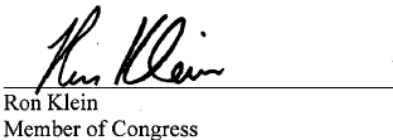

Sue Myrick
Member of Congress

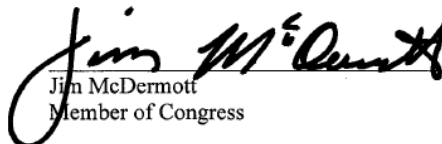

Rosa DeLauro
Member of Congress

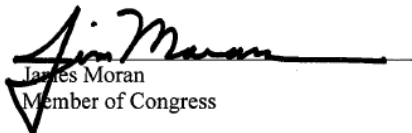

Raúl Grijalva
Member of Congress

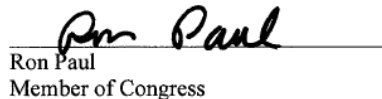

Jesse L. Jackson, Jr.
Member of Congress


Patrick J. Kennedy
Member of Congress


Ron Klein
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Jim McDermott
Member of Congress


James Moran
Member of Congress

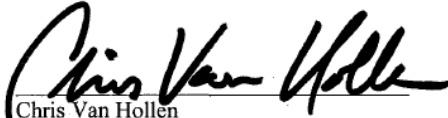

Ron Paul
Member of Congress



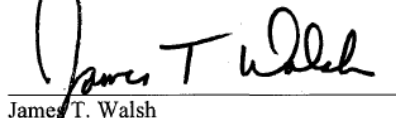
Joe Sestak
Member of Congress



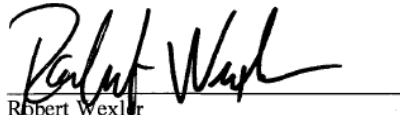
Lee Terry
Member of Congress



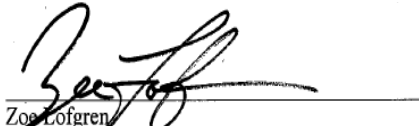
Chris Van Hollen
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Zoe Lofgren
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