

United States Senate

WASHINGTON, DC 20510

June 9, 2006

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

Dear Secretary Leavitt,

We are writing to urge you to renew the charter and fully fund the Department of Health and Human Services Chronic Fatigue Syndrome Advisory Committee (CFSAC). As you know, CFSAC is a federal advisory committee that provides evidence-based advice on the current state of research on chronic fatigue syndrome (CFS) and research opportunities, 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 research and advances.

Chronic fatigue syndrome, also called chronic fatigue and immune dysfunction syndrome, is a complex and debilitating illness that affects the brain and multiple body systems. The Centers for Disease Control and Prevention estimates that more than one million American adults and teens have CFS, costing our nation an estimated \$9.1 billion a year in lost productivity—not including medical costs. CFS warrants serious attention by the Department of Health and Human Services.

Meetings of the CFSAC provide a vital opportunity for experts selected by the Department to hear reports from, provide input to and monitor progress of the CDC, NIH, Health Resources and Services Administration, Food and Drug Administration and the Social Security Administration. The CFSAC's meetings also provide the patient community the opportunity to participate in these discussions and voice concerns through public testimony. Thus, CFSAC allows for greater transparency and accountability, helping to ensure the most effective utilization of federal resources dedicated to CFS.

In 2004, the CFSAC presented your office with 11 recommendations. While you have yet to formally respond to these and later recommendations issued by the Committee, the Centers for Disease Control and Prevention and the National Institutes of Health have implemented at least two of the recommendations — notably NIH's July 2005 issuance of a Request for Applications for CFS research and CDC's support of a national CFS awareness campaign.

The CFS Advisory Committee serves as an important forum for obtaining information, providing input and monitoring progress on federal activities pertaining to CFS. It is essential the CFSAC continue its work so that we can continue our momentum. We urge you to renew CFSAC's charter before its September 5, 2006 date of expiration, to respond to the committee about the status of earlier recommendations and to fully support its continued work.

Sincerely,





Rick Sutorius

Mary F. Ladd

Robert Mering

Frank R. Lantenberg

Chris Hald

Chuck Scherer