

United States Senate

WASHINGTON, DC 20510-7012

November 15, 2005

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

Dear Secretary Leavitt:

I am writing on behalf of the hundred of thousands of patients and families living with chronic fatigue syndrome (CFS). I first became aware of this devastating disease in 1987 when the first known "outbreak" of CFS cases was documented in Incline Village, Nevada. 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. Symptoms of CFS include severe exhaustion, widespread joint and muscle pain, cognitive difficulties and relapse after previously well-tolerated physical or mental exertion. The Centers for Disease Control and Prevention (CDC) estimates that more than 800,000 American adults and teens have CFS, costing our nation an estimated \$9.1 billion a year in lost productivity—not including medical costs. Our knowledge about CFS is limited, and there is no known cause or biologic marker to diagnose the disease. Furthermore, treatment of CFS symptoms is often ineffective, sometimes resulting in extended disability for many patients.

As you may know, the Chronic Fatigue Syndrome Advisory Committee (CFSAC) was chartered in 2002 to advise the Department of Health and Human Services (HHS) on policy and programs as they affect individuals with CFS. It is my understanding that since 2002, the Committee met quarterly, and these sessions culminated in the development of the recommendations submitted in 2004.

CFS is a significant public health concern that warrants greater attention and commitment. To that end, I would like to respectfully direct your attention to the CFSAC's recommendations submitted in August 2004.

In the CFSAC's assessment, the greatest priority for HHS is to expand research funding and scope. Future research efforts should incorporate a multidisciplinary approach, since CFS affects a number of highly integrated body systems—particularly the immune, endocrine, and nervous systems. Some of the recommendations CFSAC has urged include:

- Direct the NIH to establish five Centers of Excellence within the United States that would focus on the diagnosis, clinical research and management, and treatment of persons with CFS. Such Centers would be modeled after the existing Centers of Excellence program, with funding in the range of \$1.5 million per center per year for five years.
- Provide funds to develop an international Network of Collaborators that would allow for multidisciplinary CFS-related research.

- Provide support and funding for an intramural staffed laboratory at NIH, committed to CFS research.
- Promote, encourage, and fund research directed toward the diagnosis, epidemiology, and treatment of CFS in children and adolescents.

CFS affects the everyday lives of many Americans, and I urge you to carefully consider strategies that will help to foster research and treatment. I appreciate your attention to this matter.

Sincerely,

A handwritten signature in black ink, appearing to read "Harry Reid". The signature is written in a cursive, flowing style with a large initial "H".

Senator Harry Reid
Senate Democratic Leader