

United States Senate

WASHINGTON, DC 20510

November 14, 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:

We are writing on behalf of the hundred of thousands of patients and families living with chronic fatigue syndrome (CFS) to underscore the importance of reviewing the Chronic Fatigue Syndrome Advisory Committee's (CFSAC) recommendations submitted in August 2004. As you may know, the 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 our 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, we respectfully direct your attention to the Committee's recommendations.

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. Of course, 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.

In the CFSAC's assessment, the greatest priority for HHS is to expand research funding and scope. We believe that 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. Based on these needs, it is our understanding that the CFSAC has urged HHS to do the following:

- 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.
- Through the CDC and NIH, continue to sponsor focused workshops in specific areas of CFS and to invite investigators not currently working on CFS who have been identified as having an interest in the illness.
- Pursue making CFS a topic of training for healthcare providers, wherever appropriate at regional and national conferences sponsored by HHS.
- Encourage continuing education for Social Security reviewers and adjudicators. HHS should recommend that adjudicators follow the Social Security Policy ruling 99-2P, which specifically clarifies policies regarding CFS.
- Increase public education on CFS through a public awareness campaign. Discrimination in health care, education, and the workplace should be actively confronted.
- Through CDC, classify CFS as a “Nervous System Disease” as worded in the ICD-10 G93.3.
- Consider participation of the Department of Defense, Department of Veterans Affairs, Agency for Healthcare Research and Quality, and the National Institute of Disability and Rehabilitation Research (NIDRR) as ex-officio members of the CFSAC for future deliberations of recommendations.

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

Sincerely,


Rick Sutorum


Chris Hatch