

May 12, 2005

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 request your immediate implementation of the 11 recommendations from the Chronic Fatigue Syndrome Advisory Committee (CFSAC). The CFSAC was chartered in 2002 to advise the Department of Health and Human Services on policy and programs as they affect persons with chronic fatigue syndrome (CFS). Since 2002, the Committee has met quarterly and developed a set of 11 recommendations that were submitted in August 2004 to Principal Deputy Assistant Secretary for Health Cristina Beato, MD. The magnitude of CFS makes it a significant public health concern that warrants greater attention and commitment from the federal government. We believe the CFSAC recommendations are reasonable and should be acted upon.

Chronic fatigue syndrome, also called chronic fatigue and immune dysfunction syndrome, is a complex and debilitating chronic 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. CDC estimates that more than 800,000 American adults and teens have CFS, which costs our nation \$9.1 billion a year in lost productivity—not including medical costs. The most serious problems regarding CFS are:

- There is no known cause and no biologic marker to diagnose CFS.
- Our knowledge of the pathophysiology of CFS is very limited.
- Approximately 85 percent of patients with CFS have not been diagnosed by a health care professional.
- Treatment is limited to symptom relief and is often ineffective.
- Disability resulting from CFS is costly to the individual and the nation; CDC recently reported that at least 25 percent of CFS patients are fully disabled and the cost per affected family is \$20,000 a year.

In the CFSAC's assessment, the greatest priority for DHHS is to expand research funding and scope. Future research efforts must take a multidisciplinary approach because CFS affects a number of highly integrated body systems, particularly the immune, endocrine and nervous systems. Based on these needs, the CFSAC has urged DHHS to:

- 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 should 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.

- Direct the NIH to expedite the issue of a Request for Applications with sufficient set-aside funds to attract senior level researchers to engage in the study of CFS. DHHS should fund extramural grants, reviewed by a special emphasis panel knowledgeable in CFS, through RO1, RO3, R21, and Director's Pioneer Award mechanisms.
- 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.

Seven secondary recommendations of the CFSAC urge DHHS to:

- 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 health care providers, wherever appropriate at regional and national conferences sponsored by the Department.
- Encourage continuing education for Social Security reviewers and adjudicators. DHHS 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 all aspects of an individual's life, and the illness takes a great toll on families and society. It deserves a meaningful response from the federal government. We strongly support the CFSAC recommendations and urge you to implement them immediately.

Sincerely,

Senator
Representative