

Congress of the United States
House of Representatives
Washington, DC 20515

August 8, 2005

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 in regard to the Chronic Fatigue Syndrome Advisory Committee's (CFSAC) 11 recommendations, submitted last August. As you know, 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. CFS is a significant public health concern that warrants greater attention and commitment. We request your attention to the Committee's recommendations, and respectfully ask for a response to their suggestions.

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. 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 DHHS is to expand research funding and scope. Future research efforts should probably take a multidisciplinary approach, since 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 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.
- 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.

We would appreciate it if you could provide us with a response to these recommendations. This disease affects the everyday lives of many Americans, and we urge you to carefully consider strategies that will help to address current limitations in research and treatment.

Sincerely,


Sue Myrick


Frank Pallone, Jr.

Robert Wray

Jim M. Bennett

Jan Schabowdy

Tony Baldwin

Mrs Van Hollen

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