

**Department of Health and Human Services
Chronic Fatigue Syndrome
Advisory Committee**

August 23, 2004

Christina Beato, MD
Principal Deputy Assistant Secretary for Health
Department of Health and Human Services
200 Independence Avenue, S.W.
Room 716-G
Washington, DC 20201

Dear Dr. Beato,

The Chronic Fatigue Syndrome Advisory Committee has met on four occasions to consider how best to improve the care of persons with chronic fatigue syndrome (CFS) and to make recommendations to Secretary Thompson and the Department of Health and Human Services (DHHS). CFS is a chronic, disabling condition estimated to affect 800,000 Americans. A recent CDC study has estimated an annual economic impact of CFS of \$9.1 billion dollars, not including medical costs. The most serious current problems regarding CFS are as follows:

- 1) There is no known cause, and no biologic marker to diagnose CFS.
- 2) There is only limited knowledge of the pathophysiology of CFS.
- 3) From 70% to 90% of patients with CFS in the population are not diagnosed.
- 4) There is limited knowledge regarding effective treatment.
- 5) Disability from CFS has created a large national economic burden.
- 6) There is difficulty in determining disability.

Recommendations of the Chronic Fatigue Syndrome Advisory Committee:

Primary Recommendations

In the opinion of the CFSAC, the greatest priority for the DHHS is to substantially increase research efforts and funding. Future research efforts must apply an integrative approach because CFS is characterized by dysregulation of a number of highly integrated body systems, particularly the immune and nervous systems. Forming multidisciplinary research teams would provide a platform to conduct well controlled, methodologically sound, longitudinal studies to clarify the pathophysiology of this syndrome, and to develop effective treatment modalities. Serum and tissue banks for future investigations should be established.

1. We would urge the DHHS to direct the NIH to establish five Centers of Excellence within the United States that would effectively utilize state of the art knowledge concerning the diagnosis, clinical management, treatment and clinical research of persons with CFS. These 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.
2. We would urge the DHHS, through the NIH, expedite the issue of an RFA 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 Directors Pioneer Award mechanisms.
3. The DHHS should provide funds to develop an international Network of Collaborators that would allow for multidisciplinary CFS-related research using standardized criteria accepted by the international CFS research community. Such a network would pool a large number of patients from around the world, and would require investigators to develop and employ common protocols.
4. DHHS should provide support and funding for an intramural staffed laboratory committed to CFS research.

Secondary Recommendations

5. The DHHS should promote, encourage and fund research directed toward the diagnosis, epidemiology, and treatment of CFS in children and adolescents.
6. The DHHS, through the CDC and NIH, should continue to sponsor, even accelerate, 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.
7. The DHHS should pursue making CFS a topic of training for health care providers, wherever appropriate at regional and national conferences sponsored by the Department.
8. The DHHS should encourage continuing education for Social Security reviewers and adjudicators. The secretary of DHHS should recommend that adjudicators follow the Social Security Policy ruling 99-2P which specifically clarifies policies regarding CFS.
9. The DHHS should increase public education on CFS through a public awareness campaign. Discrimination in health care, education and the workplace should be actively confronted.
10. We would encourage the classification of CFS as a “Nervous System Disease” as worded in the ICD-10 G93.3.

11. The DHHS should 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.

Respectfully submitted,

David S. Bell MD, Chairman
Chronic Fatigue Syndrome Advisory Committee