

The CFIDS Association of America

Working to make CFS widely understood, diagnosable, curable and preventable

**Written Testimony Submitted for the Record
Department of Health and Human Services
Chronic Fatigue Syndrome Advisory Committee
In Advance of the May 10, 2010 Meeting**

**Submitted By:
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Background

The federal government has supported research on chronic fatigue syndrome (CFS) since the mid-1980s. Beginning in 1990, representatives of federal health agencies have been meeting to share information and discuss CFS issues of common interest, such as research progress, social service needs and patient concerns. The CFS Interagency Coordinating Committee (CFSICC) was the first informal body to meet. It brought together representatives from the National Institutes of Health (NIH), Centers for Disease Control & Prevention (CDC), Social Security Administration (SSA) and Food and Drug Administration (FDA) and met at least annually.

In 1994 the CFSICC was expanded to include four patient-advocate consultants, of which I was one. In 1995, Assistant Secretary for Health Philip Lee announced the department's commitment to secure a charter for a new committee with greater public representation and authority. Dr. Lee's legacy to the CFS community was a chartered DHHS CFS Coordinating Committee (CFSCC) with membership from the four agencies noted above, the Health Resources and Services Administration (HRSA) and seven members of the public representing voluntary CFS organizations, CFS researchers and CFS disability experts. The CFIDS Association of America worked with Dr. Lee, Secretary Donna Shalala and other Department staff to facilitate the chartering of the CFSCC and to ensure its renewal.

Following Inspector General and General Accountability Office reports on CFS research spending and practices at CDC, NIH and across the Department, it was announced that the CFSCC would transition to a full advisory committee, consistent with the structure for other DHHS advisory committees. (At the time, the CFS committee was the only DHHS committee chaired by a federal official and was the only body that permitted government representatives to vote on matters before the committee.) This announcement was made at the January 31, 2001 meeting of the CFSCC, the last meeting held. Progress in making this transition was slower than anticipated due to the extended presidential election, delayed installation of the Bush Administration and, later, events following the September 11 terrorist attacks.

In spite of these long delays, the CFIDS Association continued working with Principal Deputy Assistant Secretary for Health Cristina Beato, Dr. Larry Fields, Dr. Arthur Lawrence and other Department staff to install the CFSCC to a full advisory committee governed by the Federal

Advisory Committee Act. Its first meeting was held on September 29, 2003, with 11 members of the public as appointed voting members and five ex-officio agency representatives, chaired by Dr. David S. Bell, a well-known and respected clinician in private practice.

At that meeting, I made this statement about the CFIDS Association's support for the CFSAC. "The CFSAC is an important catalyst in the fight to conquer CFS. This forum provides for discussion and debate of research, policy and human service needs related to CFS; the committee gives the CFS community a means to be heard and is an important symbol of recognition by the federal government of efforts to end their suffering. The CFSAC also represents an opportunity to strengthen collaborations that will ultimately result in a deeper understanding of CFS, more effective treatments and, ultimately, cure and prevention strategies." I believe those words hold true today and that this committee is need more than ever.

Current Status of CFSAC

While there have been a number of deep frustrations with the committee's function and the lack of direct responsiveness to the recommendations submitted to the Secretary since the first CFSAC meeting in 2003, the CFIDS Association of America remains committed to sustaining this committee and maintaining an opportunity to hear from, provide input into and receive response from the federal agencies of the DHHS charged with meeting the compelling scientific, medical, public health and policy challenges imposed by CFS.

In response to the Department's request for testimony on the topic of the CFSAC's charter, the CFIDS Association makes the following recommendations.

Function

The function of the CFSAC as stated in the charter is to "advise and make recommendations to the Secretary, through the Assistant Secretary for Health, on a broad range of topics including:

1. The current state of knowledge and research about the epidemiology and risk factors relating to chronic fatigue syndrome, and identifying potential opportunities in these areas;
2. Current and proposed diagnosis and treatment methods for chronic fatigue syndrome; and
3. Development and implementation of programs to inform the public, health care professionals, and the biomedical, academic and research communities about chronic fatigue syndrome advances."

Much of the disappointment within the community as it relates to this committee stems from the relatively low rate of 18% of the recommendations made by the CFSAC having been implemented by the Department, according to the Federal Advisory Committee Act Database (<http://fido.gov/facadatabase>). This alarming statistic must be confronted and addressed.

There are two recommendations from the Association to address the purpose, scope and efficiency of the committee.

1. The function of the committee should be expanded to include the following:
 - a. Develop and annually update a summary of advances in CFS research related to causes, prevention, treatment, early screening, diagnosis or ruling out a diagnosis; intervention, and access to services and supports for individuals with CFS;
 - b. Monitor Federal activities with respect to CFS;
 - c. Make recommendations to the Secretary of Health and Human Services (Secretary) regarding any appropriate changes to such activities, including recommendations to the Director of NIH with respect to the strategic plan;
 - d. Make recommendations to the Secretary regarding public participation in decisions relating to CFS;
 - e. Develop and annually update a strategic plan for the conduct of, and support for, CFS research, including proposed budgetary requirements; and
 - f. Submit to the Congress such strategic plan and any updates to such plan.

This text mirrors the Objectives and Scope of Activities as written in the charter for the Interagency Autism Coordinating Committee (<http://iacc.hhs.gov/about/charter.shtml>), another FACA committee maintained by DHHS. Use of this model, particularly the expansion of the scope of the committee to include the **development of a strategic plan for CFS research**, would increase the likelihood that recommendations made by the committee would be consistent with a multi-year strategic and budgetary framework, rather than being responsive to topic-specific discussions at a particular meeting.

2. Revise the meeting agenda template to give more time, earlier in each session, to formulation of recommendations by the appointed members. At past CFSAC meetings, the process of developing recommendations does not begin until the very end of the meeting and the process regularly suffers from time pressures and departures by key individuals due to travel constraints.

Structure

Public Members

According to its charter, 11 appointees are selected by the Secretary according to these guidelines: "Of the 11 members, 7 shall be biomedical research scientists with demonstrated expertise in biomedical research applicable to chronic fatigue syndrome; 4 shall be individuals with expertise in health care delivery, private health care services or insurers, or voluntary organizations concerned with the problems of individuals with CFS."

FACA requires that members of the public be permitted to nominate individuals for service on this committee; however, it is often unclear which categories of membership certain individuals hold, and therefore, which positions are open for nomination. It would be helpful if the roster of appointees included a designation as to which category of membership each individual was selected to fill.

Ex-Officio Members

Representatives of DHHS and four DHHS Operating Divisions, plus the Social Security Administration, serve as non-voting, ex-officio members of the CFSAC. Stated below are the Association's recommendations for which positions should serve as ex-officio representatives as well as additions for representations from two other operating divisions to address areas not adequately covered by the existing Department staff:

Department of Health and Human Services (DHHS)

1. Principal Deputy Assistant Secretary for Health (serving as executive secretary)
2. Senior staff, Office of the Surgeon General
3. Deputy Assistant Secretary for Health (alternate)

Agency for Healthcare Research and Quality (AHRQ)

1. Director, Center for Primary Care, Prevention and Clinical Partnerships
2. Deputy Director, Center for Primary Care, Prevention and Clinical Partnerships (alternate)

Centers for Disease Control and Prevention (CDC)

1. Deputy Director, Office of Infectious Diseases
2. Director, National Center for Emerging and Zoonotic Infectious Diseases (alternate)

Centers for Medicare and Medicaid Services (CMS)

1. Deputy Director, Office of Clinical Standards and Quality
2. Deputy Chief Medical Officer, Office of Clinical Standards and Quality (alternate)

Food and Drug Administration (FDA)

1. Associate Commissioner, Office of Special Medical Programs
2. Associate Commissioner, Office of External Affairs (alternate)

Health Resources and Services Administration (HRSA)

1. Chief Public Health Officer, Office of the Administrator
2. Chief Medical Officer, Bureau of Primary Health Care (alternate)

National Institutes of Health (NIH)

1. Deputy Director, Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI), Office of the Director
2. Director, Office of Research on Women's Health, Office of the Director (alternate)

Social Security Administration (SSA)

1. Associate Commissioner, Office of Disability Programs
2. Deputy Associate Commissioner for Disability Programs (alternate)

Liaison Representatives

Although it is understood that the scope of the CFSAC is limited to the Department of Health and Human Services and its operating divisions, the addition of liaison representatives from other Departments would provide additional information and perspectives vital to the work of

the committee and would serve in the absence of a cross-department (Presidential) coordinating committee on CFS. Participation could not be legally required, but it could be regularly invited and encouraged. These departments have ongoing activities of relevance and direct importance to DHHS, its operating divisions and the public:

- Department of Defense
- Department of Education
- Department of Labor
- Department of Veterans Affairs

Meeting Structure

Under the current charter, "meetings of the full Committee shall be held not more than two times a year." It is the Association's strong recommendation that this language be amended to read, "Meetings of the full Committee shall be held not less than two times a year, for a minimum of two days each."

Notice of all meetings must be given to the public within one week of the meeting per the Government in the Sunshine Act. Because of the special needs of patients who wish to attend these meetings, it would be an apt accommodation to require a longer notice period of 30 days to maximize the opportunity for individuals with CFS to arrange transportation, lodging, and sufficient energy reserves. To ensure this accommodation is observed uniformly, the Association recommends writing it into the charter.

To preserve the opportunity that was begun with the May 2009 meeting, enhancing the ability for members of the public to attend through a live meeting webcast and archiving of the webcast recording on the CFSAC's website, we urge that both be incorporated as requirements under the revised charter.

Finally, we strongly recommend that the equivalent of one hour of each meeting day be dedicated to receive testimony from public witnesses, delivered either in person, by telephone or by video. The period of time allocated to each witness should not be less than five minutes. Priority should be given to witnesses who have not appeared before the CFSAC in the past 12 months. Witnesses should be permitted to use their allotted time to read a prepared statement, to offer comments on committee reports or discussion or to ask questions of the committee, including ex-officio members; however, in fairness to all witnesses, time limits should be enforced equitably.

Conclusion

In conclusion, the CFIDS Association of America strongly supports the continued operation of the CFS Advisory Committee and requests that its charter be revised and renewed well in advance of the September 5, 2010 expiration date. With the enormous burden of illness imposed by CFS on the individual, the community and our nation, swiftly advancing research and a deepening need for improved education and care for this underserved population, it is imperative that this forum for exchange, collaboration and accountability be strengthened and utilized to its full potential to speed progress and meaningful change.

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April 26, 2010