

Chronic Fatigue Syndrome Advisory Committee
US Department of Health and Human Services
Washington, DC 20201

December 7, 2011

The Honorable Kathleen Sebelius
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Sebelius:

The Chronic Fatigue Syndrome Advisory Committee (CFSAC) is charged with providing evidence-based advice and recommendations to you, through the Assistant Secretary for Health, on a broad range of issues and topics pertaining to chronic fatigue syndrome (CFS). The Committee met November 8-9, 2011, and developed the following recommendations with unanimous agreement, for your consideration:

Recommendation 1

This recommendation addresses the process by which CFSAC transmits recommendations to the Secretary and the Secretary communicates back to CFSAC whether or not a recommendation was acted upon. CFSAC recommends that this process be transparent and clearly articulated to include regular feedback on the status of the committee's recommendations. This communication could originate directly from the Office of the Secretary or be transmitted via the relevant agency or agencies.

Recommendation 2

CFSAC recommends to the Secretary that the NIH or other appropriate agency issue a Request for Applications (RFA) for clinical trials research on chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME).

Recommendation 3

CFSAC would like to encourage and support the creation of the DHHS Interagency Working Group on Chronic Fatigue Syndrome and ask this group to work together to pool resources that would put into place the "Centers of Excellence" concept that has been recommended repeatedly by this advisory committee. Specifically, CFSAC encourages utilizing HHS agency programs and demonstration projects, available through the various agencies, to develop and coordinate an effort supporting innovative platforms that facilitate evaluation and treatment, research, and public and provider education. These could take the form of appropriately staffed physical

locations, or be virtual networks comprising groups of qualified individuals who interact through a variety of electronic media. Outreach and availability to underserved populations, including people who do not have access to expert care, should be a priority in this effort.

Recommendation 4

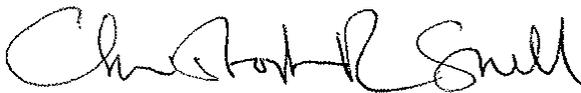
This multi-part recommendation pertains to classification of CFS in ICD classification systems:

- a) CFSAC considers CFS to be a multi-system disease and rejects any proposal to classify CFS as a psychiatric condition in the U.S. disease classification systems.
- b) CFSAC rejects the current classification of CFS in Chapter 18 of ICD-9-CM under R53.82, chronic fatigue unspecified, chronic fatigue syndrome, not otherwise specified.
- c) CFSAC continues to recommend that CFS should be classified in ICD-10-CM in Chapter 6 under Diseases of the Nervous System at G93.3 in line with ICD-10, the World Health Organization, and ICD-10-CA, the Canadian Clinical Modification and in accordance with CFSAC's recommendations of August 2005 and May 2011. CFSAC rejects CDC's National Center for Health Statistics Option 2 and recommends that CFS remain in the same code and the same subcode as myalgic encephalomyelitis because CFS includes both viral and non-viral triggers.
- d) CFSAC recommends that an "excludes one" be added to G93.3 for chronic fatigue, R53.82, and neurasthenia, F48.8. CFSAC recommends that these changes be made in ICD-10-CM prior to its rollout in 2013.

This final recommendation was also provided to the National Center for Statistics at the CDC prior to the November 18, 2011 deadline for comments along with the following rationale:

We feel that the interests of patients, the scientific and medical communities, continuity and logic are best served by keeping CFS, (B)ME (Benign Myalgic Encephalomyelitis) and PVFS (Post Viral Fatigue Syndrome) in the same broad grouping category. Current scientific evidence would indicate there are more similarities between the three entities than there are differences. Whether they are synonyms for the same underlying concept, disease entities and sub-entities, or merely the best coding guess is unclear. In reality, any or all of the above may be correct. While the relationship between CFS, B(ME) and PVFS is not stated, that they are grouped together in ICD 10 (WHO) would indicate some rationale for a connection. Our understanding is that this association will be maintained in the ICD 11, which may also include further description of the relationship. Exclusions specific to chronic fatigue (a symptom present in many illnesses) and neurasthenia (not a current diagnosis) also seem to be under consideration for ICD 11.

Sincerely,



Christopher R. Snell, Ph.D.
Chair, CFSAC

