

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

May 25, 2011

The Honorable Kathleen Sebelius
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 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 May 10-11, 2011, and developed the following recommendations with unanimous agreement, for your consideration:

1. CFSAC rejects current proposals to code CFS in Chapter 18 of ICD-10-CM under R53.82: Chronic fatigue, unspecified > Chronic fatigue syndrome NOS. 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 and ICD-10-CA (the Canadian Clinical Modification), and in accordance with the Committee's recommendations of August 2005. CFSAC considers CFS to be a multi-system disease and rejects any proposals to classify CFS as a psychiatric condition in US disease classification systems. (NOTE: no disease classification system under HHS' control proposes to move or to include CFS in or among psychiatric conditions.)
2. ME/CFS is an illness with enormous economic and human costs. The April 2011 NIH State of Knowledge Workshop indentified a number of gaps in what is known about the illness. To address these gaps warrants an interagency effort comprising, but not limited to, NIH, CDC, and AHRQ. Further, the focus should be on interdisciplinary discovery and translational research involving interacting networks of clinical and basic science researchers. Areas to be examined would include the following: identification of patient subsets for detailed phenotyping and targeted therapeutic interventions, biomarker discovery, systems biology approaches and disability assessment.

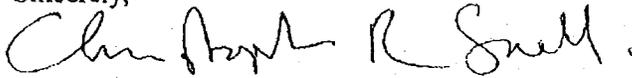
To facilitate the above goals, CFSAC recommends that ME/CFS research receive funding commensurate with the magnitude of the problem and that the NIH (and/or other appropriate agencies) issue an RFA specifically for ME/CFS.

3. CFSAC asks that HHS organize a workshop to engage experts in disability assessment, the outcome being a document useful to patients and adjudicators which could contribute to a more efficient and fair disability process.

The Assistant Secretary for Health has participated in the last three CFSAC meetings, showing high-level interest in the Committee's activities. Many developments over the past year have been very encouraging to ME/CFS patients, researchers, providers, and others, and the Department's increased visibility is most welcome. The May meeting drew a large number of in-person attendees, and featured compelling testimony from young people and families who reported onset of ME/CFS as early as age 8.

We believe action at this time is important to change the way ME/CFS is viewed in the United States and worldwide. I am happy to discuss any of these recommendations with you at your convenience.

Sincerely,

A handwritten signature in black ink, appearing to read "Chris Snell". The signature is fluid and cursive, with a large initial "C" and "S".

Christopher R. Snell, Ph.D.
Chair