

For those who are following the Chronic Fatigue Syndrome Advisory Committee (CFSAC) progress, there is little. There seems to be no forward movement or recommendations that move up to Secretary of Health & Human Services Sebelius' office.

At the Spring 2013 meeting, the CFSAC committee recommended that HHS accept the Canadian Consensus Criteria (CCC) and the Primer put out by the International Association of Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (IACFS/ME).

Quietly and rather suddenly, the the Department of Health and Human Services (HHS) have put forth a contract with the Institute of Medicine (IOM) to create a definition for CFS. The problem—this organization simply looks over already published material to reach their conclusions. There might be no experts in the field of CFS involved. If there wasn't such a wealth of incorrect studies published basically on how this illness is psychiatric in nature, it wouldn't be an issue. Then, due to an overwhelming backlash from patients and advocates, the HHS seemed to back down. But in a sudden reversal of this, the HHS signed the contract with the IOM. Although HHS claims IOM will consult with CFS/ME experts, patients have been down this road before and remain skeptical at best.

Now a large group consisting of thirty-five national and international CFS/ME researchers/clinicians have signed onto an open letter sent to Secretary Sebelius pressing the requests to accept the CCC.

The signatory names are impressive and reflect years of knowledge. We sincerely hope the government agencies will listen to them. The Open Letter was first circulated on CO-CURE on 9/24/2013. The letter was [re-issued with additional signatures](#) on October 25, 2013.

An Open Letter to the Honorable Kathleen Sebelius, U.S. Secretary of Health and Human Services

September 23, 2013

Dear Secretary Sebelius,

We are writing as biomedical researchers and clinicians with expertise in the disease of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) to inform you that we have reached a consensus on adopting the 2003 Canadian Consensus Criteria (CCC) as the case definition for this disease.

The 1994 International Case Definition (Fukuda *et al*, 1994), commonly known as the Fukuda definition, was the primary case definition for ME/CFS for almost two decades. However, in recent years expert researchers and clinicians have increasingly used the CCC, as they have recognized that the CCC is a more scientifically accurate description of the disease.

The CCC was developed by an international group of researchers and clinicians with significant expertise in ME research and treatment, and was published in a peer-reviewed journal in 2003 (Carruthers *et al*, *Journal of Chronic Fatigue Syndrome*, 2003). Unlike the Fukuda definition, the more up-to-date CCC incorporates the extensive scientific knowledge gained from decades of research. For example, the CCC requires the symptom of post-exertional malaise (PEM), which researchers, clinicians, and patients consider a hallmark of the disease, and which is not a mandatory symptom under the Fukuda definition. The CCC was endorsed in the Primer for Clinical Practitioners published by the International Association of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFSME). This organization is the major international professional organization concerned with research and patient care in ME/CFS.

The expert biomedical community will continue to refine and update the case definition as scientific knowledge advances; for example, this may include consideration of the 2011 ME International Consensus Criteria (Carruthers *et al*, *Journal of Internal Medicine*, 2011). As leading researchers and clinicians in the field, however, we are in agreement that there is sufficient evidence and experience to adopt the CCC now for research and clinical purposes, and that failure to do so will significantly impede research and harm patient care. This step will facilitate our efforts to define the biomarkers, which will be used to further refine the case definition in the future.

We strongly urge the Department of Health and Human Services (HHS) to follow our lead by using the CCC as the sole case definition for ME/CFS in all of the Department's activities related to this disease.

In addition, we strongly urge you to abandon efforts to reach out to groups such as the Institute of Medicine (IOM) that lack the needed expertise to develop "clinical diagnostic criteria" for ME/CFS. Since the expert ME/CFS scientific and medical community has developed and adopted a case definition for research and clinical purposes, this effort is unnecessary and would waste scarce taxpayer funds that would be much better directed toward funding research on this disease. Worse, this effort threatens to move ME/CFS science backward by engaging non-experts in the development of a case definition for a complex disease about which they are not knowledgeable.

ME/CFS patients who have been disabled for decades by this devastating disease need to see the field move forward and there is no time to waste. We believe that our consensus decision on a case definition for this disease will jump start progress and lead to much more rapid advancement in research and care for ME/CFS patients. We look forward to this accelerated progress and stand ready to work with you to increase scientific understanding of the pathophysiology of this disease, educate medical professionals, develop more effective treatments, and eventually find a cure.

Sincerely,

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