Public Comment
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My life took a pivotal turn in February 2003 when I became very sick with what was ultimately diagnosed as Myalgic Encephalomyelitis known as Chronic fatigue Syndrome in the U.S. Since that time I have been disabled from work and am reliant on others for my care.

Throughout my eleven year illness, I have suffered a lot but, lately what I have been feeling is anger. This anger has been fueled by the organized effort of HHS to marginalize this disease and mistreat its patients.

The following quote by Hubert H. Humphrey is highlighted on the HHS website:

'It was once said that the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; ***and those who are in the shadow of life, the sick, the needy and the handicapped****.'*

As a person 'in the shadow of life' I do not feel that HHS has my best interest in mind. HHS has repeatedly ignored the voice of the patients, advocates and the ME/CFS expert community. The NIH has repeatedly denied the appropriate funding for research into the disease and the CDC has given it the pitiful name 'Chronic Fatigue Syndrome' in 1988 after the Lake Tahoe outbreak. In 1994 the CDC produced the Fukuda Diagnostic Criteria which is a broad definition and has hampered the outcome of serious research in the disease. To date, the CDC still promotes cognitive behavior therapy, graded exercise and administration of anti-depressants in spite of the fact that this has not be proven to be successful for patients. Moreover, exercise has been proven to be damaging. **Yet, the CDC still refuses to include the two day exercise testing, in their current multi-site study, as advocated by the medical community.**

It is this perpetuation of ignorance of the real disease and the dissemination of harmful information that has had patients, advocates, clinicians and researchers in the field in an uproar at the latest activity by the HHS to continue in this vein by contracting with the IOM to re-define ME/CFS. This has been done in the most devious and deceitful way, starting in August when a sole solicitation announcement suddenly appeared on a website, until the recent anonymous Q&A sent out from CFSAC's listserv which left more questions than answers. Many really troubling questions remain, such as:

Why did HHS lie on September 4th with their announcement that they were cancelling the sole solicitation when really they were forging ahead full force?

When, where and with which voting members of CFSAC did HHS consult with before embarking on this project?

Why is it that HHS and SSA are the only agencies listed as sponsors on the IOM website when HHS has stated that 'almost all' of the agencies contributed?

HHS states that the CCC is not adequate because it is 10 years old and doesn't take into account recent information. If that is the reason, why not just revise it with the latest data, like it's done with all diseases by the experts in the field?

Why has HHS ignored and not replied to the letter form 50 experts and the supporting letter by 171 advocates urging them to cancel this contract and to adopt the CCC now?

HHS stated that they **do not** generally make formal endorsements of clinical recommendations made by **nongovernmental** groups, as an excuse of why they will not adopt the CCC. Does this mean that HHS will **not endorse** the IOM definition because the IOM is a **non-governmental** group?

How confident is the HHS in IOM's ability to deliver a non-biased definition given the results of IOM's studies on Gulf war Illness, re-named by the IOM to Chronic Multisymptom Illness? As part of the IOM's studies on GWI, sections are devoted to CFS, as the IOM feels these are similar conditions. The IOM has already coined Chronic Fatigue Syndrome as a somatoform illness fitting under the umbrella of the vague 'Chronic Multisymptom Illness', needing CBT, GET, anti-depressants and relaxation therapy for treatment.

Is it a coincidence that CFS and GWI are the only diseases tasked by the IOM, in its history, to generate new definitions for? Is this a concerted organized action by the government to distort, minimize and psyhologize these two diseases into oblivion?

There is not enough time for me to mention all the inconsistencies and holes in this nefarious action by HHS. This follows of course the most disturbing non-response by HHS to the very real allegations by some of the voting CFSAC members that they were threatened by the DFO, Dr. Nancy Lee, at the last CFSAC meeting. Is this another misdeed that will be swept under the rug? How can we be assured that these hard working voting CFSAC members can speak and act freely without feeling like they are being gagged?

I strenuously suggest that today you make two absolutely crucial recommendations:
1) that CPET be required in the CDC's multi-site study and
2) that you fully and strongly endorse the letter of the 50 ME experts demanding HHS not contract with IoM to redefine ME and that HHS immediately adopt the ME/CFS Canadian Consensus Criteria.