



As I See It: Watchful Waiting for a Transitioning CFSAC

By Kenneth Friedman, PhD

At the semi-annual CFSAC meeting held in Washington, DC, on October 28 and 29, 2008, Anand Parekh, the current Designated Federal Officer (DFO), announced that he would be stepping down from that position. He will be replaced by Wanda K. Jones, another “career” employee in the Office of the Secretary and the Deputy Assistant Secretary for Health (Women's Health). She currently serves as the Director of the Office on Women's Health (OWH). In that capacity, Dr. Jones has focused her efforts on eliminating health disparities for women.

Why the change? According to Dr. Parekh and the statement subsequently issued and placed on the CFSAC website, the CFSAC had not been in an office that could and should have been providing technical and logistical support services for the committee as well as for the illness of chronic fatigue syndrome (CFS). Thus, the change in leadership and the assignment of CFS to the Office of Women's Health, is, we are assured, a positive step forward. Dr. Parekh has also given his assurances that he would still maintain an interest in both CFS and the CFSAC, and advise both the Committee and its new DFO.

Observers who have attended Advisory Committee meetings, as well as members of the Advisory Committee, would agree that support services for this Committee have been less than ideal. Perhaps the changes will provide improvement in Committee function.

The placement of the CFSAC in the Office of Women's Health, however, seems to be an inappropriate placement. Granted, the majority of CFS patients are women. But approximately 1 out of every 4 or 5 patients is male; and in the pediatric population of CFS patients, there seems to be no or little gender preference. For an illness to be classified as a woman's illness, the ratio is more like 300 affected women ill for each affected man.

In and of itself, the placement of the CFSAC in the Office of Women's Health of the Secretary of Health and Human Services might raise little-to-modest concern or suspicion. However, the placement of the National Institutes of Health Chronic Fatigue Syndrome research program (albeit embarrassingly modest) also in its Office of Research on Women's Health seems like an extraordinary coincidence.

A question begs to be asked: Is the placement, and therefore the classification of CFS in the Offices of Women's Health by both National Institutes of Health and the Department of Health and Human Services, a coincidence or a hidden agenda?

We simply do not know.

In medicine, and particularly for some men with prostate cancer, there is a term and procedure called *watchful waiting*. Watchful waiting is used when it is unclear as to what course of treatment would be in the best interests of the patient. During periods of watchful waiting, great care is taken to be cognizant of any undesirable changes in the patient's condition.

At this juncture, it seems prudent to initiate a period of watchful waiting for the CFSAC. The CFS Community needs to pay particular attention to the work and workings of the CFSAC to determine whether what has been promised, namely, the enhanced technical and logical support of the Committee, as well as increased efficiency of implementing the Committee's recommendations, is actually being delivered.