

CFSAC Recommendations by Cort Johnson (Phoenix Rising) 4.26/ 2010

Studies suggest that chronic fatigue syndrome (ME/CFS) affects at least 1 million people in the United States, has very high rates of disability and is responsible for tens of billions of dollars of economic losses yearly. These statistics indicate ME/CFS is a major disorder that has major consequences yet they are not the most troubling statistics for the ME/CFS community. The ME/CFS community is well aware of the effects of ME/CFS, they deal with them personally every day; the loss of financial security, the deferred dreams, the blank stares at the doctor's office, the friends and family who just don't understand, the fears of declining health...these are some of the personal trials that many people with ME/CFS face regularly and they face them in large part with honor and dignity.

What they cannot understand is the indifference should the federal government has shown to them. It's almost as if the federal government decided to wave a magic wand that made a large class of people utterly disappear from its view.

For all its multi-billion dollar budgets and its commitments to tackle cancer and AIDS and all manners of vicious diseases it's clear that the NIH, at a very basic level, lacks, for a better word, "balls". If you're lucky enough to become depressed or get infected with HIV or come down with diabetes you may have a severe illness but you have the benefit of an immense infrastructure and hundreds of millions of dollars a year in funding designed to back you in your quest for health. If you're unlucky enough to get a disorder like chronic fatigue syndrome you'll have virtually nothing; few proven treatments, few doctors even able to diagnose correctly and even fewer able to treat you adequately and virtually no research devoted to it.

What did people with ME/CFS do to deserve such Third World treatment? They simply came down with a disorder that doesn't have good diagnostic criteria, is multi-systemic and complex in nature... - and has devastating results. They were unlucky enough to be born in an era when federal officials decided that 'need' counts for little in their decisions to allocate funding. They were unlucky to be alive during a time when it was quite alright, year after year, to let 1,000,000 ill people slip through the cracks because they didn't fit in the right box.

The plight CFS patients face every day is not the result of researchers making bad decisions - its result of bureaucrats who either didn't have enough guts or vision or simply compassion to stand up for all of their charges - not just the ones who fit easily into the right boxes. In the end the main problem with CFS is not the disease; it's a problem of compassion, of understanding, of simply caring...on those levels - and on the needed dedication to make a difference for people with this disorder - the federal government gets a 'F'..

The saga of the CFSAC well demonstrates the indifference that has been the hallmark of the federal government's response to chronic fatigue syndrome. Only 18% of recommendations have been acted on (probably a generous estimate) and none of the major ones. Two weeks before the meeting the agenda has still not been posted, none of the four replacements for the outgoing

committee members have been announced and the meeting time has been reduced from two days to one day. Despite the interest generated by the XMRV finding every indication is that the CFSAC committee continues to wither on the vine.

Recommendations regarding the CFSAC Charter

- Please renew the CFSAC charter and strengthen it.
- Return meeting times to four times a year to provide continuity to the committee's efforts and to allow them to respond in a timely manner to events.
- Mandate that live video presentations of the committee meetings be required and archived on the site
- Require that a complete list of all Committee recommendations with their dates and the responses to them with their dates be posted on the CFSAC website
- Given the wide variety in treatment care in the CFS community, mandate that a representative from the Agency for Healthcare Research and Quality (AHRQ) be made an ex-officio member
- Require NIH representatives to submit statistics on CFS grants received and their outcomes at every meeting.
- The CFSAC Charter should require that CFSAC members yearly produce a strategic plan for the CFS federal research effort that incorporates budgetary elements in it.
- Mandate that all ex-officio members create a report on the status of their CFS programs including relevant statistics and the fate of CFSAC recommendations specific to their programs. For instance, the Trans-NIH Working Group at the NIH should be required produce a report stating the activities they have engaged in to increase research funding, including the number of meetings they have attended and the length of those meetings, the # of CFS grants applied for and their fate including, if they were rejected, at which stage of the approval process they were rejected. All reports should identify potential roadblocks in their attempts to secure better a better federal response to CFS and actions they are taking to surmount them.
- Dr. Wanda Jones has won the appreciation of many people with CFS for her commitment to assist the Committee in their work. Please continue Dr. Jone's tenure.