

APRIL 24, 2006 CFSAC

In 2004, I reported to the CFSAC that from FY 2000 to 2003, few awards were granted to CFS proposals. That report appears at www.wicfs-me.org - Articles page, #2. At that time, my source was the CRISP database and whatever other information I could find online.

In September of 2004, Kim McCleary of the CFIDS Association presented another, more detailed report analyzing funding patterns and questioning the use of CFS funds for studies of other illnesses.

I understand that within the Office of Research and Women's Health, dollars are not designated for specific illness to include CFS. However, on NIH FY budget reports, CFS shows as a line item, which creates the impression that about 5 to 6 million dollars a year is spend on CFS investigations.

I come to this committee about 2 years later with an update. My sources include charts from the Office of Extramural Research obtained through three different FOIA requests and information from the ORWH website page – the Trans- NIH Working Group Grants information list.

I was prompted to continue my analysis because lists of Chronic Fatigue Syndrome Special Emphasis Panel (CFS SEP) reviewers show, with considerable background check, very few scientists with CFS expertise. I wrote to Antonio Scarpa, Director for the Center for Scientific Review, as well as others, some of who are CFSAC Officials, to say that with few CFS grants funded and CFS SEP panel members lacking CFS expertise, the results would show bias in granting funds for further CFS study.

Dr. Scarpa encouraged me to share this message:

Dear Ms. Fero:

We have been working to address some of your concerns and those who wrote us concerning review of Chronic Fatigue Syndrome. As you know, the Neuroimmune Mechanisms and Chronic Fatigue Syndrome RFA is about to be reviewed. We have confidence that the review team under the leadership of Chair Peter Rowe will appropriately evaluate the applications received.

By the way, you may be interested to know that the recurring special emphasis panel that has been handling CFS and related applications, ZRG1 CFS (01), has grown significantly. In fact the growth has been sufficient to establish its own percentiling base consisting of the current and two previous cycles. Our business rule is that the three-cycle base must contain at least 25 R01 applications. Thus, beginning with the 2006/05 cycle, the CFS applications will be percentiled against themselves.

I hope that you distribute this to all concerned. Thank you again for your input.

Best,

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Puzzled by the good news that CFS submissions had increased significantly, I decided to find information from the NIH to demonstrate this. I would expect to find increased CFS funding. Unfortunately, that is not the case

Using FOIA spreadsheets and the trans NIH working group information, I compiled the attached data. Several conclusions present the harsh reality that this Health and Human Services Committee developed

to help CFS patients, scientists and the general public, is at odds with NIH agencies that would, by looking at funding patterns alone, bring about the demise of CFS research.

Consider the following:

1. The data attached shows that in 2005, ONE new CFS proposal was funded. Renewed non-competing CFS grants (non reviewed) are in a downward spiral. Logically, one cannot renew grants unless funds were awarded from a new proposal. Looking back to 2004, 2003 and all the way to 1999, the year the GAO investigated CDC and NIH CFS funding, a pattern emerges that defies all GAO recommendations for the NIH.

2. I asked at the CFSAC meeting in March of 2004 if all CFS grants go to the CFS SEP. The answer was yes. That is not the case. In fact, on the Trans NIH working Group grants information pages, some years show more CFS grants reviewed by NON CFS SEP groups than by the CFS SEP. (see 2003 – 2002) This presents numerous ideology and monetary concerns. The process is so muddy that I am not able to make sense of the grants information. In addition, with the lack of transparency, patients, advocates as well as scientists may conclude that money is missing or misappropriated. Please do not infer or assume that I believe this is the case.

3. In looking at grant titles and researchers, their institutions, new, competing renewals, and non-competing grants from 2005 back to 1999, the study of 2 CFS symptoms, PAIN & FATIGUE is well underway. (See attached) These symptoms overlap with Fibromyalgia and are primary FM symptoms. Continued Fm research is noteworthy as patients suffer with daily symptoms. However, as a CFS patient and a representative of CFS patients in Wisconsin and nationally, I object to a mere 10 cents of my research dollar going to fund CFS specific research.

4. Can this HHS committee, a federal advisory committee at the highest level, continue with it's mission in light of the apparent increased opposition as expressed in ACTIONS, not WORDS, by the NIH in regard to CFS? Can the CFIDS Association and the International Association for CFS (IACFS) continue with developing public awareness, providing educational opportunities, when the situation in CFS research is dire?

Lastly, let it be known that I am not divisive. Do not conclude that I oppose FM advocacy and continued funding of FM studies. Do not conclude that I am hostile to this committee, to the CFIDS Association and the International Association for CFS (IACFS). I would propose that this committee, any organization, and all patients, ask for internal review and evaluation of CFS funding practices at the highest level and that the process be transparent to the public.

I asked for this investigation 2 years and several lifetimes ago. We did have the Request for Applications funded by \$4 million dollars set aside for areas of CFS research. To date, we have no results from the IC about awarded grants. I dearly hope that CFS specific grants are awarded, but the data contained here, tells me that this may not be the case. Perhaps, it is too late.

As I present today, this same information is being sent nationally and internationally to patients, advocates, Health and Human Services employees, and to political representatives. Be informed that I entrust you with this information. To ignore it, is to violate the public trust. I expect better.

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