

John Herd

5/10/10 Testimony to the CFS Advisory Committee

Within the past few years, CFSAC members have earned respect from the patient community by focusing on challenging issues.

Exploring our public health agencies program commitment to good science and effective use of funding must be a continued priority for this committee. In the same way that the CFSAC persisted with investigating program priorities and funding within the Centers for Disease Control, now it is time to turn to the most important and largest biological research institution in the United States, the National Institutes of Health.

Past meeting minutes indicate that CFSAC members sought out information from NIH personnel. Members have listened to testimony about the downward spiral of NIH funding for CFS, the funding of 1 to 2 new grants per year and the apparent low funding rate for CFS science applications.

On behalf of patients, their families, doctors and researchers, I believe that the CFSAC must continue to motivate the advancement of good science by exploring NIH CFS program commitment and effective use of funding.

A formal report is being prepared for the fall meeting. We formally request that the noted problems with NIH research funding and those to be submitted in the formal report be put on the fall agenda.

There has been more than an institutional scientific negligence in how the National Institutes of Health, has met the challenge to understand chronic fatigue syndrome (CFS). There has been side stepping, deception through doublespeak and collaborating systemic malfeasance within NIH.

NIH has not improved its handling of CFS matters, nor stimulated extramural research. Extramural research of CFS has had to proceed not with the help of NIH, but despite the activities and inactivities of NIH.

NIH has not met its fiduciary responsibilities to people who have CFS.

If the Department of Health can't police itself to meet those responsibilities, then it is time for our elected officials in Congress to become involved in ways we had hoped would be unnecessary.

I will email these comments in at the end of the meeting. Thank you for the time to present these statements, and thank you to all whom have given their time and energy to the work of the CFS Advisory Committee.

These two statements have been a collaboration by Pat Fero and myself,
John Herd