

Testimony

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The Department of Health and Human Services needs to take immediate action to resolve the issues of ME/CFS case definition and International Statistical Classification of Diseases (ICD) coding. The term ME/CFS is as yet undefined or one could say it has various case definitions depending on a person's orientation toward the disease. The most recent, the 2005 CDC Empiric Definition, has such poor specificity that, according to Professor Leonard Jason whom has studied this issue in depth, most persons with clinical depression would meet the CFS disability criterion. The need for a standardized case definition for research purposes came up again and again at the recent NIH State of the Knowledge Workshop. No progress can be made in understanding without consistent selection of CFS cohorts. The Canadian Consensus Criteria comes the closest of the definitions in use to describing this illness, requiring that a patient have the hallmark symptom of postexertional malaise and/or fatigue. In addition it requires that the person have two or more of a set of neurological symptoms.

Which leads me to the second issue, proposed changes for ICD10-CM which would place ME/CFS under R53: Malaise and Fatigue with a coding of R53.82 - Chronic Fatigue Unspecified. This is totally misleading and will further erode the credibility of this very real biomedical disease in the eyes of physicians. Chronic Fatigue Syndrome is a complex multisystem disease that involves the central nervous system. In the longstanding dispute over the name, much has been said about the inappropriateness and damage medically and socially of characterizing the illness in terms of fatigue. This illness should be categorized under Diseases of the Central Nervous System along with Myalgic Encephalomyelitis at G93.3, consistent with the World Health Organization and other country specific classification systems.

If HHS does nothing but adopt the Canadian Consensus Definition and require its usage in all ME/CFS research funded by the federal government and in addition acts to place ME/CFS under Diseases of the Central Nervous System within ICD10-CM, a significant start will have been made.

Lack of funding must be addressed. Pat Fero has documented the sorry state of NIH Funding. This illness ranks close to the bottom even though the illness in

severity for many patients has been compared to late stage AIDS by more than one specialist. The level of dysfunctionality on average has been rated worse than MS by one researcher. The findings of XMRV and related viruses in high numbers of persons with ME/CFS calls for the immediate funding of research into this family of gamma retroviruses. Yet there have been no grants approved for the Whittemore Peterson Institute. There needs to be an investigation into this inexplicable fact.

I request that the Department of Health and Human Services please adopt the recommendations of the CFSAC which I am sure will include at least some of the above items. I know that proposals have been made about these issues in previous years. Change is long overdue.

Thank you for your consideration.