

Public Comment
Anonymous

I would like to make a couple of recommendations:

The government should dramatically increase funding for biomedical research for ME/CFS to a level commensurate with the severity and wretchedness of the illness. It is most distressing to learn that NIH spends a meager \$3-4 per patient specifically for ME/CFS while male-pattern baldness gets \$16 per patient. This clearly shows the government's lack of understanding of and insight into the devastating nature of ME/CFS.

HHS should involve ME/CFS experts and patients in major decisions involving ME/CFS, like the FDA has done. ME/CFS experts and patients should have been involved in HHS' recent decision to develop a new ME/CFS definition at a whopping cost of \$1,000,000. If possible, HHS should cancel the IOM contract and use the Canadian Consensus Criteria. If not, it is crucial that HHS select ME/CFS experts with long-term experience with the illness as members of the panel. Otherwise, the resulting definition will likely be of little value to patients and a gigantic waste of government money. As Jen Brea, Harvard student and ME/CFS documentary film-maker has pointed out, "There is something elusive in the nature of the illness such that unless you live it, or live with and care for someone who does, it's almost impossible [to] understand or describe. You might come close after decades of treating patients. At every turn, language fails." Use seasoned ME/CFS professionals who have gained real insight into the illness over time. Do not use professionals who have not had the advantage of years of experience with the illness. They would gain a factual acquaintance with ME/CFS, but not a real understanding of the ME/CFS experience.

Thanks to all of you for your service on this committee. I hope you can move the cause of ME/CFS forward with a much greater sense of urgency to get help to patients who suffer unimaginably with this illness.

Respectfully,

Anonymous/hope