

Dear CFSAC members,

I am from the UK and understand that you are looking at ways to improve your current charter, and have requested input from the public as this is a topic to be discussed at the CFSAC meeting to be held in May. I hope you feel input from someone outside the US is acceptable and to be welcomed as I feel what happens in our respective countries tends to influence both. From the discussions I have had with interested parties in the U.S. the main points that arose with regularity and with which I concur are, 1) People feel the term CFS should be replaced and M.E. (Myalgic Encephalomyelitis) be the only name by which CFS should be known. 2) The Charter designates power to the CFSAC to call for a Congressional Inquiry if the Committee's recommendations are not responded to in an actionable intent within 60 days of each recommendation.

With regard to point, 1) The term CFS has done so much damage that it has reduced what is a serious neurological illness to nothing more than fatigue, which is plainly not true and ignores many other serious neurological symptoms that are constantly being overlooked or downplayed such as Orthostatic intolerance .

With specific regard to Point 2) it does seem pointless to hold meetings and then draw up a set of recommendations that are unlikely to be acted upon or even acknowledged. We have a similar situation in the UK in which we have a lobby group within Westminster (which sufferers and carers are allowed to attend) known as the All Party Parliamentary Group for ME, which regularly holds meetings that has a small number of MP's in attendance, but it has no official status or ability to seek a response from Government. It would be helpful from a British point of view if we could refer to your charter as a good example of what we would like to have over here in the UK.

Thank you for your time and allowing me to respond.

Yours sincerely

Ian McLachlan