

## Testimony

John Mitchell, Jr.

Dear Members of the CFSAC,

I would like to respectfully ask that the CFSAC consider if in it's previous recommendations to DHHS regarding the proposed 5 Center's of Excellence for CFS/ME, whether the CFSAC is recommending what is truly appropriate and/or adequate for a disease with the severity, prevalence, and social and economic burden of CFS, or whether it is simply begging for crumbs that it thinks might one day drop off the table.

Even if the 5 CoE's were funded at \$1.5 million each per year, that would still place CFS near the very bottom of all federally funded diseases. With the amount of research that needs to be done on the newly discovered retrovirus XMRV alone, ranging from diagnostics to pathophysiology to potential treatment, this is nowhere near an acceptable or adequate budget. This also does not begin to account for the numerous other pathogens and biological abnormalities which have been repeatedly implicated in the pathophysiology of CFS, from reactivated herpes virus infections, persistent enteroviral infection of the muscle and stomachs of CFS patients, etc. Not to mention the desperate need to subgroup patients in order to decipher appropriate treatment regimens and finally nail down the aetiology of the disease or diseases under the rubric of 'CFS'. 5 Center's of Excellence funded at \$1.5 million dollars per year simply isn't an appropriate expenditure for a disease with the impact of CFS and which has been neglected for as long and as comprehensively as CFS has been.

Therefore I suggest that CFSAC members discuss and consider what would truly be an appropriate amount of funding for the proposed CoE's, from \$5 to \$20 million per center per year. Also I would like to ask that the CFSAC endeavor to not let another meeting go by without specifically recommending these Centers. Since the purpose of the CFSAC is to 'provide advice and recommendations to the Secretary of Health and Human Services (HHS) on issues related to chronic fatigue syndrome', as stated in it's charter, if these Centers are truly what is needed, then it is by definition CFSAC's duty to recommend them. Not once a year either- CFSAC should take care that every single meeting from this day forward includes within it's recommendations these Center's of Excellence, in the strongest language, until these recommendations are heeded. We patients aren't getting any better waiting for a government that doesn't care to one day come around to it's senses and doesn't know what to do if it did. The DHHS needs advice from people knowledgeable on the condition, and that is what the CFSAC was created for. Please do not let another meeting go by without fulfilling this purpose.

Thank you very much for your time and for your work on behalf of all CFS patients around the world.

Sincerely, John Mitchell Jr.