

Testimony

Lolly McDermott

Thank you for taking the time to come together today and to address these issues. It is unfortunate, however, that there is not supposed to be a live videocast of the meeting. ME/CFS patients like myself have sensitivity to sound and difficulty with comprehension when listening, and do much better with the written word/captioning. By eliminating the videocast you are failing to accommodate our disability, as many of us will be unable to follow the meeting in real time.

I'd like to address three of the groups that are involved today, and the flawed definitions being used for ME/CFS. The first is the FDA. FDA: After over two decades of illness, I have finally been able to access Ampligen and am experiencing improvement. It is outrageous that there is still no FDA approved treatment for ME/CFS and that in order to receive treatment I must pay out of pocket for medication. If a "subset" of CFS patients improve on this drug, then why do you refuse to approve it? Obviously, given the number of flawed CFS definitions, it will be impossible to find one treatment for everyone diagnosed with this disease. So at what point will you acknowledge that the flawed CDC definitions are preventing severely ill patients from receiving the appropriate medical care? As long as you continue this charade you are as culpable as the CDC. Please approve Ampligen for ME/CFS.

This brings me to the CDC. CDC: you seem to have superficially purged the Empiric definition from your website, however, your information is still incorrect. Furthermore, it appears that the study cohorts you are still using were identified using the Empiric definition. The CDC was not given money to study "unwellness": your money is

specifically for ME/CFS. Any other use of those funds is fraudulent. You are still failing to study the role of viruses and immune dysfunction in CFS. Private institutes and other countries, such as Norway, are putting your program to shame, as you continue to waste taxpayer money. If you cannot study the disease that you are supposed to be studying and are unable to present accurate information about that disease, then your funding should be revoked. At this point you are doing more harm than good.

Finally, I'd like to address the CAA. Dr. Vernon, as one of the authors of the Empiric definition, is not the appropriate representative for ME/CFS. Additionally, the CAA now claims to be a research organization, and not a patient advocacy organization, yet you have failed to notify the press that you are no longer in a position to represent patients. If you are not representing patients, then you should not be commenting in the media as patient representatives. Frankly, you do not represent me, or my disease, in any capacity. I am not sure what disease you do represent, and I am very uncomfortable with your lack of transparency re: your funding.

We need an accurate definition for this disease. We then need government entities to basically do their jobs, i.e. disseminate accurate information about this disease, research the disease for which they are receiving funding, and approve fast-tracked medical treatments for a disease that has none. We need funding for researchers who are making progress with this disease. We need to know the agendas of non-profits who claim to represent us/our disease, and should have a say about who our representatives are.

People are dying from this disease and it is being passed between partners and from parent to child. ME/CFS is progressive, so long-term patients who were functional early in the disease are becoming increasingly sick and debilitated. Government agencies

should have addressed ME/CFS in the 1980s before a second generation was infected, but since they neglected to do their jobs it is imperative that government agencies today control the continued spread of the disease and approve treatments immediately. This disease is not going away, and your obfuscation has not been effective thus far. ME/CFS is a public health emergency and it's well beyond time for the politics and the personal agendas to be put aside.

Thank you.