

Testimony

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Dear Ms. Sibelius, Dr. Lee, Dr. Koh, ex-officio and official members of CFSAC,

If you are not aware of it, the Norwegian Directorate of Health, Norway's governmental health agency, issued an apology to their citizens with ME/ CFS last week, stating: "...we have not cared for people with ME to a great enough extent.....we have not established proper health care services for these people, and [we] apologize for that."

Why do I bring this up? Because, as a physician with experience with other illnesses, I am appalled at how the US government has mismanaged ME/ CFS over the last 25 years, leaving at least one million Americans disabled, suffering, and dead. The mainstream medical literature states no one dies from ME/ CFS but if you really paid attention to patients, you learn people can die from this illness. To some of you this is just another meeting but to patients and their families, the decisions you make or don't make has long-term repercussions for them. Patients lose days, months, years, decades to this illness, time which once lost is gone forever. I ask each of you to think about what you have done, what you can do, and how you want to be remembered when the history of this illness is written. Will you be on the right or wrong side of history?

Here are some actions you can take to begin righting the wrongs the government has done to people with ME/ CFS:

1. Continue live video streaming of the CFSAC meetings. This is the only way that many people homebound, bedridden, or impoverished by this illness are able to participate in this meeting. Having only live audio makes the meetings difficult for healthy people to follow – imagine listening to an 8-hour teleconference for 2 days – much less for people

cognitively impaired by ME/ CFS. Delayed video streaming does not allow for real time participation by patients.

2. Assure that funds are set aside specifically for ME/ CFS research and that when funds are granted, the research done with the money is directly related to ME/ CFS. After the NIH State of the Knowledge meeting held in April 2011, many researchers were hoping that a Request for Application (RFA) would be issued specifically for ME/CFS with dollars attached but nothing came out of that meeting. Furthermore, some of the projects that the government has designated as related to ME/CFS on closer examination have little or nothing to do with ME/CFS. For example, studies on a ME/CFS symptom in another medical condition are used to draw conclusions about ME/CFS. This would be like studying chest pain in pneumonia to make conclusions about heart attacks, both scientifically inaccurate and fiscally irresponsible.

3. Request that the Centers for Disease Control and Prevention (CDC) incorporate new scientific findings and medical experience from non-CDC researchers and clinicians on its website. Many researchers, healthcare professionals, lay people, and media look to the CDC's website for information about ME/CFS. There have been advances over the years regarding objective findings, possible causes, and potential treatments in ME/CFS that need to be included/ discussed on the site as well as references provided for those interested. Not including this information renders the CDC website scientifically obsolete. While I realize the website is an electronic portal for CDC research, having ONLY CDC-produced research/ information on it makes it a less informative site and more an exercise in public relations. Furthermore, CDC websites covering medical conditions other than ME/CFS do include information/ links to non-CDC non-governmental websites, guidelines, and research so this request is not out of the ordinary for CDC.

Thank you for your attention.