

Testimony

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Ladies and Gentlemen of the Committee:

The core strategy of CDC and NIH for responding to the ME (Myalgic Encephalomyelitis) (“CFS”) pandemic can be charitably described as Fiddling While Rome Burns. It is sad that it needs to be brought to the attention of HHS that this has proven, over the past twenty-five years, to be an ineffective strategy. **Time to try something new: a response proportionate to the incredible toll ME exacts on our nation.** Below are the most important and urgent demands for you to make the HHS Secretary; in declining order:

I. Drop the Fraudulent Reeves “CFS” Criteria Immediately

The patently invalid Reeves Criteria for ME (“CFS”) must be discarded and the Canadian Consensus Criteria (“CCC”) and International ME Consensus Criteria (“ME-ICC”) must be adopted by CDC. **Prof. Leonard Jason has published proof that the vast majority of people who meet the Reeves Criteria do NOT have ME (“CFS”).** The Reeves Criteria have already wasted millions of taxpayer dollars and muddied the science of ME. **Accurate ME Definitions – i.e. CCC and ME-ICC must be adopted.**

II. Appoint New Chief of the CDC Chronic Viral Diseases Branch

Demand must be made to the HHS Secretary to **appoint an outside expert to the post of CDC Chronic Viral Diseases Branch Chief.** Branch Chief Dr. Elizabeth Unger has made no significant change to the disastrous CDC “CFS” program. To my memory she has testified at her first CFSAC meeting that she did not intend to change the program or do away with the Reeves definition. **In view of CDC/s long sordid history**

regarding ME, an outside expert must be appointed or the “CFS” program must be shut down.

I suggest an expert such as Annette Whittemore, Hillary Johnson, Drs. Nancy Klimas, Leonard Jason, Paul Cheney, Daniel Peterson, Charles Lapp, Lucinda Bateman, David Bell, Judy Mikovits, or Anthony Komoroff.

III. Request from Congress an Appropriately Astronomical Increase in Funding for Bona Fide ME Research

Funding for the disease remains at a scandalously low level. Erectile dysfunction receives more than three times the NIH funding of ME. “Native American and Alaskan Health” receives more NIH money per person than ME, despite the fact that, obviously, the vast majority of Native Americans and Eskimos do not have extremely disabling diseases. **NIH and CDC funding should be increased between 100 and 200 times (not percent)** to be on par with funding for similarly disabling diseases. This means a raise from the current NIH funding of \$3M per year to the appropriate \$300M to \$600M per year.

IV. Use Appropriate Name for the Disease: ME

The committee should recommend that HHS change the name of the disease back to ME. And it should **change the name to MEAC (Myalgic Encephalomyelitis Advisory Committee)** and refer to the disease by its rightful name that assigned it by WHO ICD since 1968: ME. “CFS” is a misleading and derogatory name which causes significant medical and social harm to patients. “CFS” is totally unacceptable and must be dropped immediately.

V. Request a Congressional Inquiry

Request a **congressional inquiry into the malfeasance and nonfeasance attending the decades-long “Fiddling While Rome Burns” ME policy at CDC and NIH with the objectives of:**

- (A) Restoring misappropriated funds,**
- (B) Apportioning additional “back pay” funding of at least \$300M for each year from 1984 to present, and**
- (C) Bringing criminal charges** against those responsible for this “state terrorism”, in the words of Byron Hyde, MD, inter alia CDC’s William Reeves and Brian Mahy.

Since HHS is very unlikely to request this congressional inquiry because its malfeasance and nonfeasance would be the subject of the inquiry, the Committee should also directly request this from Congress.

Thank you for your service to our national and your consideration.