

## Testimony

**Justin Reilly, Esq.**

Fiddling While Rome Burns is Not an Effective Public Health Strategy  
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 to the HHS Secretary; in declining order:

### I. ICD-10 CM

ICD-10 CM listings for ME ("CFS") must reflect the reality of the disease. It is urgent that demand be made to the Secretary since ICD-10 CM may be set in stone as early as October. If it is not changed, it will hurt the one million Americans with ME for many years.

The existing draft has two listings for the disease. WHO does not allow two listings for the same disease, so one must be eliminated or the two must be merged under one listing.

One of the listings is for "Chronic Fatigue Syndrome, NOS" as the only condition under "Unspecified Fatigue." This is a travesty. Need it be said once more that ME ("CFS") is not synonymous with the symptom of "unspecified fatigue." And why is "Not Otherwise Specified" added to "CFS" considering that "CFS" is not mentioned anywhere else in ICD-10

CM? Obviously, this is yet another attempt by CDC to loose ME ("CFS") in a sea of "chronic fatigue."

ME is the only condition listed under "Post-Viral Fatigue" While "Post-Viral Fatigue" should be listed under ME, it is inappropriate to do the converse. **ME should be kept where it is in neurological diseases, but "Post-Viral Fatigue" should be listed under ME, not vice-versa as is currently suggested. Additionally, "CFS" should be either eliminated or also listed under ME.**

## II. Reeves Criteria and Canadian Criteria

**The patently inaccurate Reeves Criteria for ME ("CFS") must be discarded and the Canadian Consensus Criteria must be adopted by CDC. Prof. 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 tax-payer dollars and muddled the science of ME. **An accurate ME Definition- such as CCC- must be adopted.**

## III. 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.

## IV. Disease Funding

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 1,000 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 \$3B per year.

## V. Name of the Disease and Committee

The committee should recommend that HHS change the name of the disease back to ME. And it should **change its 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.

## VI. Congressional Inquiry

**A congressional inquiry into the malfeasance and nonfeasance attending the decades long "Fiddling While Rome Burns" ME policy at CDC and NIH with the objective 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.

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

Sincerely,

/S/

Justin Reilly, esq.