Justin Reilly, esq.

April 26, 2010

'Chronic Fatigue Syndrome' Advisory Committee
US DHHS
cfsac@hhs.gov

RE: Testimony for May 10, 2010 CFSAC Meeting:
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/CFIDS (Myalgic Encephalomyelitis/ Chronic Fatigue Immune Dysfunction Syndrome) 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.**

I. CFSAC Charter

It goes without saying that the charter should be renewed. The time period for the charter should be lengthened. There must, of course, be more meaningful action to address ME. CFSAC has made many excellent recommendations, that if anything, should have been more strongly worded than they are, in my opinion. It is unacceptable that only 18% have been fulfilled. **CFSAC needs to be vested with whatever tools will ensure implementation of its recommendations.** This includes a great increase in power and an increase in funding. I will leave it to the Committee to decide what changes to its charter are most appropriate for these purposes. Please, be bold in your requests and demands- the protection of public health requires this.

II. Name of the Committee

The committee 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.

III. 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, and a proportionate increase to CDC 'CFS' program funding.

IV. New Chief of 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.** I have not seen any change made by interim Chief Dr. Elizabeth Unger to the disastrous CDC "CFS" program. This highlights why **an ostensibly competent and well-meaning CDC insider is unacceptable for the post in view of CDC's long sordid history regarding ME.**

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.

V. Reeves Definition and Canadian Criteria

The patently inaccurate Reeves Definition of ME must be discarded and the Canadian Consensus Criteria must be adopted by CDC. Reeves Definition has already wasted millions of tax-payer dollars and muddied the science of ME. **The only accurate ME Definition-CCC- Must be adopted.**

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 iatrogenic holocaust 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.