Public Comment
Sister Sandra Duma

A few weeks ago I pulled out some ME/CFS videos purchased over the years and once again watched one called “Living Hell.” This was a documentary produced by Authentic Pictures in association with the CFIDS Foundation of San Francisco. I looked at the jacket to see that this excellent film came out in 1993 – 20 YEARS AGO. As far as the government’s response to this disease goes, that film might just as well have been made yesterday. The governmental issues and lack of response are the same ones ME/CFS patients face today. 20 YEARS LATER, and nothing has changed.

During all this time, no significant recommendations made by CFSAC that could affect the course of this disease in patients’ lives have ever been implemented. HHS, NIH, and CDC have not provided the necessary leadership, resolve, and financial resources needed to tackle this disease. HHS, NIH, and CDC are fiddling while Rome is burning. This disease is spreading as more and more people around the world are becoming disabled by it. Isn’t anyone in the government concerned and asking why?

In the absence of this leadership, expert ME/CFS researchers and clinicians from around the world have produced two excellent ME/CFS or ME definitions that reflect the experience and knowledge they gained by working with thousands of ME/CFS patients over many years. These definitions are the Canadian Consensus Criteria (CCC) and the ME International Consensus Criteria. Patients around the world see themselves and their illness experiences reflected in these definitions. Patients heartily support these definitions and are greatly concerned that efforts now being made by HHS with their IOM contract will undo the work of these experts and set us back for years to come. A critical question -- Is the purpose of this IOM contract to ratify and promulgate the work of these ME/CFS experts or to squelch it in order to regain control over the situation by putting ME/CFS back into the Pandora’s box of nebulous, waste-basket, meaningless “chronic fatigue syndrome”? Another critical question -- Is journalist Llewellyn King’s observation that low-cost psychiatric treatment is favored over higher-cost internal medicine treatment the driving force behind this IOM contract?

There are currently three petitions on the internet calling for the adoption of the CCC in the United States or to thank the 35 (and now 50) leading ME/CFS experts who sent a letter to Secretary Sebelius announcing that they had reached consensus on the use of the CCC as the sole definition for ME/CFS. Patients around the world are very concerned and are watching closely as their lives too will be affected by these decisions. I have kept track of the countries represented by these patient signatories. I may have missed some, but these are the 44 countries I have seen on these petitions:

Afghanistan
Argentina
Australia
Belgium
Bulgaria
Ireland
Israel
Italy
Lebanon
Malta
Slovenia
South Africa
Spain
Sri Lanka
Sweden

Canada
Costa Rica
Croatia
Denmark
Finland
France
Germany
Greece
Iceland
India
Mexico
Netherlands
New Zealand
Norway
Portugal
Poland
Romania
Russia
Saudi Arabia
Singapore
Switzerland
Thailand
Turkey
Turks and Caicos
United Arab Emirates
United Kingdom
United States
US Virgin Islands
Zimbabwe

Patients are terrified that once again, with this IOM contract, our disease, the disease that showed up in Incline Village, Nevada, will be defined out of existence and made to disappear. And with that, will go all hope that we will ever receive the recognition and help so desperately needed for a disease that has stolen our very lives.

Patients recognize in the CCC an authentic and comprehensive description of the disease from which they suffer. The CCC has captured and validated their experience. We won’t get answers as to why more and more people are becoming disabled from it by sweeping this disease under the carpet with an overly broad, all encompassing, meaningless definition, and tagging onto it a trivializing and demeaning name. Recognize this disease for what it truly is – an organic complex neuro-endocrine-immune disease with multi-system involvement and energy production problems, with post-exertional malaise as its most distinctive characteristic. For much too long, the emphasis on “fatigue” and “fatiguing illnesses” has led us down a wrong path and wasted years of our lives. Cognitive behavioral therapy and graded exercise therapy are NOT the answers or effective treatments for this complex disease. To get answers and effective treatments, we need good research, and good research depends upon a good definition that actually reflects the experience of the patients suffering from it, not some construct in the minds of the powers-that-be who may want a simple and low cost solution to a complex, organic, multi-systemic, very debilitating, life-robbing disease.

Our lives are hanging by a thread, waiting for your effective response to this devastating problem.