

## Testimony

Marly Silverman

Thank you for the opportunity to address this distinguished committee today. My name is Marly Silverman. I am the founder of PANDORA, a small but national and effective patient-driven organization. Our mission is to restore quality of life to individuals with NeuroEndocrineImmune diseases, such as ME/CFS, fibromyalgia, multiple chemical sensitivity, chronic Lyme disease, and Gulf War illness, and we are headquartered in Florida. It is important to note that I am also, and since 1998, one of the many faces among the hundreds of thousands of Americans suffering with ME/CFS and fibromyalgia. Since this devastating diagnosis, my life has indeed changed considerably and with it, I have suffered the same humiliations, challenges and hardships that sadly patients experience with the devastating diagnosis of ME/CFS.

We want to acknowledge the following:

- 1) On May 26, 2011, PANDORA met with the representatives of the CDC CFS Research Program. We met with Dr. Beth Unger, John O'Connor, Danna Brimmer, who is an individual contractor by the CDC, and, with Dr. Kimmel. The meeting was the result of a letter initiated by PANDORA welcoming Dr. Unger to her new position. The letter contained a series of crucial suggestions that are beneficial to the patient community if implemented. In our letter we strongly expressed the opportunity we identified with her new appointment to the CDC CFS research program. Our position has been that we should avail and push for strong and transparent communication with the CDC CFS research program in order to ensure positive changes and effective meaningful results for patients and for the science of the knowledge of CFS.

Two of the recommendations in the welcome letter to Dr. Unger we are pleased to say, have been put in place. One is the ongoing communication with patient advocacy organizations and the other is the granting of contracts to physician/researchers in the field of ME/CFS. These are indeed good and progressive steps to advance the science in the field of ME/CFS, a NeuroEndocrineImmune disease.

We are grateful to Dr. Unger for meeting with us and we are aware that her office continues to reach out to other patient organizations and groups. We were also pleased to hear Dr. Unger using the term CFS/ME during her presentation at the last 2011 IACFS-ME conference in Ottawa. We also acknowledge that she has publicly clarified that the CFS CDC program uses the 1994 Fukuda definition instead of the 2003 Reeves Empirical definition.

During our meeting we went over every item in the letter and mostly we reiterated our major concerns:

- 1) The revision of the overall scientific material on the CDC CFS web site, which should have a bibliography representative of the whole literature, not simply what the CDC researches.
- 2) The revision of the Physician Training Tool Kit.
- 3) And also how CDC's priorities must downsize the number of the social and behavioral studies since the CDC CFS Research is housed in the Division of High-Consequences and Zoonotic Infectious Diseases.
- 4) That CFS is both viral and non-viral.
- 5) That CFS should be classified in the neurological chapter in the ICD-10-CM. (Please see the Coalition4MECFS proposal request to reclassify CFS in the ICD-10-CM.

We hope we will continue to have this ongoing dialogue with the office of Dr. Unger. We look forward to that.

I want to provide you also with pertinent information about the Coalition4ME/CFS proposal to reclassify CFS in the ICD-10-CM.

If you are a member of this committee, here is what we suggest this committee to recommend:

- That you reiterate that CFS is a multi-system disease and reject any proposals to classify CFS as a psychiatric condition in the United States disease classification systems.
- That you continue to reject the current classification of CFS in Chapter 18 of ICD-10-CM under R53.82: chronic fatigue, unspecified>Chronic fatigue syndrome NOS.
- That you continue to recommend that CFS should be classified in ICD-10-CM, chapter 6 under “diseases of the nervous system” at G93.3, in line with ICD 10 (WHO) and ICD-10-CA (The Canadian Clinical Modification), and in accordance with the Committee’s recommendations of August 2005 and May 2011.
- That you continue to reject the National Center for Health Statistics (NCHS) and recommend that CFS remain in the same code or sub-code as myalgic encephalomyelitis because CFS includes both viral and non-viral triggers.
- That you recommend that an “Excludes1” be added to G93.3 for chronic fatigue (R53.82 and neurasthenia (F48.0).
- That you recommend that these changes be made in ICD-1—CM before its roll out in 2013.

My colleague Michael Munoz, who co-founded the Coalition with ME/CFS with me, hopefully will have the opportunity through his public input today to provide you with a more comprehensive background of this scientific initiative.

Unfortunately, PANDORA was originally denied the ability to present public testimony and so it was the Coalition4ME/CFS and many of its organization’s members. Since then, we have been told that the

DHHS/CFSAC will implement mechanisms that will afford the continuing input of patient organization representatives to represent disabled Americans stricken with ME/CFS who are our constituency. We bring their voice to the CFS Advisory Committee's attention and we make their voices count. We certainly welcome these steps and we hope they will be quickly implemented.

On the issue of the ICD-10-CM CFS reclassification proposed by the Coalition of ME/CFS:

- 1) We want to reiterate that the reclassification of CFS in the ICD-10-CM is not a patient advocacy initiative, but a long overdue scientific process that has been documented by this distinguished committee in the resolutions you put for the in 2004, 2005, and more recently on May 2011.
- 2) We also believe that because of the lack of resources, demands, and gargantuan challenges that exist within our scientific community, the proposal then was not initiated directly by the international scientific organization that represents this body of scientists, researchers, and physicians. However, it is important to mention that I am a member of the IACFS-ME and we are constructively engaging them in this process. The fact is no one can address these crucial issues alone. It takes a village.

We also would like to take the opportunity to once again recommend:

- 1) That this committee establishes a business or strategic plan in place without necessarily waiting for a new charter or by-laws to be in place. If long-term changes take time as I was told today, then the revolving door of DHHS personnel and the fact that three outstanding members of this committee are leaving the committee will not help us.

2) That in the any proposed new by-laws you look at the model of the current FACA for Autism, a committee sponsored by the NIH. In that FACA, the by-laws afford greater patient involvement and there are strategic subcommittees and panels for patient communications public communications, tracking of the committee progress, and even an annual report to Congress, all embedded in this FACA.

Thank you for your time.