

CFSAC Testimony of Bonnie G. Mayer RN

On April 7, 1994 life changed for me forever. I had gone to bed very healthy and happy on April 6. I was taking a break from registered nursing to pursue an additional degree and was very excited. I awoke with an apparent virus, very weak, and with extreme vertigo. The otologist thought it would pass. A month later, I could hardly think or walk. My neurologist (one of the finest) saw me, then saw me again and said "I don't know what is wrong with your brain but it's like more than one tube used in the old radios has smashed to the ground and broken." Things are no different today when I see the neurologist, from a medical education standpoint. I was diagnosed with acute viral onset CFIDS by the sixth physician who saw me. I have not returned to a normal life. In 2002, I finally filed for disability and received it in 2005, after the standard three year process of denials. The judge asked why I had waited so long. I said I thought I would get well. At the onset of the disease, I got short of breath scrambling an egg or blow drying my hair. That has not changed.

Because of you, the enlightened members of the committee, and with the appointment of Kathleen Sebelius, there is hope for funding and research to move forward. At the 2007 International Association for CFS/ME Conference, I heard from the many scientists about their breakthroughs in genetics, viral studies and many more areas. None of these areas of research points toward CFS/ME as being caused by my state of emotional health.

Please note the following empirically sound findings in my history. I still have a high titer to HHV6 and EBV. My vitamin B12 level was under 100 at disease onset. I had benign paroxysmal positional vertigo at onset, which later became "non-typical vertigo and imbalance" and is exhausting. I have undergone at least four series of multiple visits for vestibular rehabilitation in order to decrease dizziness, most recently thirty visits in 2009. Subtle changes in my autonomic nervous system due to CFS/ME resulted in postural orthostatic hypotension syndrome (POTS). Then, directly as a result of a surgical procedure with general anesthesia in 2007, POTS became full-blown neurally mediated hypotension (NMH). NMH resulted directly in a transient ischemic attack when by diastolic pressure fell too low, into the 50's or less from dehydration, two weeks post-operatively. Having CFS/ME also predisposed me to piriformis syndrome and a cervical strain from surgical table positioning in 2007, as a person with typical CFS/ME muscle spasms and tightness. Despite 65 very helpful physical therapy sessions since surgery, I still get piriformis and neck pain. Currently, the therapist said my recent "frozen shoulder" (my sixth one) is exacerbated by muscles that become weak from CFS/ME and can not hold things in place. This does not count the many P.T. sessions in previous years, to increase poor general strength, endurance and flexibility.

MY URGENT REQUESTS:

1. End the tenure of Dr. Reeves at the CDC immediately. The science is in. Dr. Reeves' belief that CFS/ME is a "state of unwellness" and not a disease is insulting and inappropriate in this day and age.
2. DHHS must enact all of the CFSAC recommendations set forward some time ago.

Educate our doctors. Nancy Klimas MD of the University of Miami CFS Clinic has been ready to educate physicians for many years but I have become aware that acceptance of the need to do so, as well as funding, still stand in the way nationally. Build the centers of excellence. Get us well. If we were able to work, we could contribute to the economy as well as to our own futures, instead of being a financial burden to our families. My husband is unable to retire and is wearing out himself. The financial impact of CFS/ME has been as devastating to us as my disease has.

3. If the CDC plans to replicate the recently released XMRV study, insist that they use the same criteria when selecting patients as the researchers used for the study, and NOT the empirical definition the CDC currently uses. You must have the same definition in order to duplicate the results.

4. A congress decides on health insurance reform, demand that the health insurance companies not be allowed to deny any aspect of proper testing and care for CFS/ME, as CIGNA is currently able to get away with.

Respectfully but impatiently,

Bonnie G. Mayer RN