

sent: Wednesday, May 20, 2009 6:07 PM
To: OS OPHS CFSAAC (HHS/OPHS)
Subject: For the meeting

Dear Members, I am 60 years old and have lived most of my life as a "walking dead person." For many years, my mother who was an R.N. realized there was something wrong with me and took me to many Dr.'s during my lifetime. My brother had had paralytic polio when he was 6. My mother had follicular Thyroid cancer that had eaten thru her vocal cords and that was with 2 surgeries, the second being a radical neck dissection. She died with a OX of non Hodgkin's Lymphoma and had chemotherapy for palliative reasons only. When I was 21, I had metastatic papillary Thyroid cancer with staph infection from a cultured OR lamp. I spit #25 silks and had many surgeries after the original as silks would appear as bumps in the scar and those needed to be removed. It was basically a year of hell and I lost 25 pounds in the process. I did not smoke or drink but I did drink raw cow's milk. I took the test that resulted from the 15 year fiasco of testimony about the radiation problems caused by decades of nuclear testing in the US. My score was very high. ' Since then I have had tremendous headaches, trouble sleeping and not enough energy or stamina. Blood tests showed nothing but blood tests taken just before the above surgery showed nothing out of the ordinary. Many Dr.'s tried to come up with a OX to help but basically there was no knowledge of such a disease 'as CFIDS/Myalgic Encephalomyelitis and so I left the offices feeling even worse. Yet my mother knew otherwise. I was finally DX'd with severe CFIDS and FM after having all the exclusionary testing. It was an expensive and tiring process. I applied for SSD after trying to work in 1986. Producing documentation was very difficult as most of my Dr.'s were dead and my records destroyed. In 2004 I had a recurrence of Thyroid Cancer and was treated with 1-131 Ablation Therapy. Additional radiation was given in 2005. The many symptoms of this disease is worse than the first cancer that had eaten up many of the glands around the Thyroid gland. I have no stamina or energy, my sleep is produced with pills; actually my whole existence is based around pills. On \$800 a month, less Medicare, it is a nightmare making ends meet. The Federal Government has given me these diseases and for the past 20 has basically spent billions and wasted it all as it went for perks and pay and other research. Here are some of what I find extremely distasteful. Why is this addressed as a women's disease and is put under the "Women's Health" division of the NIH? Why is it that there has been NO input regarding cause and treatment and that there has never been? I wrote to the Women's Health Dept a few years ago and shared my pathetic story and received a letter back apologizing and saying that she was sorry!! Why is it that the minutes of these meetings take an inordinate amount of time to be disseminated? Why do we have conference after conference with the same stories told over and over again and nothing is ever done about it? You should have the drive and will to not only hear us speak but to read all the facts of the studies that have shown how abnormal our physiology is, the vast amount of valid research studies that has been done and still, nothing is ever done to help us with housing, transportation, cooking, cleaning, heating and cooling our home, getting to and from Dr.'s offices, being able to afford organic food so as not to consume more toxins and poisons, being able to afford a car, repairs, gas and insurance, a lot of us have been treated very poorly because we are on 5S which is just another slap in the face and no fault of our own, there are so few Dr.'s that know the remotest way to help us nor do they care because the CDC has spent precious taxpayers money trying to say we are fruit cakes and lazy when the truth is we are very sick and there are many of us who have lost college degrees with no job, lost our spouses, lost our homes, lost the respect that we deserve because although the budgets for the CDC are very rich in money, the substance of what they produce and provide scientists for grants

are producing nothing of substance and have not for the past 20 years. Dr. Reeves needs to go. Why someone who ignores all the 4000+ scientific papers -and then waters down the definition of such a debilitating disease stays in charge is a BIG BLACK EYE for the NIH. He has even discounted the WHO's definition regarding this disease. Too much money and nothing to show for it but a lot of sick and dead people. Have you all read the continual Obituary List. These are our family, friends and they have died because the US Government does not care to help the 4 million Americans that this disease affects. It is cruel to deny us the truth and probably the cure but you deny us everything else so we either await death from heart disease, cancer or if we can not tolerate the misery of the whole disease spectrum, we take our lives to stop the pain. This do nothing approach for this disease is unacceptable to us and we implore you to start doing the jobs that you are paid to do and to tell the truth and provide scientific studies that will benefit us. No spend it on an office in Hawaii or really comfortable chairs that are more expensive than our monthly stipend. Offended by your lack of taking care of this many Americans, you should all be ashamed and start earning your generous paycheck.

Linda C. Ferris