

Testimony
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For the new on-line viewers I would like to quickly re-state that the name Chronic Fatigue Syndrome does not appropriately represent Myalgic Encephalomyelitis more commonly known as M.E. And this is not a new syndrome but one that has been destroying lives for many decades. Ultimately the CDC had renamed ME to the demeaning name of Chronic Fatigue Syndrome. I believe this is a major reason this disease is not taken serious by our peers, politicians and most of our medical community.

I recommend the panel visit or revisit the topic of changing the name CFS to its original name M.E. in addition to identifying other conditions in the CFS spectrum and properly naming them as well.

This disease has got to be taken serious as it renders many of its sufferer's bedbound for decades in many cases. These patients suffer with brutal physical and neurological disability. In addition, reports have indicated significant reduction in life-span in those afflicted with ME/CFS. Most of us in this room know of patients who have died from this illness.

Today, I ask that the committee to read a paper submitted by Pat Fero titled INADEQUATE NIH FUNDING FOR CFS. I support her paper and the recommendation this committee begin investigations to focus on how researchers went from a funding rate of 24% in 2000, for grants in which "CFS is the primary focus, as indicated in the GAO report. To the current 5- 6% funding rate for grants where "CFS is the primary focus."

So as funding decreases the numbers of those afflicted with this disease grows. And as the number of those afflicted grows, so does the neglect and abuse. My fellow sufferers are still being stuck with a psychiatric label in many cases, a great majority of our doctors have no clue how to manage their M.E./CFS patients, sufferers still have a hard time obtaining disability when claiming under CFS and insurance rarely covers treatment and care.

Outside this room...out in the real world, there has been very little change for ME/CFS patients and their families...after all these years we continue to wait.