

## Testimony

Beth Schipper

Dear Chair Chris Snell, Nancy Lee, Designated Federal Official and members of the CFSAC Committee,

Officials sit from a distance and make health policy decisions without any understanding of the devastating impact those decisions may have on a ME/CFS patient's ability to recover.

Could it be possible that the CC and NCHS are more interested in statistical information than effective treatments, ground-breaking research, and clinical data?

Your policies trickle down and have a profound impact for good or ill in the clinical setting. There are countless stories from ME/CFS patients of neglect and mistreatment bordering on abuse from ignorant or misinformed physicians towards their ME/CFS patients.

My primary care physician has strongly recommended that I do not provide my CFS diagnosis to emergency room personnel for fear that my legitimate and potentially life-threatening symptoms will not be treated with the seriousness they deserve. He has based that recommendation on a number of his other patients who were told by ER staff they were simply drug seeking and sent home without appropriate evaluation or care. I have heard of four others in the last two years who were pulled out of the emergency room and put into the psychiatric unit.

I am one of the fortunate patients with a physician who was willing to educate himself on the IACFS website about this disorder, and he takes my symptoms seriously, however unusual or confusing they may be. He is one mainstream physician in a city of a quarter of a million people that has been willing to properly educate himself about the neurological dysregulation of the ME/CFS brain. According to conservative

estimates, there are approximately 8,000 people in my city with ME/CFS, yet I have not heard of any other patients who are happy with the level of knowledge their primary care physician demonstrates regarding this disease.

In the past two years, I have heard dozens of horror stories from patients in the Greater Grand Rapids area who were dismissed, ridiculed, or even severely impaired by their physician's lack of appropriate care or inappropriate treatment regimens, i.e. "Graded Exercise Therapy".

I am begging the NIH and CDC to provide accurate and legitimate information to emergency room personnel so that ME/CFS patients are not dismissed as attention-seeking individuals. This can be accomplished by updating the CDC website to reflect the internationally-accepted diagnosis and treatment protocols that are on the IACFS website, and updating the ICD-10-CM to read as follows:

## **Chapter 6 – Disease of the Nervous System**

Tabular

G93 Other disorders of brain

G93.3 Post viral fatigue syndrome

Myalgic encephalomyelitis (benign)

Chronic fatigue syndrome

Excludes chronic fatigue unspecified (R53.82)

Words cannot convey how desperate these patients are for basic compassionate care, let alone educated, knowledgeable and proactive treatment protocols. It is hard to believe that this level of barbaric treatment continues to be practiced by some in the medical profession towards ME/CFS patients unless you witness this in person.