

Good afternoon members of the committee as well as members of the CFS patient population. My name is Claudia Goodell and I have CFS and Fibromyalgia. I also have a bachelor's degree in psychology with a minor in American Sign Language and a Master's degree in Audiology. I am an accomplished artist and a fit athlete. I have always considered myself a pioneer of change, and have applied my influence in situations I believed required more forward thinking.

I pushed to become the first female grocery sacker at the local Piggly-Wiggly at the age of 16, and the first female in the high school weight lifting class. During graduate school I initiated the addition of a course in counseling to be added to the curriculum for the audiology program. Following an 8 year career in audiology I enjoyed three successful years working in the pharmaceutical industry, where I was recognized and rewarded by my peers and management until CFS symptoms made this impossible.

I fought the onset of CFS like a lion. In the face of unrelenting fatigue and constant pain I continued to push myself to go to work until I no longer could. I battled cognitive dysfunction while working as a pharmaceutical representative, not understanding why I was suddenly struggling to recall standard vocabulary. Standing upright became difficult. Although my doctors and I suspected CFS, this diagnosis would not come for months, as I was constantly pressured by my company to return to work or resign. I was told that a diagnosis of CFS would entitle me 3 days off, however a diagnosis of depression or cancer would allow more.

Exhausted, confused, and without a proper advocate, I was ill equipped to wage the necessary battle against my employer for the long term disability benefits that I should have been granted, and that I was entitled to receive. Instead I was forced to resign.

Unrelenting fatigue and disabling pain shattered my ability to be a traditional wage earner, and forced me to receive a pittance of a monthly disability check. CFS reduced me from the rewarding position of a professional to the unfamiliar territory of being completely dependent on my husband for income and health insurance, while my only means of contribution is the tedious and unrewarding role of housekeeper. Pacing my energy has become a daily practice. There is a constant question of whether I will get enough sleep, proper nourishment, and sufficient water intake to stave off the secondary issues of a sleep disorder, chronic migraines, Irritable Bowel Syndrome, and chronic infections. In addition to supplements I rely on prophylactic prescription medication to treat migraines and chronic pain. Western medicine offers little or no solutions to this situation, so instead I have been forced to seek treatment through methods such as weekly therapeutic massage, acupuncture, chiropractic treatments, yoga and meditation.

CFS is a thief of time that reduces a functional day to a fraction of that of a normal healthy person. It is an energy crisis that forces us to sacrifice the things that bring us joy and are often taken for granted. CFS has relegated 4 million Americans to be partial-participants in life; it has stripped our ability to contribute as well as forces us to be a drain on society. I am learning to accept CFS, however I still wage war against the total lack of control I have over my own life. I am a keen mind trapped in a dysfunctional body, treading in a society that is mostly unaware of CFS and the scope of its violation.

Without public recognition of the scope of CFS, progress toward approved treatment options is hopeless. We must shake the ground enough to gain the necessary attention to solve CFS. We must provide public awareness messages to gain acceptance of CFS as a real illness with a biological basis. We must educate in order for patients to be diagnosed early and properly. We must educate healthcare providers so that they are comfortable and competent in diagnosing and treating CFS. Proper research must be conducted to find the cause of CFS, as well as to develop safe and effective treatments for the disease.

With regard to CFS, previous efforts made by the CDC have been static, and my hope is that with the new appointments to the federal health agencies, the ground beneath CFS will become more dynamic.

So, although I am plagued with CFS and Fibromyalgia, I am also a successful educator, an avid cyclist, an accomplished artist, a wife, a mother, a daughter, and a sister. I implore this committee to hold the CDC accountable for their past negligence, as well as the future direction of the CFS research program.