

Public Comment
Samantha Hodge-Williams

Hello, my name is Samantha Hodge-Williams. I greatly appreciate this committee's work and support your recommendations to improve research and provider education on Chronic Fatigue Syndrome (ME/CFS).

In 1997, when I was 21, I graduated Summa Cum Laude from the Wharton School of Business and received the Deans Award for Service to the Community. In the same year, I became suddenly ill and was diagnosed with ME/CFS.

Prior to ME/CFS, I had been a highly motivated student and hard-working volunteer. In middle school, I was one of the youngest people to testify before the United States Senate in support of service-learning programs. In high school, I was invited to New York for a live interview on Good Morning America about my volunteer work in nursing homes. During vacations I had been fortunate to travel extensively and even worked several summers abroad.

At 21, I became so dramatically ill that my family flew me to the Mayo Clinic for a week of diagnostic testing. There, I was diagnosed with Chronic Fatigue Syndrome. The physicians explained that I was unlikely to ever be able to work or to live alone again. Since I'd always been able to apply myself to accomplish a goal, I was determined to prove them wrong. I refused to apply for disability and worked part-time against medical advice. My ER visits became more frequent, my health and quality of life deteriorated. One by one, I let go of my former hopes and dreams.

It is now 15 years later. I am providing my comment to you remotely because for the past 6 weeks, I have been bedbound on a continuous IV saline drip which helps me to stay conscious. Sometimes, even this is not enough and we have to rapidly infuse one or two liters of the saline, with the bag fully open, before I am able to regain consciousness.

This ME/CFS treatment was discovered over a decade ago by Dr. Rowe at Johns Hopkins Tilt-Table Center. However, to date, I have not yet met a physician or nurse who knew about ME/CFS and NMH treatment, unless they had a daughter or son with the illness. More than once, I have been forcibly held upright and refused adequate rehydration whilst losing consciousness in an ER. These life-threatening situations can be averted with federally-sponsored practitioner education and centralized information on ME/CFS.

For this reason, I strongly support that this committee be appointed the designated DHHS experts on ME/CFS. Accordingly, all DHHS agencies should be required to obtain CFSAC approval before posting on ME/CFS to ensure accurate information is disseminated. The CFSAC should be given additional authority to ensure transparency and accountability in DHHS decisions concerning ME/CFS.

Years ago in high school, I received a national prize for perseverance. Despite my enthusiastic and determined nature, I am not sure how I will endure another 40+ years of this degenerative illness. I have already been hospitalized for a week in the ICU for ME/CFS. I have

watched my mother, a formerly athletic physical therapist and author, also become bed-bound on IV's with the same condition. Last week, her core body temperature deregulated from 98 to 93 degrees in minutes, her GI symptoms exacerbated, and her heart rate jumped from 80 to 150 upon standing. This illness is clearly disabling and life-threatening. Without a breakthrough in ME/CFS research and treatment, I dread to think of the burden I will become on my siblings and on the state as my illness continues to worsen.

As you know, while the DHHS allocated \$428 million to research depression this year, less than \$6 million was spent on ME/CFS research. The national cost of delaying research is conservatively \$47 billion per year in ME/CFS lost wages and medical expenses¹. These costs will continue to skyrocket as young people like myself degenerate and require a lifetime of basic care. It is critical that the DHHS dramatically increases funding to scientifically investigate and treat ME/CFS.

¹ A 2011 NIH study reported CFS affects 4 million people in the US. They calculated the combined economic burden of CFS, including both direct & indirect annualized costs, was \$11,780 patient. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3033815/>.