Testimony

Cheryl Marshall

Dear Ladies and Gentlemen of CFSAC Committee:

Thank you for allowing my testimony today by phone. I am saddened to be too sick to be there in person.

I am as invisible to you today as my illness is to everyone who comes into contact with me. But trust me, I *am* a real person. I am a wife and a mother. I used to be a church leader and a social worker and it was all stripped away from me. Now I have been reduced to a bed-bound woman who is a drain on my family finances. It makes me feel horrible. I have been judged, misdiagnosed and humiliated more times in my life with ME/CFS than you could ever begin to imagine. I have been spoken to by doctors, who do not understand this illness, as though I am not a real person with real feelings. It is beyond disappointing that they are allowed to be called doctors because, unlike the Hippocratic rule of medicine, they *do* harm.

I have about 15 co-morbidities that go along with my ME/CFS that I must manage and try to stay on top of. My body has rejected me and last year, as I was in my third year of being homebound and most days feeling chained to my bed, I was diagnosed with cancer. I had to crawl out of bed to have surgery and treatment. The hardest part of it was being told that my body was too weak for chemotherapy, which was considered the best option for the type of cancer that I had because it was a rare type that offered no other after-treatment. I now live with the reality of having a higher risk of recurrence on top of living with my ME/CFS.

As I lay in my bed every morning, I have to make hard decisions every day on how to spend my energy. Do I shower today or do I use the energy to fix myself something healthy to eat, or can I do either?

Patients that are this sick should not also have to be the main *advocates* for this disease. We need more doctors, scientists, and researchers screaming for us that we need serious answers and we need them now! As the few ME/CFS specialists begin to retire, who is going to step up to take their place? We do not have enough doctors now and not seeing many coming up in the ranks is very unsettling for patients.

Has there ever been an illness in the history of this great nation where people who have suffered so much been ignored by the medical community and been forced to live this way? With little hope of recovering as the decades slip by? It is *disgraceful* that this is being allowed to happen here in the United States, of all places on Earth. Already, there is another generation suffering from this illness who did not ask for this either. How many generations are we going to have to lose before aggressive action starts taking place?

I would like to send a message to Director Collins and Ms. Sebelius: I have seen the 2011 federal budget and I know that there is $81 Billion dollars for HHS, including a $1 billion increase for bio medical research.
Why is the budget for ME/CFS research only $6 million? We need you to dig deep, deeper than you have *ever* imagined and come up with the money to adequately fund a cure for us. We need doctors and researchers collaborating to race for a cure. From a patient's perspective, it feels like we have a significant lack of sharing research information in the medical community. Does it matter who finds a cure as long as a cure is found?

Our nation needs leaders like many of us once were. Prior to being diagnosed, we were in the work force and out there making a difference in the world. Imagine the money that could be saved if we would still be able to work instead of being on disability.

I am not done living!! I have dreams that I want to see happen. My dream is to be able to become active in my church and community again, to take a walk around the block with my husband on my own two feet without the assistance of my scooter, and to take some of the burdens of my life off of him. I want my life back!! Is this too much to ask?

Thank you for your time today. God Bless each of you as you make good decisions for us.

Sincerely,

Cheryl Marshall