

To: CFSAC Committee Hearing on Chronic Fatigue Syndrome

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Thank you to all members of the Committee for allowing me to comment today via telephone. The challenge of travel and a full day of meetings would have been a deterrent to my participation. I appreciate the technology which allows me to speak over the phone and view the hearings via webcast.

I am 55 years old and have had ME/CFS for 20 years, after a serious reaction to Lyme Disease. Prior to my illness, I worked on Wall Street in demanding positions as Portfolio Manager, Trader, Software and Technology Integration Consultant and Marketing Manager. My job required that I travel to many cities around the country and around the world. I loved my career and my professional life. 20 years ago I was on a plane several times a week and today I could not drive to Washington DC without assistance.

I appreciate that members of this committee understand the overwhelming fatigue, pain, headaches, sleep problems, hypersensitivity to light, sound, medication and stress which defines ME/CFS. I am fortunate because only the first 5 years of my illness confined me to bed and changed my life so dramatically. Today I can function for hours at a time and sometimes feel pretty good for days at a time. But I can never predict or control my good or bad days. I have learned to adapt my daily schedule to my symptoms. Please understand that I do not yield to my symptoms, I simply make adjustments. I am unable to work at this time and it is unlikely that I will ever work on Wall Street again.

As a co-leader of a Support Group in northern New Jersey, I speak for many when I say that a major issue we have as patients is that our symptoms are not visible to others so that even family and friends do not always understand why we are "still sick". The sad truth is that most people have only a short term compassion for illness, especially when there is so much misunderstanding and a lack of respect for the seriousness of this disease. Another burden of ME/CFS is the powerful strain on a marriage. This disease and its stigma have destroyed many relationships. It was not until I

became sick that I truly understood my husband's 10 year struggle with this same illness.

Physicians also get frustrated with us because CFS is a very complex illness, which means time consuming, and yet there is still no medical test to validate our diagnosis, and there is no treatment which can cure our symptoms. Some doctors do not want to be known as a physician who takes *ME/CFS* patients because of its stigma, or because they simply do not know what to do with us. This is a chronic and unpopular illness which gets no respect from society or from the medical community and of which both patients and doctors are embarrassed to be associated.

It is not enough that we simply raise awareness *of ME/CFS* as a medical condition; we need to change the image and perception of this illness across all levels of society. We need to reject the notion that this is a mental health condition and articulate the physical symptoms. If you compare *ME/CFS* to other chronic health conditions like Diabetes, Multiple Sclerosis, or even Rheumatoid Arthritis, there is no reason why we should be dismissed as a lesser illness. Fibromyalgia, Lyme Disease, Lupus, Sjogren's all overlap in many symptoms and yet they are not ridiculed by society. Perceptions must change so that patients and doctors can stop wasting time proving they are sick, and focus on improving their life.

People come to our support group desperate for validation and acknowledgement of their illness. They need information on treatment and a cure. They need doctors who are compassionate and who are knowledgeable about *ME/CFS*. Unfortunately we can not always give them what they need. Please help us change this situation.

I ask the committee to consider these specific needs:

1. We need to verify and validate our condition-- hopefully with a blood test, or find methods to test for physical imbalances and health problems.
2. We need to remove the diagnosis of "being tired" and --define *ME/CFS* with appropriate medical terms---perhaps describing it as *disregulation of the immune, endocrine and neurological systems*.

3. We need to educate senior executives of the medical community about the seriousness of this illness, and ask their help to educate doctors, nurses and patients.
4. We need ME/CFS as a priority topic in Physician's programs for Continuing Medical Education to develop their understanding of ME/CFS so they learn how to guide us through medication and coping therapies.
5. We need to remove the stigma of this disease and acknowledge ME/CFS as a legitimate illness. Once that happens, the funding, the research, the treatments and the acceptance of this illness should follow.
6. We need to enforce the legitimate diagnosis of ME/CFS among insurance companies so they do not deny payment for medical treatments or for disability benefits.

Thank you for the opportunity to share my ideas and experiences with you today. We appreciate all you have accomplished in the past 10 years to fund research, and to bring discussion of ME/CFS to this committee level. Much progress has been made, but we need to do more to help the millions of patients like myself who expend precious and limited energy and money to cope with this debilitating condition.

I would be happy to answer any questions by phone or email.  
Thank you.

Respectfully submitted:  
Judy Machacek

Chronic *Fatigue* Syndrome™

Flu-like symptoms, immune system dysfunction  
Arthritis-like pain, muscle and joint pain, headaches  
Tender lymph nodes, sore throat  
Impairment of memory or concentration, word confusion  
Gastrointestinal problems, nausea  
Unrefreshing sleep, insomnia  
Exercise intolerance, exhaustion after mild activity

(Acronym created by Judy Machacek)

