

Testimony

Anonymous #5

Dear CFSAC Members:

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex and extremely debilitating neurological illness that wrecks normal, healthy, productive lives and costs the U.S. economy billions in lost productivity. According to the CDC, between one and four million Americans are affected by ME/CFS. As one who has lived with this devastating malady for nearly three decades, I would like to make the following recommendations:

1. Require the CDC to develop a more narrow and specific case definition of ME/CFS. The current Empiric Definition is too broad and includes persons whose major health problem is Major Depressive Disorder. Dr. Leonard Jason, who spoke about the importance of a precise case definition at the recent NIH State of Knowledge of ME/CFS meeting, should be made a consultant to the group in charge of formulating a new definition at the CDC.

<http://videocast.nih.gov/Summary.asp?File=16575>. The definition matters!

2. Increase funding for biomedical research of ME/CFS, which has been under-funded for decades. NIH currently spends between four to six million on ME/CFS research. For an illness that affects over one million people, that amount is woefully lacking. Biomedical research should include studies of XMRV and other viruses. Post-exertional malaise is another important area that merits research.

3. Work toward changing the name, Chronic Fatigue Syndrome, which trivializes a very serious illness. Use the name, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), temporarily until further research points us toward a more appropriate name.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome should appear on all relevant government documents and publications and be used in all communications with the public.

4. Fund five regional centers specializing in research and clinical treatment of ME/CFS.

Thank you for serving on the CFSAC. Your efforts are genuinely appreciated. I live for the day when this illness is better understood and effective treatments are available that will allow sick persons to return to normal, healthy, productive lives.

Sincerely,

Anonymous