

Testimony
Anonymous 6

Dear CFSAC Members:

Thank you for your service on this committee. I have had CFS for over 25 years and look to this committee to help guide federal activities concerning CFS.

CFS has been a debilitating and life-altering illness for me. Once I was a teacher and active in community affairs. The long-term illness has robbed me of basic energy needed for every day activities. My energy has been stripped to a minimum. Gainful employment is not an option, and performing even light housework duties is a struggle.

My recommendations concerning CFS include:

1. Require the CDC to develop a more adequate definition for CFS. The definition must have sensitivity and specificity. Dr. Leonard Jason should be made a consultant to the CDC to help formulate a more precise case definition for CFS.
2. Increase federal funding for CFS. CFS is grossly under-funded. In 2009, the NIH spent about five million dollars on CFS. According to CDC estimates, there are between one and four million Americans with CFS. Using CDC's estimates, the NIH is spending somewhere between \$1.25-\$5.00 per CFS patient. This is a woefully inadequate amount given the huge amount of suffering, disability, and the cost to our economy caused by CFS. The estimated cost to the American economy is 9.1 billion dollars in housework and labor losses alone.
3. Expand research into XMRV and other murine leukemia viruses, which have been linked to CFS. Explore other viruses and/or bacteria, which have been linked to CFS.
4. Establish five regional centers specializing in CFS research and clinical treatment. Centers should be established in areas with a doctor or researcher with demonstrated expertise in CFS. Locations could include Utah with Dr. Lucinda Bateman and Florida with Dr. Nancy Klimas.
5. Require the CDC to establish a patient registry for CFS to help understand the scope of the illness and the impact of CFS on patients.

Thank you for reading my recommendations. I look forward to a time when there will be effective treatments and hopefully a cure.

Sincerely,

Anonymous 6