

CFSAC Public Comment

Anonymous Submission

Dear CFSAC Members:

A huge thank you to all of you for lending your time and expertise to help those with M.E.! I realize it takes a great deal of effort and sacrifice for you to serve on this committee.

I would like to make several recommendations, most of which I have made in the past.

1. Develop a definition for M.E. that is sensitive and specific and would rule out general chronic fatigue and depression. I am uneasy with regard to the work of the IOM, which includes members who are not experts in the field of M.E. M.E. is a complex illness that requires years of observation and experience before a physician can develop real insight into the illness. I would much prefer that the \$1,000,000, which is going to the IOM, be spent on biomedical research and to use the CCC or ICC.
2. Use a name for the illness that does not trivialize the illness, like 'chronic fatigue syndrome' has done. The name matters! Perhaps 'Ramsay's Disease' would be a name that could be used and would not have to be changed as more research findings emerge.
3. Fund M.E. biomedical research commensurate with the seriousness and severity of the illness. Male pattern baldness gets about three times the amount allocated to M.E. That is a travesty! Members of Congress, who allocate funding, are under-informed concerning this complex illness and the suffering it causes!
4. Educate members of Congress, public health officials, health care providers, and medical students about the complex and serious nature of M.E. It was very enlightening when Dr. Susan Maier from NIH shared at a 2012 CFSAC meeting that some of her colleagues ridicule her when they learn she is serving on the CFSAC. It is enormously disturbing that there are professionals at NIH who do not realize that M.E. is a serious illness! How can we expect legislators to allocate an equitable amount of research funding for M.E. when those in government working closely with health issues do not understand that M.E. is a devastating illness! M.E. education for government health officials and members of Congress is critically needed! We also need to get medical information on M.E. to practicing physicians and to fund summer internships in M.E. for medical school students.
5. Establish regional centers of excellence for M.E. Fully fund Dr. Lucinda Bateman's Shauna Bateman Horne Center of Excellence in Salt Lake City, Utah in the amount of \$1.5 million. In succeeding years, fund a new center of excellence each year until there are a total of five centers in the United States. Make sure those staffing the centers have many years of experience with the illness!

Thank you for reading my recommendations! I am tremendously grateful to all those who have worked extremely hard to benefit M.E. patients. I am also hopeful that government can move at a faster pace in the future to help M.E. patients struggling with this trivialized, stigmatized, complex illness!

Sincerely,
Anonymous