

**Public Comment**  
**CFSAC | December 2014**  
**Anonymous**

Dear CFSAC Members:

Thanks to all of you who are serving on this committee. Your efforts are greatly appreciated!

As a long-time patient, I would like to make the following recommendations to the federal government regarding ME and CFS:

First of all, delineate the two illnesses – myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS).

Focus, primarily, on ME patients, those who have multi-systemic neurological illness with post-exertional relapse. Once we gain a better understanding of ME, greater emphasis can be given the broader group of CFS patients.

Fund research on ME and CFS commensurate with the devastation these illnesses cause in individual lives and the tremendous burden they place on the economy. NIH spends only \$5 to \$6 per ME/CFS patient at the present time. We will never make much headway until the amount for biomedical research of ME alone is at the very least \$16 million per year – the amount now allocated for studying male pattern baldness. Additional amounts are needed for CFS studies.

Establish clinical and research centers of excellence to study and treat ME and CFS patients. Staff centers with health care professionals who are extremely experienced in working with ME and CFS. Work to identify causes of ME and CFS and successful methods of medical treatment. Cognitive behavior therapy and graded exercise therapy are NOT the answer!

Establish patient registries for ME and CFS. Data from centers of excellence and primary care physicians and specialists can be fed into the registries. Self-assessments and questionnaires can be completed by patients. Work to identify causes and appropriate methods of treatment. Share findings with other researchers, academics, health agencies, and physicians both nationally and internationally.

Educate physicians and medical students about ME and CFS. Provide them with the physician handbook developed by IACFS/ME members.

Spend no more precious dollars on efforts such as P2P and IOM.

At least one million ME and CFS patients are suffering in this country. We need to move quickly. Both groups of patients are struggling and in dire need of the federal government's help!

Respectfully,

Anonymous