Request for FY 16 and 17:

- Support a letter to NIH Director Francis Collins requesting that an equitable share of the $2 billion increase in FY 16 NIH funding be used to fund ME/CFS research.
- Include the following recommendations in the 2017 Appropriations Report language:
  - NIH to make a set of investments to spur ME/CFS research and drug development,
  - CDC to reinstate and increase CDC funding and conduct a broad-based medical education campaign leveraging recommendations of the IOM and of the CFS Advisory Committee,
  - HHS to identify ways to creatively fund Centers of Excellence that include a clinical care component.

Rationale

- The 2015 Institute of Medicine (IOM) report noted that ME/CFS is a “serious, chronic, complex, multisystem disease that frequently and dramatically limits the activities of affected patients.”
- Between 836,000 and 2.5 million U.S. residents are afflicted with ME/CFS and at least one quarter of them are housebound or bedbound, often for years. 50-75% are unemployed. ME/CFS-related medical expenses and lost productivity cost the U.S. $17 to 24 billion annually.
- Patients with ME/CFS score more poorly on quality of life surveys than patients with multiple sclerosis, stroke, renal failure, heart failure and other chronic diseases.
- Yet, the IOM report noted a “paucity of research” and “remarkably little research funding.” As a result, there are no diagnostics and no FDA-approved treatments. Prominent scientists have stated they are eager to study ME/CFS but have been unable to get NIH funding. Funding has remained static at about $5M a year, far below other similarly disabling illnesses. For instance, in 2015, ME/CFS got about $2 per patient per year compared to $250 for multiple sclerosis. Based on prevalence and disease burden, funding should be an estimated $250 million a year.
- ME/CFS is not taught in most medical schools or in continuing education, so health professionals do not receive the training to diagnose or treat patients. ME/CFS has no home in any medical specialty. As a result, 81-94% of patients are undiagnosed.
- The $2 Billion dollar increase in NIH’s FY16 budget and the reports by the IOM and NIH’s 2015 Pathways to Prevention Workshop have provided the unprecedented opportunity to address this long-neglected disease.


   This article includes a link to an August 17, 2015 letter from 27 disease experts to Senator Mikulski stating their interest in research in this disease. The letter to Senator Mikulski is also available here: http://www.cfstreatmentguide.com/blog/an-open-letter-from-researchers-to-senator-mikulski-patients-suffering-from-mecfs-deserve-funding


   Also see:


9 Ibid. Page 1.