

**CFSAC Meeting June 16-17, 2014**  
**Washington, DC**  
**For the Public Record**  
**Mary E. McNamara**

The method NIH uses to prioritize and allocate funds across diseases is currently being scrutinized by Congress in response to complaints from patient advocacy groups that they're being shortchanged.<sup>1</sup> In a General Accounting Office report released on April 30, 2014, NIH defended its funding practices by saying funding levels reflect scientific opportunity, the burden of disease, and global as well as national public health needs.<sup>2</sup>

ME/CFS is a disease being shortchanged by NIH funding practices. NIH officials—

- overlook the needs of one million ME/CFS patients in the U.S. and 17 million worldwide;
- ignore the incredible level of debility and suffering experienced by severely ill patients; and
- turn down distinguished scientists applying for research grants.

Patients need—

- new and expanded clinics and centers across the country with outreach to the homebound;
- additional trained physicians and healthcare professionals to deliver informed care; and
- cutting edge research to close gaps in scientific knowledge identified in 2011 during their -- NIH's -- "ME/CFS State of the Knowledge Workshop."

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1. *Science*, Vol. 344, 9 May 2014, "NIH Disease Funding Scrutinized," p.564
2. General Accounting Office (GAO-14-246), Report to the Chairman, Subcommittee on Labor, Health & Human Services, Education & Related Agencies, Committee on Appropriations, House of Representatives, "National Institutes of Health: Research Priority Setting, and Funding Allocations across Selected Diseases and Conditions," Published 31 March 2014, Released 30 April 2014. Also see GAO-14-490R April 2014.