



congress@meaction.net

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Request

- Sign on to the letter being circulated by Reps. Zoe Lofgren (CA-19) and Anna Eshoo (CA-18) to NIH Director Collins in support of ME/CFS patients and research. Due date 8/31.
- Support the NIH to establish an intramural and extramural ME/CFS program, funded at levels comparable to illnesses with similar prevalence and economic cost to society.

Rationale

- NIH Director Francis Collins has announced the launch of new research and an ME/CFS working group to encourage external research, but the budget has yet to be developed.¹
- There are **no FDA-approved treatments** and **no diagnostic tools** for ME/CFS.
- Between **836,000 and 2.5 million** U.S. residents are afflicted with ME/CFS, with 84 to 91 percent not yet diagnosed.
- ME/CFS-related medical expenses and lost productivity cost the U.S. **\$17 to \$24 billion** annually.²
- The Institute of Medicine, a special HHS advisory committee³, and a recent NIH-appointed expert panel all agree: It is imperative to increase research funding for ME/CFS.⁴
- In research funding, ME/CFS receives about the same money for research as hay fever, and ranks far below similarly disabling illnesses:
 - ME/CFS: About \$2 per patient per year in NIH funding (\$6 million in FY2015)
 - Multiple sclerosis: About \$235 per patient (\$94 million in FY2015)
 - HIV/AIDS: About \$2500 per patient (\$3 billion in FY2015)
- Myalgic encephalomyelitis is a **debilitating, often disabling**, illness recognized as a neurological disorder by the World Health Organization since 1969.⁵
- Patients with ME/CFS **score more poorly on quality of life** surveys than patients with multiple sclerosis, stroke, diabetes, renal failure, lung disease, heart failure and various cancers.⁶

¹ Bernstein, L. (2015, Oct. 29). NIH announces new effort to tackle chronic fatigue syndrome. *The Washington Post*.
<https://www.washingtonpost.com/news/to-your-health/wp/2015/10/29/nih-announces-new-effort-to-tackle-chronic-fatigue-syndrome/>

² Institute of Medicine “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness” 2015. Available:
<http://tinyurl.com/ljt9p96>

³ HHS Chronic Fatigue Syndrome Advisory Committee (CFSAC) “Recommendations” June 2014. Available: <http://tinyurl.com/ozv3eqd>

⁴ NIH Pathways to Prevention, “Advancing the Research on ME/CFS” June 2015. Available: <http://preview.tinyurl.com/pqcptnl>

⁵ Dimmock, M, “Thirty Years of Disdain: How HHS Buried ME”, May 2015. Available: <http://tinyurl.com/owonsn7>

⁶ “Health-Related Quality of Life for Patients with ME/CFS,” [PLoS One](#), 2015