



Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Request

- NIH will establish authority for treating ME/CFS within the National Institute of Neurological Disorders and Stroke (NINDS).
- NINDS will establish an intramural and extramural ME/CFS program, funded at levels comparable to illnesses with similar patient numbers and economic cost to society.

Rationale

- 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. True numbers are highly underreported.¹
- ME/CFS-related medical expenses and lost productivity cost the U.S. **up 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 less money for research than hay fever, and ranks far below similarly disabling illnesses:

ME/CFS: About \$2 per patient per year in NIH funding (\$5 million in FY2015)

Multiple sclerosis: About \$250 per patient (\$103 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
- At least one quarter of ME/CFS patients become **housebound or bedbound**, often for years. Many become unemployed.⁷

¹ Institute of Medicine “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness” 2015. Available: <http://tinyurl.com/ljt9p96>

² Ibid.

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/pqcpntl>

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](https://doi.org/10.1371/journal.pone.0158888), 2015

⁷ IOM, see “[Key Facts](#)”