



Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS): An Example of the Critical Need for NIH and CDC Funding

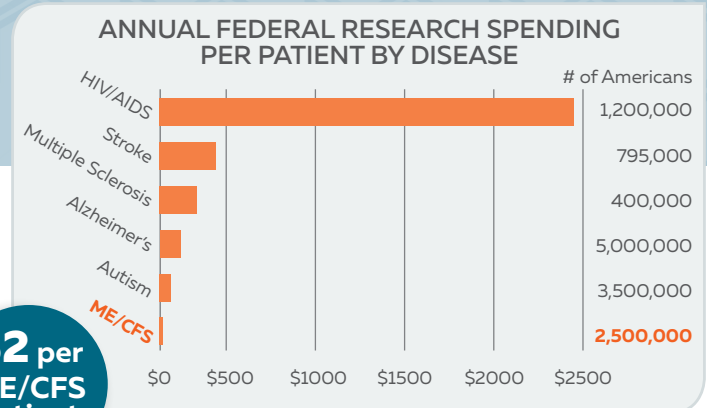
Myalgic Encephalomyelitis (ME), commonly known as Chronic Fatigue Syndrome (CFS) or ME/CFS, is a devastating multi-system disease that causes dysfunction of the neurological, immune, endocrine and energy metabolism systems.

DID YOU KNOW?

- ME/CFS affects an estimated 1 to 2.5 million American children and adults of all races, income levels, and geographic areas.
- 75 percent of patients are women.
- There is no diagnostic test, no FDA-approved treatment, and no cure.
- At least 25% of ME/CFS patients are home- or bed-bound.
- People with ME/CFS have lower quality of life measurements than any other disease tested.
- 84-91% of ME/CFS patients either are not yet diagnosed or are misdiagnosed.
- Symptoms typically persist for years; recovery is rare.
- ME/CFS costs our economy \$17 to \$24 billion annually.

AND YET...

- The 2015 National Academy of Sciences' Institute of Medicine noted that "remarkably little research funding has been made available to study...this disease, especially given the number of people afflicted." Despite NIH Director Francis Collins announcing his intention to "ramp up" funding for ME/CFS, funding levels have increased by only \$1 million since FY15 and ME/CFS continues to be in the lowest 4% of diseases funded by the NIH.
- ME/CFS faces a crisis in clinical care and is adversely impacted by poor medical education. Fewer than 12 ME/CFS specialists are available to treat up to 2.5 million patients nationwide. Fewer than 30% of medical curricula address ME/CFS with the tragic consequence that recommendations are made that exacerbate symptoms.



\$2 per ME/CFS patient

Source: U.S. National Institutes of Health. "Estimates of Funding for Various Research Condition and Disease Categorization (RCDC). NIH, published March 7, 2014.

WHAT IS NEEDED:

- An HHS strategic plan to address research, clinical care, medical education, and drug development needs.
- An overall robust NIH budget including dedicated ME/CFS funding reflecting the true burden to patients, our economy, and our communities.
- Retention of CDC's Prevention and Public Health Fund to prevent the elimination of the CDC's efforts on ME/CFS including a research study, medical education efforts, and addressing barriers to patients obtaining expert clinical care.

WHAT MEMBERS OF CONGRESS CAN DO:

- May 12:** is ME International Awareness Day. Show your support for patients and help us raise awareness by posting on social media.
- May 18:** Learn more by attending Senator Markey's ME/CFS briefing, "The Invisible Health Crisis: ME/CFS [Chronic Fatigue Syndrome]" from 12:00pm - 1:30pm at SVC-201 (lunch provided).
- FY 17:** Please call or write the NIH and ask them to prioritize ME/CFS research funding as part of their recent \$2 billion increase. Using just 1% of these funds would more than triple the current research investment in ME/CFS.
- FY 18:** ME/CFS is entirely funded by the NIH and the CDC's Prevention and Public Health Fund. Please preserve these funding sources next year. Cuts will hit small programs, like ME/CFS, the hardest.