



# Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

*“Of the many mysterious illnesses that science has yet to unravel, ME/CFS has proven to be one of the most challenging,” Francis S. Collins, Director, National Institutes of Health.*

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

- ME/CFS affects an estimated 1 to 2.5 million American children and adults of all races<sup>1</sup>.
- 75 percent of patients are women.<sup>2</sup>
- There is no diagnostic test<sup>3</sup>, no FDA-approved treatment and no cure<sup>4</sup>.
- At least 25% of ME/CFS patients are home- or bed-bound at some point in their lives.<sup>5</sup> Many are unemployed or have reduced productivity.<sup>6</sup>
- People with ME/CFS have a lower quality of life<sup>7</sup> and more functional impairment<sup>8</sup> than those with other disabling illnesses such as multiple sclerosis, heart disease, and end-stage renal disease.
- Symptoms typically persist for years. Recovery is the exception.<sup>9</sup>
- An estimated 84-91% of ME/CFS patients are not yet diagnosed<sup>10</sup> or have been misdiagnosed.

- ME/CFS costs our economy \$17- \$24 billion annually in lost productivity and direct medical costs.<sup>11</sup>
- Clinical care and medical education are in a crisis. Less than 12 clinics in the U.S. treat ME/CFS patients.<sup>12</sup> Few physicians have received training about how to treat ME/CFS<sup>13</sup> and, consequently, often recommend treatments that exacerbate symptoms.<sup>14</sup>

### **And yet....**

- ME/CFS has been in the bottom 5% of NIH funding for decades, typically less than \$6 million a year.<sup>15</sup>
- The 2015 National Academy of Sciences' Institute of Medicine report noted the essential need for more research, observing that "remarkably little research funding has been made available ...especially given the number of people afflicted."<sup>16</sup>

**We urgently need NIH funding to be commensurate with diseases of similar burden and prevalence - approximately \$200 million per year.<sup>17</sup>**

### **Endnotes**

1. February 10, 2015: Institute of Medicine "[Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness](#)," page 1. [IOM report]
2. [Ibid](#), Page 243
3. [Ibid](#), Page 39
4. [Ibid](#), Page 259
5. [Ibid](#), Page 2. This figure is likely an underestimate since it does not include those undiagnosed or unable to access health care. Page. 32. One study found that as many as 61% were bedbound or housebound on their worst days and that only 13% could work, some of those only part-time. Chu L (2013). US ME/CFS Patient Survey – April to May 2013. Presented at FDA Drug Development Workshop, April 25-26, 2013. <http://iacfsme.org/portals/0/pdf/FDA-AugustFinalReportforUS-Version2.pdf>.
6. [Ibid](#), page 31
7. "Health-Related Quality of Life for Patients with ME/CFS," PLoS One, 2015
8. [Ibid](#), report, Page 31-32
9. [Ibid](#), Page 1

10. [Ibid](#), Page 1
11. [Ibid](#), Page 2
12. Solve ME/CFS Initiative
13. [Ibid](#), Page 2
14. [Ibid](#), Page 2
15. [https://report.nih.gov/categorical\\_spending.aspx](https://report.nih.gov/categorical_spending.aspx). Chart also contains link to 2008-2012 data.
16. [Ibid](#), Pages 9, 225
17. Dimmock ME, Mirin AA, Jason LA (2016), "[Estimating the disease burden of ME/CFS in the United States and its relation to research funding](#)." J. Med Therapy 1.