



## **FACT SHEET ON MYALGIC ENCEPHALOMYELITIS /CHRONIC FATIGUE SYNDROME**

**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.**

- 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>
- People with ME/CFS have a lower quality of life<sup>6</sup> and more functional impairment<sup>7</sup> than those with other disabling illnesses such as multiple sclerosis, heart disease, and end-stage renal disease
- An estimated 84-91% of ME/CFS patients are not yet diagnosed.<sup>8</sup>
- ME/CFS costs our economy \$17- \$24 billion annually in lost productivity and direct medical costs.<sup>9</sup>

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

- Actual NIH funding has been around \$6 million for decades, millions of dollars below funding for diseases with similar burden and prevalence.<sup>10</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 to study the etiology, pathophysiology, and effective treatment of this disease, especially given the number of people afflicted."<sup>11</sup> CDC funding is also very low.
- Clinical care and medical education are in a crisis. Less than 12 clinics treat the millions of patients nationwide.<sup>12</sup> Very few doctors have training about how to care for patients<sup>13</sup> and, consequently, often recommend treatments that exacerbate symptoms.<sup>14</sup>

**Endnotes:**

1. February 10, 2015: Institute of Medicine "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness," page 1. Available <http://tinyurl.com/h83rp83>.
2. Ibid, Page 243
3. Ibid, Page 39
4. Ibid, Page 259
5. Ibid, Page 2
6. "Health-Related Quality of Life for Patients with ME/CFS," PLoS One, 2015
7. Ibid, Page 31-32
8. Ibid, Page 1
9. Ibid, Page 2
10. 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. <http://bit.ly/2mR7yG4>
11. Ibid, Pages 9, 225
12. Solve ME/CFS Initiative
13. Ibid, page 2
14. Ibid, page 2