

Massachusetts CFIDS/ME & FM Association

Education, Support and Advocacy since 1985

About CFIDS/ME (also known as ME/CFS)

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is an acquired, chronic multi-systemic disease characterized by significant relapse after physical, cognitive, or emotional exertion of any sort. The disease includes immune, neurological and cognitive impairment, sleep abnormalities, and autonomic dysfunction, resulting in significant functional impairment accompanied by a pathological level of fatigue. The cause of the disease remains unknown, although in many cases symptoms may have been triggered by an infection or other prodromal event¹. There is no cure, and no diagnostic test or FDA-approved treatment. **There are an estimated 28,000 patients, including children as young as 10, in Massachusetts.**

Recent reports have called for more research and more medical education on ME/CFS

- Institute of Medicine: **Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness**, 2015 (sponsored by 6 HHS agencies)
- NIH: Pathways to Prevention Workshop, Final report: **Advancing the Research on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome**, Dec. 2014

Leading Scientists say...

“We’re going to solve this in three to five years provided the resources are made available”²
Dr. Ian Lipkin speaking at Simmaron Research Foundation, December 2015

“It’s probably the last major disease that we don’t know anything about. . . .”³ Dr. Ron Davis as reported in the Washington Post, October 5, 2015

How Congress can HELP

- **Thank NIH for their recently announced research initiatives on ME/CFS^{4,5} and support our request for funding at a level commensurate with the burden of the disease.** NIH funding in 2015 was about \$2 per ME/CFS patient, compared with \$235 per patient for Multiple Sclerosis, which has a similar burden of illness but only one quarter the number of patients.⁶
- **Restore funding in the FY2017 budget for the CDC’s ME/CFS program** at a level of \$6MM or higher, to allow completion of the multi-year multi-site research study and implement a program of broad-based medical education.
- Encourage NIH and CDC to work together to **establish a network of Centers of Excellence** which include both research and patient care.

About Massachusetts CFIDS/ME & FM Association

The Massachusetts CFIDS/ME & FM Association, a 501(c)3 founded in 1985, exists to meet the needs of patients with CFIDS (Chronic Fatigue and Immune Dysfunction Syndrome, also known as Chronic Fatigue Syndrome), ME (Myalgic Encephalomyelitis) or FM (Fibromyalgia), their families and loved ones. The Massachusetts CFIDS/ME & FM Association works to educate health-care providers and the general public regarding these severely-disabling physical illnesses. We also support patients and their families and advocate for more effective treatment and research. Learn more at www.masscfids.org.

¹ <http://www.hhs.gov/advcomcfs/recommendations/2015-08-18-19-recommendations.pdf>

² <http://simmaronresearch.com/2015/12/ian-lipkin-three-to-five-years-to-solve-chronic-fatigue-syndrome-mecfs>

³ https://www.washingtonpost.com/national/health-science/with-his-son-terribly-ill-a-top-scientist-takes-on-chronic-fatigue-syndrome/2015/10/05/c5d6189c-4041-11e5-8d45-d815146f81fa_story.html

⁴ <http://www.nih.gov/news-events/news-releases/nih-takes-action-bolster-research-myalgic-encephalomyelitis/chronic-fatigue-syndrome>

⁵ <http://mecfs.ctss.nih.gov/>

⁶ https://report.nih.gov/categorical_spending.aspx