

Massachusetts CFIDS/ME & FM Association

Education, Support and Advocacy since 1985

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

March 10, 2016

Request for FY 16 and 17:

- Support a letter to NIH Director Francis Collins requesting that an equitable share of the \$2 billion increase in FY 16 NIH funding be used to fund ME/CFS research.
- Include the following recommendations in the 2017 Appropriations Report language:
 - NIH to make a set of investments to spur ME/CFS research and drug development,
 - CDC to reinstate and increase CDC funding and conduct a broad-based medical education campaign leveraging recommendations of the IOM and of the CFS Advisory Committee,
 - HHS to identify ways to creatively fund Centers of Excellence that include a clinical care component.

Rationale

- The 2015 Institute of Medicine (IOM) report noted that ME/CFS is a “serious, chronic, complex, multisystem disease that frequently and dramatically limits the activities of affected patients.”¹
- Between **836,000 and 2.5 million** U.S. residents are afflicted with ME/CFS and at least one quarter of them are **housebound or bedbound**, often for years. 50-75% are unemployed.² ME/CFS-related medical expenses and lost productivity cost the U.S. **\$17 to 24 billion** annually.³
- Patients with ME/CFS **score more poorly on quality of life** surveys than patients with multiple sclerosis, stroke, renal failure, heart failure and other chronic diseases.⁴
- Yet, the IOM report noted a “paucity of research” and “remarkably little research funding.”⁵ As a result, there are **no diagnostics** and **no FDA-approved treatments**. Prominent scientists have stated they are eager to study ME/CFS but have been unable to get NIH funding.⁶ Funding has remained static at about \$5M a year, far below other similarly disabling illnesses. For instance, in 2015, **ME/CFS got about \$2 per patient** per year compared to **\$250 for multiple sclerosis**. Based on prevalence and disease burden, funding should be an estimated \$250 million a year.⁷
- ME/CFS is not taught in most medical schools⁸ or in continuing education, so health professionals do not receive the training to diagnose or treat patients. ME/CFS has no home in any medical specialty. As a result, **81-94% of patients are undiagnosed**.⁹
- The \$2 Billion dollar increase in NIH’s FY16 budget and the reports by the IOM and NIH’s 2015 Pathways to Prevention Workshop¹⁰ have provided the unprecedented opportunity to address this long-neglected disease.

¹ Institute of Medicine of the National Academies. “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.” Institute of Medicine of the National Academies. Final report May 2015. <http://www.iom.edu/Reports/2015/ME-CFS.aspx> Page 5

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- ² Centers of Disease Control and Prevention. “CDC Public Health Grand Rounds. Chronic Fatigue Syndrome: Advancing Research and Clinical Education.” Centers for Disease Control and Prevention. February 16, 2016. <http://www.cdc.gov/cdcgrandrounds/pdf/archives/2016/feb2016.pdf>
- ³ Institute of Medicine of the National Academies. “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.” Institute of Medicine of the National Academies. Final report May 2015. <http://www.iom.edu/Reports/2015/ME-CFS.aspx> Page 2
- ⁴ Hvidberg M, Schouborg Brinth L, Olesen A, Petersen K, Ehlers L. “The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS).” PLOS One. July 16, 2015. <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0132421>
- ⁵ Institute of Medicine of the National Academies. “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.” Institute of Medicine of the National Academies. Final report May 2015. <http://www.iom.edu/Reports/2015/ME-CFS.aspx> Page 9
- ⁶ Underwood, E. “Lobbyists seek new funds for chronic fatigue syndrome research.” Science Insider. August 17, 2015. Last accessed August 28, 2015. <http://news.sciencemag.org/biology/2015/08/lobbyists-seek-250-million-new-funds-chronic-fatigue-syndrome-research>
- This article includes a link to an August 17, 2015 letter from 27 disease experts to Senator Mikulski stating their interest in research in this disease. [The letter to Senator Mikulski is also available here: http://www.cfstreatmentguide.com/blog/an-open-letter-from-researchers-to-senator-mikulski-patients-suffering-from-mecfs-deserve-funding](http://www.cfstreatmentguide.com/blog/an-open-letter-from-researchers-to-senator-mikulski-patients-suffering-from-mecfs-deserve-funding)
- ⁷ U.S. National Institutes of Health. “Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC).” National Institutes of Health. Published March 7, 2014. http://report.nih.gov/categorical_spending.aspx
Also see:
Solve ME/CFS. “Solve ME/CFS Initiative Hosts IOM Briefing in D.C.” Solve ME/CFS. March 25, 2015. <http://solvecfs.org/iom-briefing-in-d-c/>
- ⁸ Institute of Medicine of the National Academies. “Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness.” Institute of Medicine of the National Academies. Final report May 2015. <http://www.iom.edu/Reports/2015/ME-CFS.aspx> Page 15-16.
- ⁹ Ibid. Page 1.
- ¹⁰ National Institute of Health. Office of Disease Prevention. “Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. December 9-10, 2014. Executive Summary.” National Institute of Health. Office of Disease Prevention. Final Report June 16, 2015. <http://prevention.nih.gov/docs/programs/mecfs/ODP-P2P-MECFS-FinalReport.pdf>