Determining the Disease Burden of ME/CFS

By SMCI Board Member Mary Dimmock

Those touched by ME/CFS have long known what the 2015 Institute of Medicine (IOM) report and other recent publications confirmed: ME/CFS causes more debilitation than diseases such as congestive heart failure, multiple sclerosis, and end-stage renal disease. And yet, in spite of this, the IOM reported "remarkably little research funding" for ME/CFS.

Mary Dimmock, SMCI Board Member and ME/CFS Advocate

The impact a disease has on patients is called its "disease burden." The World Health Organization has pioneered a single measure of disease burden, disability-adjusted life years (DALY), which combines the number of years of premature death with the magnitude and number of years of disability caused by a given disease.

Though it may sound cold, this quantifiable measure of pain and suffering allows federal policy makers to compare very different diseases—for instance, the burden of a disease that primarily causes premature death with that of a disease that causes decades of debilitation. DALY also provides a means to evaluate whether public health responses and policies are decreasing a disease's burden over time. For instance, likely as a result of new treatments the US burden of AIDS fell by 61% between 1990 and 2010.

The National Institutes of Health (NIH) uses disease burden, in addition to scientific opportunity, quality of science, and researcher interest, in deciding where to focus its research. In 2015, the NIH published an analysis[1] of how its funding levels compared to DALY figures for 68 disease areas. A Washington Post article[2] on this analysis by journalist Carolyn Johnson detailed how diseases with higher disease burden could sometimes have dramatically lower levels of research funding, noting that "in 2010, HIV research received nearly $3.1 billion in funding, while a deadly lung disease that has more than six times the health toll in the United States got only $118 million."

The reasons for these differences are complex and, as was the case with HIV/AIDS, can also include the opportunity to permanently eradicate a disease. But scientists told Johnson the NIH's analysis also suggested less funding may be provided to diseases "where we blame the victim" or there is less public support.

ME/CFS wasn't included in the 2015 NIH analysis because the US DALY had never been calculated for the disease. To address this gap, Dr. Leonard Jason, Arthur Mirin, and I recently published a paper estimating DALY for ME/CFS and its relation to research funding.

The impact on DALY due to disability was based on reports of decreased quality of life. Given that ME/CFS is underdiagnosed and not effectively tracked in electronic medical records, it's difficult to directly estimate the impact on DALY from deaths resulting from ME/CFS and its complications. However, several small studies provided reports of increased numbers of premature deaths due to cancer, heart disease, and suicide.

[1] https://nexus.od.nih.gov/all/2015/06/19/burden-of-disease-and-nih-funding-priorities/

[2] https://www.washingtonpost.com/news/wonk/wp/2015/07/17/why-the-diseases-that-cause-the-most-harm-dont-always-get-the-most-research-money/?utm_term=.7649893a968b

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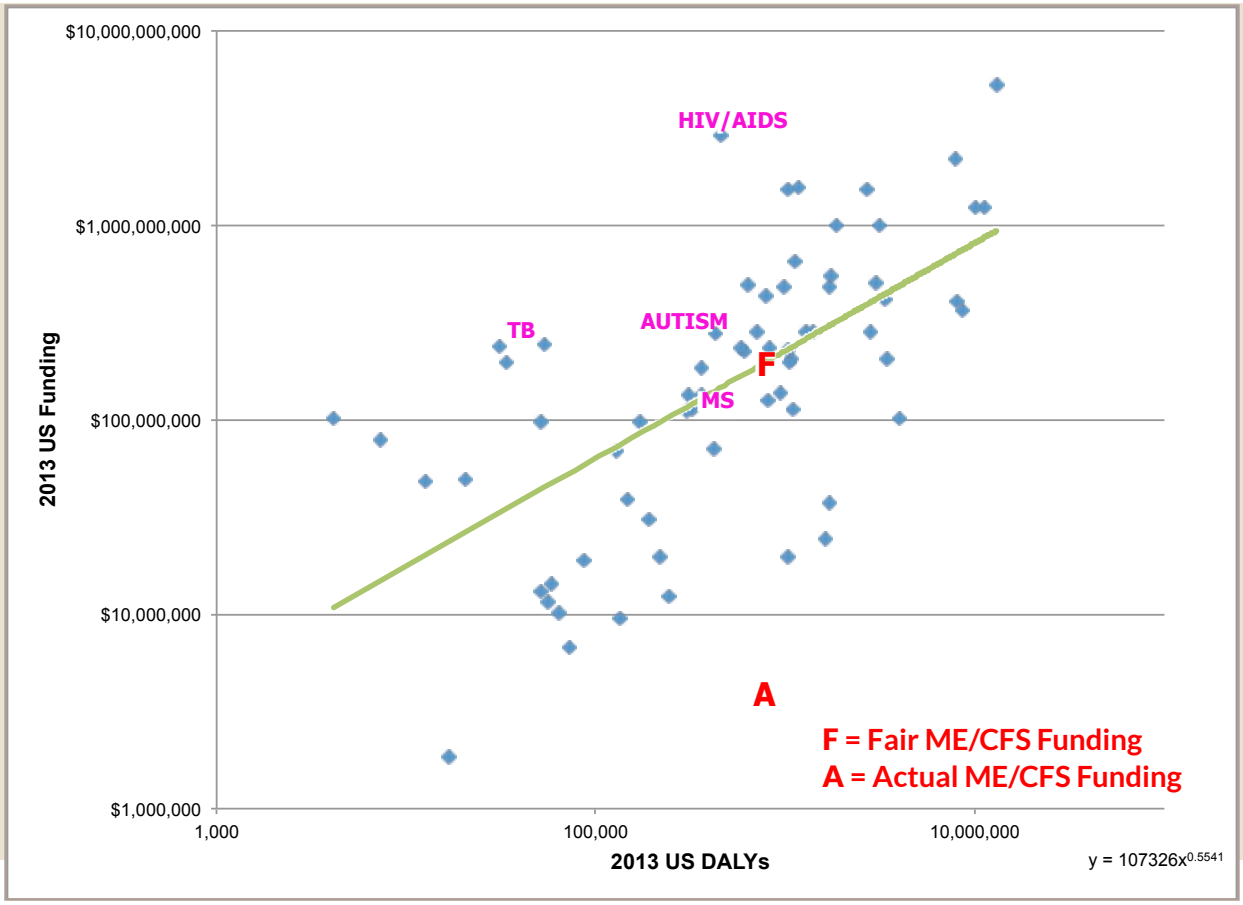

The resultant DALY was then compared to the NIH's analysis of funding versus disease burden to estimate the level of NIH funding that would be commensurate with that of these other diseases (Figure 1).

This analysis suggests that NIH funding for ME/CFS would have to increase roughly twenty-five-fold to $188 million per year (from $7 million per year) to be commensurate with disease burden.

Our paper describes significant limitations that could impact the accuracy of estimates of DALY and commensurate NIH funding. These include lack of quality research on prevalence, levels of disability, and causes of premature death. Other limitations include missed and mistaken diagnoses of ME/CFS patients and inadequate tracking of ME/CFS in medical and death records. But even considering these limitations, this analysis demonstrates a remarkable level of underfunding, significant gaps in research, and inadequate clinical care practices.

Dr. Nancy Klimas once noted her HIV/AIDS patients were "hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested," while her ME/CFS patients "are terribly ill and unable to work or participate in the care of their families."

As was done with HIV/AIDS, the Department of Health and Human Services has the real opportunity to decrease the terrible burden of ME/CFS by providing commensurate funding and the leadership necessary to address gaps in research, provide for accurate disease tracking, and correct the misperceptions in the medical community that have magnified the burden of an already horrific disease. ■