

Submission by Susan Kreutzer, patient advocate and advisor for MEAdvocacy.org¹

The National Institute of Health's funding and handling of myalgic encephalomyelitis (ME) urgently needs overhauling. We are asking for \$250 million a year to bring ME funding up to an appropriate level.

Dear Ladies and Gentlemen of the Committee:

Myalgic encephalomyelitis (ME), also known in the U.S. as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), is a seriously disabling neuro-immune disease. It sickens an estimated 850,000 to 2.5 million² in the U.S. and 17 million worldwide. A majority of patients are disabled, unable to work, attend school or participate in activities of daily life. A quarter are so severely affected as to render them bedbound, unable to care for themselves.

The disease has a long history, appearing worldwide in epidemic and endemic forms. Myalgic encephalomyelitis was described, defined and coined by Dr. A. Melvin Ramsay after a 1955 outbreak in London. The first major clusters reached the U.S. in the mid 1980s in Incline Village, Nevada and Lyndonville, New York. In response, the CDC broadly redefined the disease and renamed it the marginalizing name; chronic fatigue syndrome (CFS).

For the past three decades, ME patients' voices have been ignored. The Department of Health and Human Services (HHS) has continuously attempted to bury this disease, by neglecting and marginalizing the patients. To accomplish this, HHS has repeatedly used overly broad definitions, trivializing disease names, and grossly underfunded it. This has resulted in substandard care for ME patients by the medical community, leaving a generation of ME patients suffering with little hope for the future. Unconscionably, the upcoming generation of patients are facing the same issues as thirty years ago.

MEAdvocacy.org¹ is a growing grassroots movement of advocates and patients who are rising up and saying we have had enough of empty promises and lies. We want the right to life, liberty, and the pursuit of happiness that is afforded to us by the Declaration of Independence. We want the same chance at life and health as patients who suffer from other similarly burdened diseases. We are lawyers, laborers, teachers, students, fathers, mothers, and children. Our productive lives have been cut short by this debilitating disease and we have no hope of treatment or cure. We have had enough and are saying, **“No More!”**

Disease Burden and Funding:

Some ME patients have died prematurely from complications of ME. Others have died at their own hands due to the severity and length of their suffering without proper palliative care, dismissed and stigmatized by the medical community. The patients will not carry this burden quietly any longer and we are looking at Congress to require HHS to properly fulfill their duty to

ME sufferers. If you do not act on behalf of these severely affected patients, you are complicit in their suffering and untimely deaths.

In 2006, Dr. Nancy Klimas, then the director of AIDS research at the Miami Veterans Affairs Medical Center as well as a CFS researcher/clinician stated in a press conference, “They [ME/CFS patients] experience a **level of disability equal to that of patients with late-stage AIDS and patients undergoing chemotherapy.**” In the intervening years, nothing has changed. It is very clear that real change at HHS regarding this disease will not come about naturally. We have come to you, the Appropriation Committee, for help in addressing this dire need for funding, oversight and investigation.

It is estimated that the burden to the economy for ME is between \$17 to 24 billion,³ yet NIH funding for research has stagnated at a mere \$5 million a year. HHS has placed funding for ME at the rock bottom of their funding budget list.⁴ The yearly allocation for ME/CFS is a tiny fraction of what other similarly burdened diseases receive.

<i>NIH Funding Data for 2014</i>	<i>US Patient Population</i>	<i>Funding per Patient</i>
<i>HIV/AIDS - \$ 2 billion, 978 million</i>	<i>1,200,000</i>	<i>\$2,481</i>
<i>multiple sclerosis - \$ 102 million</i>	<i>400,000</i>	<i>\$255</i>
<i>lupus - \$ 99 million</i>	<i>350,000</i>	<i>\$283</i>
<i>myalgic encephalomyelitis - \$5 million</i>	<i>1,000,000</i>	<i>\$5</i>

The great divide between NIH funding for ME and other diseases cannot be explained away. Simply advising and recommending that NIH increase funding for ME, has not worked. The Secretaries of Health and Human Services have not responded to most of the 77 recommendations made by the Chronic Fatigue Syndrome Advisory Committee (CFSAC)⁵ during the past ten years. The department did not heed the call by President Obama⁶ as a result of a call out at a townhall meeting by the wife of a patient. In order to fund ME on par with MS, a similarly serious disease, ME would need \$250 million a year. Perhaps a proportional allocation from other diseases related to immune, cognitive and nervous system dysfunctions could be utilized by this committee to find the additional funding needed for ME.

The following are the recommendations and goals that we at MEadvocacy.org feel the Appropriations Committee needs to require that NIH meet, in order to bring Myalgic Encephalomyelitis on par with other similarly burdened diseases:

- 1. Fund biomedical research for ME commensurate with its severity and burden to patients and the economy.** We are asking for specific funding in the amount of **\$250 million**, the amount we believe is needed to bring ME funding to an appropriate level. HHS should clearly allocate funds to study patients from past ME cluster outbreaks as well as the study of the epidemiology of patients with severe ME. The additional funding needed for ME might be accomplished **by means of prorating the allocation** from other diseases related to immune, cognitive and nervous system dysfunctions.

2. Return ME to the National Institute of Allergy and Infectious Disease (NIAID) or place it in the National Institute of Neurological Disorders and Stroke (NINDS), which also manages similar neuroimmune diseases such as multiple sclerosis. The **Office of Research on Women’s Health, where ME is currently housed, is entirely inappropriate** for a disease which also strikes men and children.

Very truly yours,

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Links
1) http://www.meadvocacy.org/
2) https://www.iom.edu/~media/Files/Report%20Files/2015/MECFs/MECFs_ReportBrief.pdf
3) https://www.iom.edu/~media/Files/Report%20Files/2015/MECFs/MECFs_ReportBrief.pdf
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