

Open letter on funding for biomedical research into Myalgic Encephalomyelitis in the European Union

Myalgic Encephalomyelitis (ME), sometimes referred to as Chronic Fatigue Syndrome (CFS), is a chronic, debilitating illness characterized by extreme exhaustion, cognitive dysfunction, and post-exertional malaise. [1] ME patients are frequently unable to work, study or participate in social activities. Some are house- or bedbound and fully dependent on the care of family members.

In the United States (US) the direct and indirect economic costs of ME have been estimated at 17 to 24 billion dollars annually. In the European Union (EU), the impact on society is expected to be even higher with approximately two million EU citizens suffering from ME.

Despite its high economic costs, ME has long been a neglected area in medicine. There is currently no effective treatment and the estimated prognosis is poor. Many patients remain ill for decades. Although biomedical research is making progress, the pathology of the illness is still poorly understood.

Because of the high disease burden, more funding for biomedical research into ME is urgently needed. We would like to express our support for a special provision in the Horizon research program to address the lack of funding for neglected chronic diseases such as ME.

In the US, Australia, and Canada, governments have earmarked funding for ME research, a strategy that will attract new scientists and will further develop the field. Biomedical research into ME is taking place at prestigious research institutes including Stanford, Cornell, and Columbia Universities. A new ME research collaboration has recently been formed at Harvard-affiliated hospitals. A key priority is to develop a diagnostic test for ME to increase the accuracy of diagnosis and provide reliable outcomes in treatment trials.

The EU, unfortunately, is running behind. As a global forerunner in healthcare and medical research, it is notable that the EU is currently funding little to no biomedical research into ME. Some of the rare European research projects into ME had to be financed by charities, patients and their loved ones.

We recommend that the EU align itself with international developments by issuing a long-term commitment to invest in biomedical research into ME. A special provision in the Horizon research program to address the underfunding of neglected chronic diseases could help remove some of the barriers for European scientists to study ME. Hopefully, this will lead to a better understanding of the disease mechanism and eventually, an effective treatment for this devastating illness.

Sincerely,

[1] Institute of Medicine (IOM). Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington, DC: The National Academies Press; 2015.
https://www.ncbi.nlm.nih.gov/books/NBK274235/pdf/Bookshelf_NBK274235.pdf

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