

Petition No 0204/2019 by Evelien Van Den Brink (Dutch) on a request for funding for biomedical research on Myalgic Encephalomyelitis

Response by Evelien van den Brink to the reply of the European Commission

First of all I would like to thank the European Commission for its reply received by the Committee on Petitions on 30 August 2019.

I am glad to read that the Commission recognises the importance of research on myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS) and acknowledges that this is an underserved population of patients. It is encouraging to see that the Commission has recently made a start with funding research into ME by making funds available for a project aimed at correcting the gut microflora disbalance under the SME Instrument funding mechanism in April 2019.

However, as the Commission states, the cause of ME is not yet known. Imbalance of gut microflora, damaged gut barrier functions and dysfunctional immune responses are one possible hypothesis. I would like to emphasise that there are many more interesting biomedical hypotheses that deserve to be investigated. (1) This is an extremely complex disease and a structural commitment to funding biomedical research is needed, which will allow researchers to attack the problem from all possible biomedical sides.

I believe equitable funding is warranted, given the large number of patients, the disease burden and the economic impact. At least 25% of ME/CFS patients are home- or bed-bound at some point in their lives. (2)

Many are unemployed or have reduced productivity. (3, 4)

People with ME/CFS have a lower quality of life (5) and more functional impairment (6) than those with other disabling illnesses such as multiple sclerosis, heart disease, and end-stage renal disease.

I understand that no specific projects have been funded that could lead to the development of a biomedical diagnostic test. This is however a very important part of the research into ME that could lead to a better understanding of the disease and improvements in the situation of patients. Moreover, this is now technically possible. There are many promising potential diagnostic tests under development. (7, 8)

The Commission's response mentions that the current EU Framework Programme for Research and Innovation continues to provide opportunities for research funding on ME/CFS, fibromyalgia, as well as other neuro-immunological disorders, including better diagnostics and care. It is my understanding from various contacts with ME researchers that their grant proposals, that have been submitted since 2007, have all been turned down under these general calls, which is extremely unfortunate. Correspondence with ME researchers indicates that ME often loses out in competition with other more established diseases that are already better researched and understood. They strongly believe that more specific calls for ME, for research into the development of a biomedical diagnostic test for ME and biomedical treatments for ME, would be very helpful to advance the field. Another option would be to include researchers with specific biomedical knowledge of ME in the general Horizon Europe grant evaluations panels.

Scientifically the goals of developing a biomedical diagnostic test and biomedical treatments are achievable and yet scientists from respected ME research groups cannot access the necessary funding under Horizon 2020/Horizon Europe. This understandably leads to frustration among both scientists and patients and their families. Funding the establishment of Centres of Excellence, following the example of the NIH in the USA (9), would be an option to solve these issues successfully in a comprehensive way and provide researchers with the infrastructure they need to make headway.

I strongly believe that unless the Commission introduces specific measures to ensure funding of biomedical research into ME that properly reflects the disease burden, then the current underfunding will continue.

I hope together we will be able to develop a strategy to create the best conditions under which major scientific progress will be achieved in the shortest possible time.

Thank you very much.

Evelien van den Brink

- (1) ME Research Summary 2019; An abbreviated summary of ME research over the past ten years. http://www.meaction.net/wp-content/uploads/2019/06/19_MEA_Revised_2019_Research_Summary_190610.pdf
- (2) IOM (Institute of Medicine). 2015. Beyond myalgic encephalomyelitis/chronic fatigue syndrome: Redefining an illness. Washington, DC: The National Academies Press. <https://www.nap.edu/read/19012/chapter/1>
Page 2. This figure is likely an underestimate since it does not include those undiagnosed or unable to access health care. Page 32. One study found that as many as 61% were bedbound or housebound on their worst days and that only 13% could work, some of those only part-time. Chu L (2013). US ME/CFS Patient Survey – April to May 2013. Presented at FDA Drug Development Workshop, April 25-26, 2013. <http://iacfsme.org/portals/0/pdf/FDA-AugustFinalReportforUS-Version2.pdf>.
- (3) Ibid, Page 31
- (4) EUROMENE - COST Action - is currently working on an estimate of the economic impact of ME in the EU
- (5) “Health-Related Quality of Life for Patients with ME/CFS,” PLoS One, 2015
- (6) Ibid, report, Page 31-32
- (7) “A nanoelectronics-blood-based diagnostic biomarker for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).” Esfandyarpour R, et al. Proc Natl Acad Sci U S A. 2019. <https://www.pnas.org/content/116/21/10250/tab-figures-data>
(...) *we developed a nano- electronics blood-based assay that can potentially establish a diagnostic biomarker and a drug-screening platform for ME/CFS. Given the significance of this assay, we envision it has the potential to be widely employed in research laboratories and clinics in the future as an aid to physicians as well as to our colleagues in the ME/CFS research community.*
- (8) “The expression signature of very long non-coding RNA in myalgic encephalomyelitis/chronic fatigue syndrome.” Yang CA, et al. J Transl Med. 2018. <https://translational-medicine.biomedcentral.com/articles/10.1186/s12967-018-1600-x>
- (9) The National Institutes of Health (NIH) in the United States of America awarded grants to three Collaborative Research Centers (CRCs) and one Data Management Coordinating Center. <https://mecfs.rti.org/research-centers/>