

Response by Evelien Van Den Brink (petition 0204/2019) to the Commission's written answer to question E-003764/2020 by Mr. Cañas MEP

I would like to thank Commissioner Gabriel for responding on behalf of the European Commission to parliamentary question E-003764/2020 by Mr. Cañas MEP on additional funding for research on Myalgic Encephalomyelitis (ME/CFS).

Unfortunately, however, the answer by the Commission does not acknowledge the underfunding of ME/CFS research in Europe nor does it propose new initiatives to address this urgent problem.

Addressing the needs of patients

The Commission's response stresses that ME/CFS scientists should have fair access to research funding through the Horizon Europe program. The recent parliamentary resolution, however, does not only address the difficulties of ME/CFS scientists in accessing research funding but focusses specifically on the rights of ME/CFS patients to have their illness studied so that effective treatments can be found.

As the commission previously acknowledged, little to no biomedical research projects on ME/CFS have been supported by the European Union. This indicates that the current system is not working satisfactorily for ME/CFS, an illness that is marked by stigma, misunderstanding and a historic neglect by the international research community. Currently, scientists need to have exceptional dedication to enter the ME/CFS field, because of the aforementioned issues, the absence of clear leads and uncertainty about their chances of success.

Rising up to international standards

I think, as European citizens, we can expect the Commission to make sure that there is some mechanism to direct science to areas with a high societal need. Incentives will have to be provided for the field to grow. In countries such as Australia [1], Canada [2], and the United States [3], governments have earmarked funding for ME/CFS research to further develop the field. These decisions were based on disease burden as ME/CFS has a high prevalence, a low recovery rate, and morbidity higher than many other chronic illnesses. [4-5] It is unclear why the European Commission, a global forerunner in medical research, does not initiate similar initiatives as commended by resolution 2020/2580(RSP). This would ensure that the European Union does its fair share in the international collaborative effort to unravel the underlying pathology of ME/CFS.

Long-term Covid-19 and ME/CFS

Lastly, it is unfortunate that the Commission's response does not consider the possibility that COVID-19 might lead to an increase in the incidence of ME/CFS and related postviral syndromes. Scientists have repeatedly warned about this possibility and highlighted the need for further research [6-7]. Longitudinal studies on the long-term effects of COVID-19 and the risk of developing ME/CFS need to be initiated now. Although SARS-CoV-2 has caused enormous health- and economic crises, it also provides an exceptional opportunity to conduct prospective research and further our understanding of why some persons fail to recover from viral infections.

I hope that the Commission will demonstrate a sense of urgency by introducing new strategies to tackle the underfunding of ME/CFS research in Europe. Initiatives abroad demonstrate that more can be done.

Yours faithfully,

Evelien Van Den Brink

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