



Mariya GABRIEL

Commissioner for Innovation, Research,
Culture, Education and Youth

Brussels, 14 October 2022

Dear Honourable Members of the European Parliament,

I would like to thank you for your letter of 10 February 2022 to Commissioner Kyriakides, in which you put forward your concerns regarding the follow-up of the European Parliament resolution on funding for research on Myalgic Encephalomyelitis (ME/CFS). As the matter is in my portfolio, I am replying to you and wish to give my apologies for the delay.

The scoping study, which will help identify high-burden medical conditions like ME/CFS that remain under-researched, was launched in March (2022) and is expected to be completed by the end of this year. The study will put forward a definition of what constitutes a condition that is under-researched while being a high-burden to patients or society as a whole, as well as a non-exhaustive list of potentially concerned conditions. Key stakeholders, including patient representatives, are also being consulted to help define the type of research and/or research priorities for better addressing needs of patients affected by these conditions.

In reference to your concerns over COVID-19 patients who might develop ME/CFS, you will know from earlier communications that the EU also funds research into post-COVID-19. For example, the ORCHESTRA project¹ looks into the long-term consequences of COVID-19 infection, as well as the IMI2-funded project, DRAGON². Other EU-supported projects researching post-COVID-19 stem from the call topic 'Cohorts united against COVID-19 variants of concern'³ and these have recently started. For example, the VERDI project⁴ is evaluating both the short and long-term clinical outcomes of virus variants in children and pregnant women. Interestingly, the 'Long-COVID' project⁵, one of the projects from the call topic 'Personalised medicine and

¹ <https://cordis.europa.eu/project/id/101016167>

² <https://www.imi.europa.eu/projects-results/project-factsheets/dragon>

³ <https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/opportunities/topic-details/horizon-hlth-2021-corona-01-02;callCode=HORIZON-HLTH-2021-CORONA-01>

Noteworthy projects include VERDI, CoVICIS, EuCARE and END-VOC.

⁴ <https://cordis.europa.eu/project/id/101045989>

⁵ Long-COVID project: Decision support for prediction and management of Long Covid Syndrome (LCS)

infectious diseases: understanding the individual host response to viruses (e.g. SARS-CoV-2)⁶ is comparing defined therapies in patients with long-COVID and a number of other conditions, including ME/CFS. We expect that the supported research will provide insight regarding the long-term consequences of COVID-19 and ways to address these. It is also likely that this research will benefit our understanding of ME/CFS.

Regarding current and future funding opportunities for ME/CFS research, Horizon Europe offers a variety of possibilities from European Research Council grants to grants for collaborative projects in the Health cluster. Note that for the latter, call topics are generally broad and as such can cover a variety of areas, including ME/CFS. All calls can be found on the 'Funding and Tender Opportunities portal'⁷.

On your question addressing the European Reference Networks (ERNs) and the possible expansion of their diseases coverage, the process enabling the existing 24 ERNs to adjust the scope of the diseases they cover is currently ongoing. The ERNs were requested to submit their proposals for the amendments of their disease coverage by 31 August 2022. However, the European Reference Network for Rare Neurological Diseases (ERN-RND) has not submitted any application to this call. The submitted proposals by the ERNs have been sent to the members of the ERNs Board of Member States (ERNs BoMS) for formal approval at the semestral meeting on 5 October 2022.

Yours faithfully,



Mariya Gabriel

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Alex Agius Saliba, MEP
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<https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/how-to-participate/org-details/999999999/project/101057553/program/43108390/details>

⁶ 2021-2022 Work Programme of Horizon Europe's Health cluster; Topic ID: HORIZON-HLTH-2021-DISEASE-04-07

<https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/opportunities/topic-details/horizon-hlth-2021-disease-04-07>

⁷ <https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/home>