

15 July 2021

Dear Director-General Paquet,

On 30 June 2021, a webinar titled "Challenges and Opportunities for ME/CFS research in Europe", was organized in honor of the anniversary of Resolution 2020/2580(RSP) on additional funding for biomedical research on Myalgic Encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Dr. Catherine Berens attended the meeting on behalf of DG-RTD and gave an update on the plans of the Commission to support research on ME/CFS. We were told that the need to amend the Horizon Europe program, to address poorly understood illnesses with a high disease burden, like ME/CFS, has been accepted. This amendment, to the Horizon Europe program, is to be progressed via a scoping study, and the Commission plans to issue such a study to allow under-researched illnesses like - but not limited to - ME/CFS to be included structurally in future work programs.

We are grateful for the work the Commission has done so far. We can, however, not help but miss a sense of urgency. Dr. Berens mentioned that the scoping study should be initiated by the end of 2021. Although we understand that the exceptional circumstances of the COVID-19 pandemic must have had an impact, we regret that one and a half years on there are still no tangible results, meaning that ME/CFS patients have lost another year and a half. And it is an unfortunate fact that it will take even longer before the scoping study is finished and sufficient funding may become available for actual research projects.

Representatives of the Commission have frequently stated that the Horizon Europe work program contains ample opportunities for ME/CFS researchers to apply for funding under the broad existing calls. The Commission seems to trust that the current system is working, while ME/CFS researchers say that although they have repeatedly tried to apply (under the FP7 and Horizon 2020), none of their applications have been approved and no funds have been awarded. This means there is a substantial gap between the Commission's view and the reality of ME/CFS researchers.

We would like to emphasize that ME/CFS patients and researchers are not asking for much. They just want normal care and a normal amount of funding, in accordance with the disease burden. The two million European citizens suffering from ME/CFS deserve to have their illness studied, after years of having been neglected.

Dr. Berens told us that the information shared during the Research and Innovation Days and Horizon Europe Introduction Days would help ME/CFS researchers to find ways to be more successful in applying for funds. Unfortunately, this does not seem to take into account that the number of ME/CFS researchers is very limited. They are competent and motivated, but filing a successful application takes a lot of time, funds, and educated personnel, which is everything most ME/CFS researchers do not have. They often do not, like scientists in other fields who are affiliated with large institutions, possess of a team specialized in obtaining

funds from Horizon Europe. It is quite difficult for them to compete with larger groups, who frequently have lobbying structures in place. The field is small, underdeveloped and without appropriate financial incentives, it will not grow to become successful. It would be particularly good to attract new researchers with a fresh perspective from outside the field, but nothing is more unattractive to a successful scientist than a field where there is no funding.

The EUROMENE Network of ME/CFS scientists was funded as a COST Action, and although the network clearly identified and published about the problems associated with ME/CFS research and the dire need for change, no funding has become available for actual research.

We are sure that with power and institutional creativity, the Commission could allocate funds for specific areas as you have done for coronavirus and cancer research.

We hope all parties will keep working together to solve this serious problem and that we can count on the Commission's dedication and support to bring about change as quickly as possible.

Yours sincerely,



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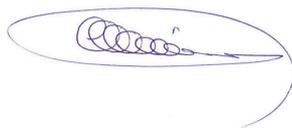


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