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Brussels, 9 September 2020

Dear Ms. Kyryakides,
Dear Ms. Gabriel,

The world is experiencing an unprecedented health and economic crisis, because of the pandemic caused by the COVID-19 virus. Throughout the entire world, we are all drifting into the unknown and the most vulnerable people suffer tremendously the brunt of this crisis.

In this regard, patients of Myalgic Encephalomyelitis (ME/CFS) are no exception, experiencing serious and debilitating symptoms with overwhelming disruptions in their daily lives.

Given the current lack of proper funding and the need of the patients diagnosed with this disease for an answer, on the 18th of June 2020 the European Parliament showed its full commitment and adopted almost unanimously (676 in favour, 4 against, 8 abstentions) the resolution 2020/2580(RSP)¹, which calls on the Commission to allocate additional funding for biomedical research on Myalgic Encephalomyelitis.

Having taken a personal interest in the matter, I decided to pursue the advancement of this important issue and turned to the European Commission² in order to seek reassurances that this topic was indeed included in the works of the Institution.

To my utmost disappointment, and that of millions of patients in Europe, I received the following reply³:

A better understanding of diseases and their drivers, including pain and the causative links between health determinants and diseases, has been identified as one of the priorities of Horizon Europe. Therefore, scientists and other actors with a specific interest in Myalgic Encephalomyelitis (ME/CFS) should have many possibilities to support their research and their goals in improving the condition of patients.

¹ https://www.europarl.europa.eu/doceo/document/TA-9-2020-0140_EN.pdf

² https://www.europarl.europa.eu/doceo/document/E-9-2020-003764_EN.html

³ https://www.europarl.europa.eu/doceo/document/E-9-2020-003764-ASW_EN.html

It should be noted that the topics to be addressed for funding under Research and Innovation programmes are generally broadly conceived without focusing on any specific disease or condition. With this approach, researchers dispose of wider opportunities within the area of their specific interest. This approach also assures that excellence, the major criterion to be selected for funding, is met by the proposals submitted. Moreover, their evaluation is carried out by independent experts.

The proposed EU4Health programme is still under negotiation and designed to fund policy relevant actions rather than research. One of its main proposed objectives is to strengthen health systems, including through increased integrated and coordinated work among Member States and sustained implementation of best practices. Priorities for the latter are set via the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases(1). As of yet, ME/CFS has not been identified as a priority for this purpose.

Finally, the Commission would like to recall that ME/CFS cannot be classified as a rare disease.

It is surprising and deeply disappointing to receive such an answer that conveys the message that the European Commission does not live up to the requests as adopted by the European Parliament, the only institution formed by members directly elected by the European citizens, in a such a sensitive and urgent matter.

It is of our great concern the lack of support that patients affected by this disease are repeatedly encountering. Around two million people in the EU, of whatever ethnicity, age or gender, are believed to be affected by ME/CFS, and women are hit hardest and are the most exposed. All those affected people and their families are expecting Europe to respond to their calls. Nonetheless, the overwhelming feeling of all of them would be one of disappointment and helplessness at the Commission's lack of commitment with ME/CFS research, following the recent calls of the European Parliament.

National associations found a ray of hope in the EP Resolution and are looking forward to the Commission to attend their demands. They have been waiting years to be listened and, together with members of the scientific community, they have been claiming the insufficient funding and opportunities to research for preventive treatments and discover the causes of this unknown neurological illness. Furthermore, preliminary scientific evidence suggests that an increase of ME/CFS is likely because of the COVID-19 virus⁴, thus revealing the absolute necessity to focus our efforts on medical research.

For this reason, forces must be united here and biomedical research must be supported in order to help the affected people and their families. In the light of this, I urge the European Commission to reconsider the position formulated in this written answer and to take due consideration of the calls of the European Parliament, in the hope that all together we can work on the benefit of ME/CFS patients.

Yours sincerely,

Jordi Cañas Pérez, Renew Europe

⁴ <https://www.newscientist.com/article/mg24632783-400-could-the-coronavirus-trigger-post-viral-fatigue-syndromes/>