



To:

Stella KYRIAKIDES, Commissioner for Health and Food Safety

Brussels, 10/02/2022

Lack of results after the European Parliament resolution of 18 June 2020 on funding for biomedical research on Myalgic Encephalomyelitis

Dear Commissioner,

On 18 June 2020, the European Parliament adopted resolution 2020/2580(RSP) to request funding for biomedical research on Myalgic Encephalomyelitis (ME/CFS) and measures to improve treatment and care for ME/CFS patients in Europe.

We as MEPs are in constant contact with patient's organizations affected by the disease. We want the recommendations of the resolution to be finally turned into meaningful action.

ME/CFS is a chronic and debilitating illness of which the cause and pathology remain poorly understood. The World Health Organization (WHO) classifies ME/CFS as a neurological illness (G93.3). The leading scientists in this field agree that Long Covid will lead to a large increase in the number of ME/CFS patient, while today already an estimated 2 million people suffer from the disease in Europe alone. ME/CFS might become the biggest long-term health problem of the pandemic.

Almost two years after the adoption of resolution 2020/2580(RSP), we have to note that the EU Commission did not produce tangible results in the spirit of the resolution:

So far, there has not been a single biomedical study on ME/CFS with European funding. Europe is still running behind the US, Canada, and Australia. Projects in Europe depend mostly on charitable funding by patients. Research centres like the ME/CFS research centre in Uppsala are entirely funded via donations from the US or crowdfunding.

In the face of a public health crisis with 2 million patients in the EU before the pandemic – and each month tens of thousands additional ones due to Long Covid – this is simply not acceptable!

Even though the European Commission announced a "scoping study" in order to investigate how ME/CFS and other under-researched conditions can be included in future Horizon Europe work programs, there is still no official starting date, and there already was a lot of delay even in announcing this step.

If we want to really tackle the disease, we also need European support for research funding on biomarkers, clinical research centres, and clinical trials in cooperation with the pharmaceutical

industry. Even though the number of people affected by ME/CFS is rising on, pharmaceutical companies did not yet engage in ME/CFS research as needed.

In addition, the ERN for neurological diseases would consider including ME/CFS, but the Commission and the Member States as well as the ERNs apparently did not agree upon an official opening for expansion of the ERN disease coverage. The European ME Coalition (EMEC) has contacted many people at DG SANTE, hoping they would assist, but the organization never got an answer from the Directorate-General (please find attached for your information our letter to DG SANTE in this regard).

We however urgently need a European network for biomedical ME/CFS research that could, for example, build on the experiences and knowledge of the existing EUROMENE network and lead to the creation of a European Centre of Excellence for ME/CFS to spearhead the establishment of regional centres in Member States.

In order to discuss these and other questions/demands in the presence of patient representatives and interested researchers, **we ask you for a personal exchange**, which, in view of the current epidemic situation, can of course also take place virtually.

We look forward to your response.

Yours sincerely,

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