



To:

Sandra GALLINA, Director-General – Directorate General for Health and Food Safety (DG SANTE)

Brussels, 10/02/2022

Expansion of the ERN disease coverage in order to include ME/CFS

Dear Ms Gallina,

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 also agree that Long Covid will lead to a large increase in the number of ME/CFS patients, while today already an estimated 2 million people suffer from the disease in Europe alone.

On September 7th 2021, the representative of the European ME Coalition (EMEC), Ms Evelien Van Den Brink, sent a letter to DG SANTE for the first time in order to inquire about the possibility to include the illness in the European Reference Network (ERN) for neurological diseases.

The ERN for neurological diseases would consider including ME/CFS, but the organization was informed that such an inclusion was only possible if the ERN(s), the Commission and the Member States agreed upon an official opening for expansion of the ERN disease coverage.

Since ME/CFS is seriously under-researched, patients would greatly benefit from a network that would allow the scarce physicians specialized in this disease to share knowledge and experiences. There are still no effective treatments, but some physicians prescribe medications that can offer symptomatic relief. Exchanging experiences could at least partially improve the quality of life of patients.

Furthermore, as it is known that ME/CFS can be triggered by a viral infection, scientists are convinced that the COVID-19 pandemic will boost the importance of knowledge exchange in this field, as mentioned earlier.

EMEC has contacted many people at DG SANTE, hoping they would assist, but Ms Evelien Van Den Brink and her organization never got an answer from your service.

Since we assume that your Directorate-General and the Commission's employees should take such a citizen's request seriously, and that the patients concerned have a right to information and clarification, we would like to ask you to give us an answer to these very relevant questions.

We look forward to your response and are also open for a personal exchange on that matter.

Yours sincerely,

Pascal ARIMONT, MEP

Radan KANEV, MEP

Ulrike MÜLLER, MEP

Alex AGIUS SALIBA, MEP

Jordi CAÑAS, MEP

Cindy FRANSEN, MEP

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