Response to the Commission's contribution

By the European ME Coalition (EMEC)

On 1 December 2021, during the meeting of the Committee on Petitions, representative of the Commission, Ms. Berens argued that the EU has supported ME/CFS research and referred to the following projects:

EUROMENE

EUROMENE was a COST Action that supported a network of ME/CFS researchers and clinicians. The project ended in 2020 and was useful in coordinating activities and signaling gaps in our knowledge about ME/CFS. The COST Action, however, did not provide funding for actual scientific research. Several leading members of EUROMENE have signed our open letter to Director General of Research and Innovation Jean-Eric Paquet to highlight the lack of funding opportunities for ME/CFS research. The letter noted: *"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."*

VirA twinning project

The VirA twinning project encourages collaboration between centers that are studying viral-induced autoimmunity research. The main aim of the project is "*to promote autoimmune disease research capacity and fill networking gaps in the institution (RSU) of the low-performing Member State – Latvia, by establishing a consortium with leading research institutions*." Like EUROMENE, this is not a grant for a specific research project, but a grant to improve networking and exchange expertise in a field that is only indirectly related to ME/CFS.

Help4ME

Help4ME focused on correcting gut microflora imbalances in ME/CFS patients using a commercially developed probiotic. The probiotic, GutMagnific™, was created by the Swedish company ImmuneBiotech for the treatment of irritable bowel syndrome, not ME/CFS. The study was completed in September 2019 and no results have been published. EU funding was not used for biomedical research, but to deliver a business plan for the clinical validation and launch of the supplement GutMagnific™. A randomized trial to test the supplement has meanwhile been started, but there was no EU funding reported for this study.

DISCOvERIE

Project DISCOvERIE is studying the causative mechanisms of irritable bowel syndrome (IBS). It is not a study on ME/CFS. IBS seems to be a common comorbidity in ME/CFS, but this is true in

many other conditions. The only publication resulting from the project so far does not relate to ME/CFS but studies IBS as comorbidity of depression.

Mastfast

Mastfast is a "proof of concept" grant on mast cell dysregulation that has already been completed in 2019. Its main objective is the rapid production of mast cells from stem cells. The only connection to ME/CFS is that “chronic fatigue syndrome” is mentioned in the project abstract as one of many conditions where mast cell activation has sometimes been observed. ME/CFS is so peripheral to this study that it is not even mentioned in the only publication that resulted from it.

Long COVID research

Ms. Berens also highlighted the research efforts taken to study COVID-19 and its long-term sequelae. In the studies mentioned such as Orchestra and CoVICIS long COVID is, however, only a small part of the research effort. And although there are similarities, definitions of long COVID are significantly different from the diagnostic criteria used for ME/CFS. The latter usually require multiple symptoms of a certain severity that persist for a period of (usually 6) months. Therefore, definitions of long COVID are less strict than those of ME/CFS, and only a subgroup of long COVID patients are expected to meet ME/CFS case definitions. Long COVID research will only be relevant to ME/CFS if patients are evaluated using the correct criteria.

Projects studying pain and fatigue

The Commission also referred to general projects dedicated to pain or fatigue and argued that these could also indirectly provide some insight into ME/CFS. Pain and fatigue, however, are ubiquitous symptoms that are common in many diseases. Again this is not research into ME/CFS and, as such, is not evidence that the Commission has funded research that is relevant to ME/CFS.

Summarizing, there is so far no EU-funded project that has ever led to even a single piece of published biomedical research on ME/CFS. While excellent ME/CFS research certainly exists in the EU, such as the examples listed below, it is hampered by a lack of funding, which often needs to rely on private sources.

The start of the scoping study that was announced by the Commission has unfortunately been delayed again. ME/CFS will likely be included in a range of under-researched illnesses. Nevertheless, we hope this study will be of help to get high-quality research specifically on ME/CFS funded and that patient organizations will be consulted to make sure that mistakes from the past will be avoided and progress will be made, leading to meaningful results for those affected and their families.

List of European research:

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van Campen CL, Verheugt FW, Rowe PC, Visser FC. Cerebral blood flow is reduced in ME/CFS during head-up tilt testing even in the absence of hypotension or tachycardia: a quantitative, controlled study using Doppler echography. Clinical neurophysiology practice. 2020 Jan 1;5:50-8.

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Polli A, Ghosh M, Bakusic J, Ickmans K, Monteyne D, Velkeniers B, Bekaert B, Godderis L, Nijs J. DNA Methylation and Brain-Derived Neurotrophic Factor Expression Account for Symptoms and Widespread Hyperalgesia in Patients With Chronic Fatigue Syndrome and Comorbid Fibromyalgia. Arthritis & Rheumatology. 2020 Nov;72(11):1936-44.

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https://www.sciencedirect.com/science/article/pii/S2666354620300727?via%3Dihub

Lutz L, Rohrhofer J, Zehetmayer S, Stingl M, Untersmayr E. Evaluation of Immune Dysregulation in an Austrian Patient Cohort Suffering from Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Biomolecules. 2021 Sep;11(9):1359.

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