



EMEC

EUROPEAN ME COALITION

22 November 2020

Hulst, The Netherlands

Dear Sir/Madam,

On behalf of the European ME Coalition (EMEC) I would like to ask your support for biomedical research on Myalgic Encephalomyelitis.

Myalgic Encephalomyelitis, sometimes called Chronic Fatigue Syndrome (ME/CFS), is a debilitating illness that has a profound impact on those suffering from it and their loved ones. Twenty-five percent of ME/CFS patients are home- or bed-bound at some point in their lives. Many are unemployed or have reduced productivity. [1]

ME/CFS has an estimated prevalence of 400 per 100.000 persons meaning that approximately 250.000 French citizens suffer from this illness. The European Network on ME/CFS, EUROMENE, estimated that the annual burden of ME/CFS in Europe could be in the region of 40 billion euros annually. [2]

The cause and pathology of ME/CFS are unknown. There is currently no diagnostic test, no FDA- or EMA-approved treatment, and no cure for ME/CFS.

On 18 June 2020, the European Parliament adopted a resolution on additional funding for biomedical research on Myalgic Encephalomyelitis (2020/2580(RSP)). The resolution calls on Member States to ensure due recognition of ME/CFS and organize targeted training to raise awareness among healthcare providers. It recommends to allocate funding and prioritize calls for projects specifically focused on biomedical research on ME/CFS.

In Germany, the Federal Ministry of Education and Research (BMBF) has responded to the resolution by a targeted call for research on poorly understood conditions with a large disease burden and insufficient treatment options. [3] In the Netherlands, the Organization for Health Research and Development (ZonMw) has outlined an ME/CFS research agenda for ten years with a budget of 20 to 29,5 million euros. [4] In Belgium, the Supreme Health Council recently published a new report highlighting an urgent need for more biomedical research on ME/CFS, given its high societal burden. [5]

These developments are a source of hope for ME/CFS patients, whose illness has been neglected for far too long. With prestigious biomedical research centers such as the Institut Pasteur and the Institut national de la santé et de la recherche médicale (Inserm), France could make a groundbreaking contribution to ME/CFS research.

We, therefore, support the requests sent to you by the French patient organizations Association française du Syndrome de Fatigue Chronique (ASFC) and Millions Missing France. It would be wonderful if France would join other countries in bringing about much-needed change.

Yours sincerely,

Evelien Van Den Brink on behalf the European ME Coalition

References

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- [5] Conseil Supérieur de la Santé. Avis 9508 - Syndrome de fatigue chronique. 28 October 2020. Available at: <https://www.health.belgium.be/fr/avis-9508-syndrome-de-fatigue-chronique>