



30.8.2019

NOTICE TO MEMBERS

Subject: Petition No 0204/2019 by Evelien Van Den Brink (Dutch) on a request for funding for biomedical research on Myalgic Encephalomyelitis

1. Summary of petition

The petitioner refers to her poor health conditions, as she suffers from Myalgic Encephalomyelitis (ME). Such disease, sometimes called Chronic Fatigue Syndrome, is a devastating chronic disease that causes dysfunction of the neurological, immune, endocrine and metabolism systems. The petitioner states that ME affects approximately two million EU citizens, with huge economic and societal costs, thus representing a hidden public health crisis. The petitioner calls on the European institutions to make sufficient funds available for biomedical research into ME, in order to deliver a diagnostic test, clinical trials and effective treatments for this disabling disease.

2. Admissibility

Declared admissible on 14 June 2019. Information requested from Commission under Rule 227(6).

3. Commission reply, received on 30 August 2019

Petition 0204/2019

The Commission recognises the importance of research on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) that is diagnosed for around 24 million people worldwide, which is considered to be only 10% of the whole ME/CFS population. Although frequently triggered by infection, the cause of CFS is not yet known. Researchers look for its source in the guts, which are inhabited by billions of microorganisms and form a complex ecosystem with profound impact on the whole body. Imbalance of gut microflora, damaged gut barrier functions and dysfunctional immune responses are known in CFS and shared with another

disease - Irritable Bowel Syndrome (IBS), which frequently accompanies ME/CFS. Horizon 2020, the EU Framework Programme for Research and Innovation (2014-2020)¹, supports research on neurological disorders of different etiology, as well as research on pain. Recently, a project Help4Me (evidence-based probiotic for Chronic Fatigue Syndrome)² has been funded under the SME³ Instrument funding mechanism. Funding has been provided to develop a product GutMagnific™, an evidence-based probiotic scientifically designed and shown to be effective in correcting the gut microflora disbalance – a source of CFS and Irritable Bowel Syndrome (IBS) symptoms. The novelty of the product lies in the unique combination of five lactobacilli strains with evidence-based efficacy and shows a life-changing promise to a severely underserved population of CFS patients.

Moreover, Horizon 2020 funds the GLORIA project⁴ which is investigating the pathophysiology of chronic pain conditions including fibromyalgia, while the project RTCure⁵ aims to improve diagnostics and treatment of the rheumatic and other autoimmune diseases largely associated with fatigue and pain. The current EU Framework Programme for Research and Innovation continues to provide opportunities for research funding on ME/CFS, fibromyalgia, as well as other neuro-immunological disorders, including better diagnostics and care. One of the key elements of Horizon 2020 was the development/promotion/advancement of scientific excellence using a variety of funding schemes, including bottom-up approaches. This flexibility gives excellent science the opportunity to select the most appropriate funding mechanism. Horizon Europe⁶, building upon Horizon 2020, will continue to support research in a similarly flexible manner to improve the health of European citizens.

Conclusion

Research on ME/CFS and the related diseases has received support through the EU Framework Programme for Research and Innovation and future calls will provide further opportunities to fund such research.

¹ <https://ec.europa.eu/programmes/horizon2020/>

² <https://cordis.europa.eu/project/rcn/223054/factsheet/en>

³ Small and medium-sized enterprise.

⁴ Understanding chronic pain and new druggable targets: Focus on glial-opioid receptor interface
<https://cordis.europa.eu/project/rcn/110940/factsheet/en>

⁵ Rheuma Tolerance for Cure <https://cordis.europa.eu/project/rcn/211964/factsheet/en>

⁶ https://ec.europa.eu/info/designing-next-research-and-innovation-framework-programme/what-shapes-next-framework-programme_en