Resolution on additional funding for biomedical research on Myalgic Encephalomyelitis

2020/2580(RSP) - 17/06/2020 - Text adopted by Parliament, single reading

The European Parliament adopted a resolution on additional funding for biomedical research on Myalgic Encephalomyelitis.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a debilitating chronic multisystem disease of unknown origin, whose symptoms, severity and progression are extremely variable. Around 17 to 24 million people worldwide suffer from ME/CFS, with approximately two million people in the EU, with women being the most affected. Quality of life may be severely affected and patients may end up being bedbound or housebound with severe suffering, negative impacts on social and family relationships and significant costs to society in terms of lost working capacity.

To date, research efforts on ME/CFS remain rather fragmented and coordination of research at EU level is missing.

Increased funding and awareness raising

Parliament welcomed the Commission’s support for the organisation European Cooperation in Science and Technology (COST), which recently created an integrated network of researchers working on ME /CFS (Euromene). It also welcomed the work currently being carried out by the Euromene network aiming at establishing a common Europe-wide approach to address the serious gaps in knowledge of this complex disease and to deliver information on the disease burden in Europe and on clinical diagnosis and potential treatments to care providers, patients and other stakeholders.

While welcoming the Commission’s commitment to provide further opportunities for research into ME /CFS through the forthcoming research and innovation framework programme which will succeed Horizon 2020, namely Horizon Europe, Members regret that the funding initiatives adopted so far by the Commission are not sufficient.

They underlined the increasingly urgent need to address the human and socio-economic consequences of the growing number of individuals living and working with these long-term disabling and chronic conditions that affect the sustainability and continuity of their work and employment. All possible measures should be taken to adjust the working conditions and environment of employed people suffering from ME/CFS and they should also be entitled to the adaptation of the workplace and working time.

In this regard, Members called for greater awareness and additional funding to support progress in research in this area. In order to stop the stigma related to this disease, they stressed that there is a need for better recognition of this type of disease at Member State level.

More specifically, Parliament called on the Commission to:

- allocate additional funding and prioritise calls for projects specifically focused on biomedical research into ME/CFS, with a view to the development and validation of a biomedical diagnostic test and of effective biomedical treatments that can cure the disease or alleviate its effects;

- promote cooperation and the exchange of best practices among Member States as regards screening methods, diagnosis and treatment, and to create a European prevalence register of patients affected by ME /CFS;

- provide funding to ensure appropriate and improved medical education and training for health and social care professionals working with ME/CFS patients;

- study the feasibility of an EU fund for the prevention and treatment of ME/CFS;

- launch information and awareness raising campaigns among health professionals and the public in order to alert the population to the existence and symptoms of ME/CFS.

Lastly, the Council is called on, in the context of the ongoing negotiations on the next EU multiannual financial framework, to accept Parliament’s request for an increased budget for Horizon Europe and the swift adoption of that budget so that work can start on time to ensure research into ME/CFS.