



2020/2580(RSP)

17.3.2020

DRAFT MOTION FOR A RESOLUTION

pursuant to Rule 227(2) of the Rules of Procedure

on additional funding for biomedical research on Myalgic Encephalomyelitis
(2020/2580(RSP))

Dolors Montserrat
on behalf of the Committee on Petitions

B9-0000/2020

European Parliament resolution on additional funding for biomedical research on Myalgic Encephalomyelitis (2020/2580(RSP))

The European Parliament,

- having regard to Articles 168 and 179 to 181 of the Treaty on the Functioning of the European Union,
 - having regard to Article 35 of the Charter of Fundamental Rights of the European Union,
 - having regard to the question for written answer to the Commission of 2 September 2019 (E-002599-19) on ‘Research into myalgic encephalomyelitis (ME)’ and the Commission’s answer of 28 October 2019,
 - having regard to the question for written answer to the Commission of 4 December 2018 (E-006124-18) on ‘Chronic fatigue syndrome’ and the Commission’s answer of 30 January 2019,
 - having regard to the question for written answer to the Commission of 28 August 2018 (E-004360-18) on ‘Myalgic encephalomyelitis: recognition by the World Health Organisation and Commission support for research and training’ and the Commission’s answer of 1 November 2018,
 - having regard to the question for written answer to the Commission of 9 November 2017 (E-006901-17) on ‘Funding of research on ME/CFS’ and the Commission’s answer of 18 December 2017,
 - having regard to Rule 227(2) of its Rules of Procedure,
- A. whereas the Committee on Petitions has received several petitions raising concerns over the absence of treatments and the current underfunding of biomedical research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) within the EU;
- B. whereas under Article 35 of the Charter of Fundamental Rights of the European Union everyone has ‘the right to benefit from medical treatment under the conditions established by national laws and practices’, while other international human rights instruments, including the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities, recognise or refer to the right to health or elements of it, such as the right to medical care;
- C. whereas the actions of Member States and the Union must be directed towards improving public health; whereas this objective should be achieved through the Union’s support to Member States, by fostering cooperation and by promoting research into the causes, transmission and prevention of illnesses;

- D. whereas ME/CFS is a debilitating chronic multisystem disease of unknown aetiology, whose symptoms, severity and progression are extremely variable;
- E. whereas ME/CFS is classified as a disorder of the nervous system by the World Health Organisation under the International Classification of Diseases (ICD-11) under code 8E49 (Postviral fatigue syndrome);
- F. whereas ME/CFS is a complex, highly disabling disease, as extreme tiredness and other physical symptoms can make it impossible to carry out everyday activities; whereas quality of life may be severely affected and patients with ME/CFS 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;
- G. whereas special attention needs to be paid to the high risk of social exclusion of persons affected with ME/CFS; whereas in this sense, for employed persons suffering from the disease it is crucial to be able to keep their jobs in order not to find themselves isolated;
- H. whereas all possible measures should be taken to adjust the working conditions and environment of employed people suffering from ME/CFS; whereas they should also be entitled to the adaptation of the workplace and working time;
- I. whereas there are still no established biomedical diagnostic tests for ME/CFS, nor are there any EU/EMA-approved treatments;
- J. whereas the incidence and prevalence of ME/CFS in the EU are unknown, as is equally the overall social and economic burden arising from it, owing to the lack of coordinated and comprehensive data collection at EU level;
- K. whereas according to the Commission's answer of 30 August 2019 to Petition No 0204/2019, ME/CFS is diagnosed for around 24 million people worldwide but this is considered to be only 10 % of the total ME/CFS population;
- L. whereas the American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society estimates that around 17 to 24 million people worldwide suffer from ME/CFS;
- M. whereas approximately two million people in the EU, of whatever ethnicity, age or gender, are believed to be afflicted with ME/CFS; whereas among adults, women are the most affected;
- N. whereas to date ME/CFS is poorly understood and, consequently, underdiagnosed, owing to insufficient knowledge about this disease among healthcare providers, or else because of the difficulties encountered in the detection of symptoms and the absence of appropriate diagnostic tests; whereas the lack of understanding of ME/CFS can considerably hamper the recognition of occupational disability of patients;
- O. whereas the patients' community feels deprived and ignored by public authorities and society as a whole, and legitimately asks for greater awareness and additional funding to support progress in research; whereas patients denounce being victims of stigmatisation as a result of poor knowledge of this disease; whereas the stigma surrounding the rights of persons with ME/CFS and the psychological distress associated thereto, which has a

dramatic impact on individuals, families and society and on every aspect of citizens' lives, is too often poorly recognised;

- P. whereas children and young people afflicted with ME/CFS could potentially see their access to education hampered;
- Q. whereas the need for better recognition of this type of diseases at Member State level is evident; whereas specifically targeted training should be provided to raise awareness among public authorities, healthcare providers and officials in general;
- R. whereas Petition No 0204/2019 received and continues to receive a significant number of signatures of support, from patients and their families and also from the scientific community, calling for more resources to be invested in biomedical research into ME/CFS and patient support;
- S. whereas over the years several Members of the European Parliament have tabled questions to the Commission regarding the availability of EU funding for research on ME/CFS;
- T. whereas research efforts on ME/CFS remain rather fragmented and coordination of research at EU level is missing; whereas, despite support granted by Horizon 2020, the EU Framework Programme for Research and Innovation (2014-2020), to a number of research projects on neurological disorders of different aetiologies as well as research on pain (such as Help4Me, GLORIA and the RTCure), the Commission admitted in its answer of 30 January 2019 to question for written answer E-006124-18 that 'to date no specific projects on diagnosis/treatment of ME/CFS have been supported by the EU Framework Programmes for Research and Innovation';
1. Expresses its concern at the high incidence of ME/CFS within the EU, with an estimated 2 million citizens affected by the disease;
 2. Welcomes 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); believes that Euromene can 'add value' to activities that would not be so effective if carried out at national level alone;
 3. Welcomes 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;
 4. Welcomes the Commission's commitment made in its answer of 28 October 2019 to question E-002599/2019 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;
 5. Regrets, however, that the funding initiatives adopted so far by the Commission are not sufficient; is worried about the current underfunding of research into ME/CFS, which may be considered as a hidden public health problem in the EU; underlines 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;

6. Calls 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;
7. Believes that the current underfunding of biomedical research into ME/CFS is unjustified considering the estimated large number of patients and the consequent economic and social impact of this disease;
8. Stresses the need to implement innovative projects that can ensure coordinated and comprehensive data gathering on this disease within the Member States, and calls for mandatory reporting in all Member States affected by ME/CFS;
9. Calls on all Member States to take with determination the necessary steps to ensure the due recognition of ME/CFS;
10. Calls on the Commission to 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;
11. Requests that the Commission provide funding to ensure appropriate and improved medical education and training for health and social care professionals working with ME/CFS patients; calls, therefore, on the Commission to study the feasibility of a EU fund for the prevention and treatment of ME/CFS;
12. Calls on the Commission to ensure the funding of the necessary logistic support for researchers with a view to promoting the coordination of research activities in this field within the EU, in terms of identifying the complexity of the ME/CFS diagnostics and patients' care challenges and unlocking the full potential of access to innovation and health data collected through experts' input and all stakeholders' engagement, in order to prioritise the right policy;
13. Calls for increased international cooperation on research into ME/CFS, with a view to accelerating the development of objective diagnostic standards and effective forms of treatment;
14. Calls on the Commission to commission a study assessing the overall social and economic costs attributable to ME/CFS within the EU;
15. Invites the Commission and the Member States to launch information and awareness campaigns among health professionals and the public in order to alert the population to the existence and symptoms of ME/CFS;
16. Calls on the Council, 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;

17. Calls on the Commission to recognise the special challenges faced by researchers working on diseases of unknown cause, such as ME/CFS, and to ensure that despite these difficulties biomedical research on such diseases is given fair access to the funding provided by Horizon Europe;
18. Stresses the importance of raising awareness on the matter by further promoting activities at Union and Member State level around the ‘Rare Disease Day’ commemorated on the last day of February each year;
19. Instructs its President to forward this resolution to the Council, the Commission and to the governments and the parliaments of the Member States.