

**Follow up to the European Parliament non-legislative resolution on additional funding for biomedical research on Myalgic Encephalomyelitis**

- 1. Resolution tabled pursuant to Rule 227(2) of the European Parliament's Rules of procedure**
- 2. Reference numbers:** 2020/2580 (RSP) / B9-0186/2020 / P9\_TA-PROV(2020)0140
- 3. Date of adoption of the resolution:** 18 June 2020
- 4. Competent Parliamentary Committee:** Committee on Petitions (PETI)
- 5. Brief analysis/assessment of the resolution and requests made in it:**

The resolution inter alia:

- underlines that there are an estimated two million people in the EU believed to be afflicted with myalgic encephalomyelitis and Chronic fatigue syndrome (ME/CFS), and expresses concern on widespread underdiagnoses due to poor understanding of the disease and lack of specific diagnostic tools and treatments;
  - stresses that ME/CFS may be considered as a hidden public health problem in the EU and underlines the 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;
  - welcomes 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;
  - welcomes the Commission support for Euromene, a European Cooperation in Science and Technology (COST) Action, which recently created an integrated network of researchers working on ME/CFS, aiming at establishing a common Europe-wide approach to address the serious gaps in knowledge of this complex disease;
  - expresses concerns on the lack of larger funding initiatives from the Commission dedicated to research on ME/CFS and stresses the need to implement innovative projects that can ensure coordinated and comprehensive data gathering on this disease within all Member States;
  - calls on the Commission and the Member States to promote cooperation on improving clinical management and therapy development for ME/CFS;
  - invites the Commission and the Member States to support awareness campaigns and recognition on the disease.
- 6. Response to the requests and overview of the action taken, or intended to be taken, by the Commission:**

The Commission acknowledges that ME/CFS poses a heavy burden on patients and their families, and recognises that the lack of specific diagnostics tools and treatments to tackle this serious condition is a matter of concern.

Research into new treatments and diagnostics is clearly important. The Commission has proposed an ambitious EUR 100 billion Horizon Europe research and innovation programme, succeeding Horizon 2020, with a substantial health component; Following the Coronavirus outbreak, the Commission has also proposed a EUR 9.4 billion health programme, EU4Health. Therefore, scientists and other actors with a specific interest in ME/CFS should have more possibilities to support their research and their goals in improving the condition of patients, using these financial instruments as appropriate.

Research on ME/CFS and the related diseases has received support throughout the current Horizon 2020 research programme, of which the Euromene COST Action is a good example. Horizon Europe will continue to provide opportunities to support research in ME/CFS. Indeed, a better understanding of diseases and their drivers, including pain and the causative links between health determinants and diseases, has been identified as one of its priorities.

### **Responses to specific points of the resolution:**

In response to:

#### Paragraph 6 and 17

The Commission would like to recall that the topics to be addressed for funding under its Research and Innovation programmes are generally broadly conceived without focussing on any specific disease or condition. With this approach, researchers dispose of wider opportunities within the area of their specific professional interest. This approach also assures that excellence, the major criterion for the evaluation and selection for funding, is met by the submitted proposals. The evaluation of the submitted proposals is done by the independent evaluators, and applications are never selected based on the incidence or significance of a particular disease.

#### Paragraph 8, 9, 10

The Commission would like to recall that any EU action in the field of public health must fully respect the responsibilities of the Member States for the organisation and delivery of health services and medical care. This includes screening methods, diagnosis and treatment.

The Commission strongly supports best practice exchange among Member States, notably through scaling up of best-in-class approaches. The Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases is the key mechanism for this, setting priorities for such learning to help advance of national health ministries' policy priorities. The Steering Group does not address clinical guidelines or management of specific diseases, but does include implementable research results in their prioritisation process. Should the Steering Group decide to consider ME/CFS as a priority issue (which it has not done until now) the outcomes of the Euromene COST Action could thus inform this process.

Supporting the provision of providing high-quality, comparable and reliable data is one of the specific objectives of the proposed EU4Health programme, as is support action on surveillance, prevention, diagnosis and treatment and care of non-communicable diseases, and sustained implementation of best practice.

#### Paragraph 12

The Commission supports the European Research Area (ERA) that is open to the world and based on the internal market. The ERA enables free circulation of researchers, scientific knowledge and technology. ERA aims to support more effective national research systems, optimal transnational cooperation and competition, including optimal transnational

cooperation and competition and research infrastructures, optimal circulation, access to and transfer of scientific knowledge including knowledge circulation, and open access International cooperation.

#### Paragraph 13

The Commission is well aware that health-related issues have a global nature and require a global solution. Therefore, the Commission is committed in attracting international stakeholders and their resources into EU-led collaborations that will help the EU to combine best skills and outcomes, and deliver tangible results to patients. International cooperation is therefore not an option but a fundamental and inherent component of health research and innovation.

#### Paragraph 11, 15, 18

One of the three general objectives of the proposed EU4Health programme centres on strengthening health systems and the healthcare workforce. As listed in the proposed Programme Annex on possible eligible actions, this can also be pursued via specific training programmes for health professionals, as well as communication and outreach to stakeholders and citizens. Meanwhile the Commission would like to recall that, based on an estimated prevalence between 0.11% and 0.56 %, ME/CFS cannot be classified as a rare disease.