

Contribution of Evelien Van Den Brink to the meeting of the Committee on Petitions on 1 December 2021

President Montserrat, Members of the Committee on Petitions,

First of all, I would like to express my gratitude for your follow-up of the petition and the adoption of the first resolution on ME by the European Parliament. This was a historic moment for the ME community.

After the PETI meeting in 2019, I founded a small advocacy organization “the European ME Coalition”. We are all ME patients or caregivers.

The Commission shared its plans with us and we were hopeful to see their words turned into deeds. But to be honest, the results so far have been rather bleak. Things are moving very slowly and, frankly, it is not clear in which direction.

The Commission told us there could be no calls specifically for ME, because calls in Horizon Europe do not focus on individual diseases. So, a broader category of “poorly understood illnesses” had to be created. A scoping study would be needed to provide the justification to include this new category in future working programs of Horizon Europe. Representatives of the Commission said this would be the right way to ensure a more permanent solution, similar to what was previously created for rare diseases.

However, the Director General of Research and Innovation wrote in his letter of October this year, that “no topic will be “structurally included” in future work programmes”. This puts the purpose of the scoping study into question.

Nevertheless, we believe the scoping study can be helpful, if done the right way. The importance of inclusion of the patient voice in this process cannot be overemphasized. We have, unfortunately, seen endless delays and the starting date of the study is still unknown. If the Commission is not really driven to turn this into a success, it likely won't be one.

We also tried, as recommended by the Director General, to see if ME could be included in one of the European Research Networks, since the budget for these ERNs had increased considerably. ME patients would greatly benefit from a network, allowing the scarce physicians specialized in this disease to share knowledge and experiences. We face great difficulty to get diagnosed and it is nearly impossible to find a specialist who can help.

We have contacted many people and services, hoping they could assist. But to our disappointment this led to nothing. We didn't even get a reply from SANTE, the responsible service.

The ERN for neurological diseases would consider including ME, but this requires an official opening to expand the disease coverage, with approval from the Commission, Member States and other ERNs.

Exchanging clinical experiences could improve the quality of life of patients. There may be no cure yet, but that doesn't mean nothing can be done.

Actively taking away the stigma by education, and stopping harmful treatments, would undo some of the damage we've had to endure for decades on top of the devastation of the disease.

Countries like the United States, Australia and Canada have reserved substantial funding specifically for ME research and created specialized centers. To me, this means that more can be done. It would be a shame if there was nothing moving at the EU level.

ME has been ignored for decades and the size of the problem will only increase if we keep ignoring it. ME is often triggered by an infection, and scientists believe that many patients who currently suffer from Long Covid will go on to develop ME. The neglect of ME and related post-viral fatigue syndromes has left us unprepared for the long-term consequences of the COVID-19 pandemic.

We are not asking for much. Just a fair amount of funding proportionate to the disease burden. ME has an economic impact of approximately 40 billion euros a year. Taking action is the sensible thing to do. But most of all, it is the human thing to do.

Patients have already waited for decades. And we can't afford to lose more years waiting. Right now, ME is a life verdict. For us, it continues to be a tough battle and we cannot do this alone. Please, do not let the hope that you gave us perish.

Thank you.