

The meeting of the Committee on Petitions on 3rd October 2019 in which petition no 0204/2019 was discussed has made a significant impact. The decision of the Committee to keep the petition open and monitor the needed progress, was very well received by the patient community and seen as a valuable start to bring about real change for people with ME. There is so much enthusiasm and support for the goals that were mentioned that will help to achieve the scientific progress that is so desperately needed. You have given patients, not just in Europe, but worldwide, hope.

As I said during the meeting it is vital that we make sure this hope is translated into results. Therefore I would like to outline some important requirements to ensure the success of our efforts and will hopefully help to shape the policy that needs to be developed.

- The most important key to success will be the criteria that are used to select the patients for scientific research. I would like to request that the use of the Canadian Consensus Criteria (CCC 2003) (1) and/or the International Consensus Criteria (ICC 2011) (2) will be included as a fixed condition for studies to receive funding. The CCC and/or ICC should be adopted until better criteria and/or preferably a biomedical test exist that will ensure reliable patient selection. This would guarantee the reliability, homogeneity and quality of the scientific biomedical studies and make sure they are mutually comparable. I cannot emphasize enough how important the selection of the right set of patients included in scientific studies on ME will be.

(1) <http://www.mereseearch.org.uk/wp-content/uploads/2012/11/2003-Carruthers-Canadian-Definition-JCFS.pdf>

(2) <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2796.2011.02428.x>

- It is of major importance to include activity-matched controls in ME studies. This should ideally be determined by using actimeters for a two-week period on the ME patients and on the age and gender matched healthy controls. The included controls need to have the same activity level as the patients to get meaningful and reliable results. For the severely affected this means they will have to be compared to activity-matched controls diagnosed with other disabling diseases.
- I have mentioned the importance of calls, specifically focused on ME, in my response to the Commission's reply of 30 August 2019. This would ensure that ME researchers do not have to compete with researchers who focus on other well-established diseases. ME scientists have clearly stated that ME loses out in competition with these diseases.
- I also wrote about the importance of a review panel that consists of informed scientists with knowledge of the biological basis of ME. This will be a vital part of the success of the grant allocation for biomedical research. The development of a biomedical diagnostic test and biomedical treatments should get priority, in order to accomplish our goals of helping patients within an acceptable, short timeframe.
- The development of Centers of Excellence is a useful way to streamline the work that needs to be done and will help researchers to improve their efficiency by providing them with the needed infrastructure. These Centers should collaborate as closely as possible with those in the United States to amplify the success of scientist on both sides of the Atlantic.
- Funding will have to become commensurate with the number of patients and disease burden. Given the decades of underfunding a, compared to the investments in other diseases, relatively small investment, can lead to meaningful results that will substantially improve the quality of life of ME patients.
- I kindly request that the patient community will be closely involved and informed of the progress. The support and feedback of the ME community, which is very knowledgeable about the science of ME, can be a helpful and positive addition that we can use to our advantage.

I believe these main points will ensure that the available funding will lead to high quality science that will help to unravel the biological cause(s) of ME in the shortest timeframe possible.

Thank you very much for your continued support. This is a beacon of hope for many.