

Petition 0204/2019 by Evelien van den Brink

On 2 September 2019 MEP Pascal Arimont asked a parliamentary question about ME research [1]. The Commission answered on 28 October 2019 [2].

In response to the Commission's answer I would like to point out that, despite the fact that I'm happy that the Commission has made a start to funding research on ME, the mentioned projects seem very meager.

The GutMagnific project that was mentioned involves a probiotic. Probiotics do appear to help some people with ME, if they have severe enough gut problems. However, I'm not confident that the claim, that this probiotic will be "lifechanging" is correct. Most patients with digestive issues and the financial means to do so have likely already given similar probiotics a try and there seems to be no scientific evidence that this product will work or will be any better for people with ME than the probiotics that are already commercially available. The cause(es) of ME have not yet been identified and assuming that the solution lies here is a bit premature. There are many more interesting scientific avenues that deserve attention.

The mentioned GLORIA project aimed at unraveling chronic pain pathophysiology may be of relevance, but is of course very broad. This may help many diseases, but cannot be seen as specific ME research.

There are estimated to be 2 million people in the EU with ME (500 million population prevalence approx 0.42%). Many people are house bound or bed bound (approx 25%). Considering these numbers, research specifically aimed at ME is justified. Broad research like GLORIA may yield (partial) answers some day, but will be far less effective and take far more time than needed.

A small study, published in 2011, on a drug (Rituximab) used to treat B-cell auto-immune disorders such as rheumatoid arthritis, indicated that ME may be a B-cell auto-immune disease i.e. similar to rheumatoid arthritis [3]. However, a subsequent larger randomized, double-Blind, placebo-controlled trial demonstrated that ME is not similar to rheumatoid arthritis [4]. Therefore, the RTCure (Rheuma Tolerance for Cure) research the Commission refers to does not appear to be particularly relevant to ME.

If ME is an autoimmune disease or not remains to be determined. At this point in time there is no clear scientific evidence that ME is caused by autoimmunity. There may also be subgroups within the disease. Keeping an open mind is crucial in this phase.

All in all, I believe this is unfortunately an inadequate response from the Commission and this doesn't solve the issue of underfunding. The proposed projects are not specific nor particularly relevant to ME. It is not what will allow to make progress on ME.

To end on a high note, I think there is a major opportunity for the Commission to fund more ambitious research projects specifically aimed at ME that will make a positive impact. As the new financial framework is being discussed, the Horizon Europe programme offers a great chance for the EU to help scientific research into ME move forward. There is a document

available with requirements [5] that can help us to ensure that future research will be of high quality and produce meaningful results.

I hope ME patients can count on your continued efforts to help us to create the desperately needed change.

[1] http://www.europarl.europa.eu/doceo/document/E-9-2019-002599_EN.pdf

[2] http://www.europarl.europa.eu/doceo/document/E-9-2019-002599-ASW_EN.pdf

[3] reference <https://me-pedia.org/wiki/Rituximab>

[4] reference <https://me-pedia.org/wiki/Rituximab>

[5] <https://docs.google.com/document/d/1AJPs4GJztlyx5tE2zKxzc9tjZtTljCpw0FijzBHXNao>