

Email from Clare Ogden, head of Communications and Engagement , Action for M.E.

7th November 2019

Dear Colleagues

As Sonya explained in her email, I am getting in touch to let you know that a short statement has been issued today by the MRC regarding a workshop they are hosting to help inform an application that has been invited jointly by the MRC and NIHR from a new research collaboration, the ME/CFS Biomedical Partnership. Please find below two statements from the UK CFS/ME Research Collaborative (CMRC) and CureME Biobank alongside an FAQ document, attached. Please do share this amongst your networks. Do also note that the Partnership is still setting itself up and while we recognise there will be lots of questions, please bear with us while we establish communication channels with the wider community. More information will follow shortly.

For your reference, I've attached a news story that we'll be posting imminently. In response to further questions, we will use the following statement:

"The ME/CFS Biomedical Partnership has asked us to thank everyone for their interest in this exciting project, and your questions. Its immediate priority is to focus on the upcoming MRC workshop, and on drafting the grant application. The Partnership will aim to address further questions in due course by updating its existing Q&A, which we will share on the Action for M.E. website and our social media, as soon as it becomes available."

Statement from Stephen Holgate on behalf of the CMRC

The UK CFS/ME Research Collaborative (CMRC) was set up to trigger new scientific directions and build research capacity. Over the last seven years, we have run five successful conferences, with a sixth planned for March 2020, fostered new collaborations and have established a series of working groups to drive forward specific areas such as medical education. We have worked in collaboration with researchers, the patient advisory group, charities and mainstream funders throughout this time and are delighted to see that our collective effort has led to the ME/CFS Biomedical Partnership being established. This new team will now work together to submit an application for funding to drive forward this ambitious project.

Statement from CureME Biobank Team

The CureME team at the London School of Hygiene & Tropical Medicine is excited to announce that it is collaborating with the UK CFS/ME Research Collaborative (CMRC), to submit a research proposal on ME/CFS to the Medical Research Council (MRC) and the National Institute for Health Research (NIHR). The CureME team is a critical partner in this informed and competitive submission, and is focusing at this early stage on developing the research proposal and ensuring the accurate categorisation of people with ME/CFS, using diagnostic criteria harmonised with our own protocols and with the US Centers of Excellence for ME/CFS (NIH funded). We will also continue our own research within the London School of Hygiene & Tropical Medicine, supporting transparent, multidisciplinary research informed by and for the benefit of people with ME/CFS. We are confident that this collaboration will help to accelerate much-needed research in this field, enabling further biomedical studies into well-defined ME/CFS.

Many thanks and best wishes

Clare