

From: [REDACTED]
To: [REDACTED]
Sent: Wed Oct 16 2024 15:57:22 BST
Subject: RE: Death of Maeve Bernadette Boothby O'Neill (ref: 8057264)

(Attachments:) Maeve Boothby reg 28 report amended .docx

Ref: [REDACTED]

Dear [REDACTED]

Thank you for your request of 7th October.

We are specifically responding to section 5 (2) 'During the course of the inquest it became clear that there was no current available funding for the research and development of treatment and further learning for understanding the causes of ME/Chronic Fatigue Syndrome (CFS).'

UK Research and Innovation (UKRI) recognises the unmet clinical need for better diagnosis and treatments for people living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and has prioritised research into ME/CFS for a number of years. Since 2019, the Medical Research Council (MRC), part of UKRI, has invested £3.6m in research in partnership with the National Institute for Health Research (NIHR) addressing ME/CFS and maintains an [open highlight notice](#) to encourage ME/CFS research. MRC continues to engage with researchers, patient representatives and charity funders to identify routes to catalyse biomedical research in this area.

The [DecodeME](#) study, a major investment co-funded with the NIHR, is a £3.2m programme investigating the genetic underpinning of ME/CFS. The study will analyse samples from 25,000 people with ME/CFS to search for genetic differences that may indicate underlying causes or an increased risk of developing the condition. This study aims to increase our understanding of the disease and therefore contribute to the research base on diagnostic tests and targeted treatments for ME/CFS. In 2020, the NIHR, the Chief Scientist Office (CSO) in Scotland, and the MRC also funded the [James Lind Alliance Priority Setting Partnership for ME/CFS](#), facilitated by the charity Action for ME, seeking to identify and publicise research priorities in this area

More broadly, the MRC funds research across the research and development pathway to improve human health, including fundamental and mechanistic biology, and translational research through to early phase clinical trials. Applications are judged in open competition and the primary considerations in funding decisions are scientific quality and importance to human health.

Kind regards,

[REDACTED]

Medical Research Council

www.mrc.ukri.org

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