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Date: December 5, 2023

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<https://questions-statements.parliament.uk/written-questions/detail/2023-11-27/3686>

<https://questions-statements.parliament.uk/written-questions/detail/2023-11-27/3687>

Ref: <http://www.me-net.combidom.com/meweb/web1.4.htm#westminster>

[Written Answers]

Chronic Fatigue Syndrome: Research

John McDonnell

To ask the Secretary of State for Science, Innovation and Technology, what assessment she has made of the potential merits of increasing public funding for research into Myalgic Encephalomyelitis.

To ask the Secretary of State for Science, Innovation and Technology, what steps her Department is taking to help facilitate research into the (a) causes and (b) treatment of Myalgic Encephalomyelitis.

Andrew Griffith

Since 2012, UK Research and Innovation (UKRI)'s Medical Research Council (MRC) has awarded 6.2 million pounds for research on myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). This includes DecodeME,

<https://www.decodeme.org.uk>

a significant strategic initiative co-funded by the National Institute of Health and Care Research in 2020, which aims to find genetic causes of ME/CFS in order to better understand the disease and ultimately to find treatments.

The Government works with the ME/CFS Priority Setting Partnership to identify research priorities in this area and MRC has an open highlight notice(opens in a new tab) to encourage ME/CFS research.

<https://www.ukri.org/opportunity/researching-me-cfs-highlight-notice/>

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Date: December 15, 2023

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<https://questions-statements.parliament.uk/written-questions/detail/2023-11-29/4324>

<https://questions-statements.parliament.uk/written-questions/detail/2023-11-29/4325>

Ref: <http://www.me-net.combidom.com/meweb/web1.4.htm#westminster>

[Written Answers]

Chronic Fatigue Syndrome: Diagnosis

John McDonnell

To ask the Secretary of State for Health and Social Care, what assessment she has made of the potential merits of (a) improving and (b) adapting the SNOMED CT classification system in primary care when diagnosing suspected myalgic encephalomyelitis.

To ask the Secretary of State for Health and Social Care, if she will make an estimate of the number of patients with suspected myalgic encephalomyelitis that have been (a) misdiagnosed and (b) missed due to the SNOMED CT classification system in primary care.

Andrew Stephenson

NHS England has not undertaken an assessment of the coding for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Whilst we are unable to estimate the numbers of patients misdiagnosed or missed, the National Institute for Health and Care Excellence guideline NG206 estimates that there are over 250,000 people in England and Wales with ME/CFS. The guideline is available at the following link:

<https://www.nice.org.uk/guidance/ng206>

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