ME in Westminster: APPG Inaugural Meeting.

Go to,
https://appgme.co.uk/meetings/appg-inaugural-meeting-17-december-2024/

Source: UK House of Commons
Date: December 9, 2024
URL:
https://questions-statements.parliament.uk/written-questions/detail/2024-12-04/17890
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Health Services

Munira Wilson

To ask the Secretary of State for Health and Social Care, when he plans to publish his Department's final delivery plan on myalgic encephalomyelitis (ME).

Andrew Gwynne

The final myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS), delivery plan is a priority for the Department, and we aim to publish it in March 2025. We cannot comment on the exact content of the final delivery plan at this time, but it will be shaped by the consultation responses, along with continued close engagement with ME/CFS stakeholders, with three broad themes of attitudes and education, research, and living with ME/CFS.

Source: UK House of Commons
Date: December 12, 2024
URL:
https://questions-statements.parliament.uk/written-questions/detail/2024-12-06/18389

https://questions-statements.parliament.uk/written-questions/detail/2024-12-06/18390
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Health Services

Jo Platt

To ask the Secretary of State for Health and Social Care, what assessment his Department has made of the adequacy of implementation of NICE guideline NG206 on myalgic encephalomyelitis.

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to improve the provision of care for people with ME.

Andrew Gwynne

No assessment has been made on the adequacy of the implementation of National Institute for Health and Care Excellence (NICE) guidance NG206 on myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS). NICE guidelines are not mandatory, but the Government does expect healthcare commissioners to take the guidelines fully into account in designing services to meet the needs of their local population, and to work towards their implementation over time.

There are steps that the Government is taking to improve care for patients with ME/CFS. It is a priority for the Department to publish the final ME/CFS delivery plan. We cannot comment on the exact content of the final delivery plan at this time, but it will be shaped by the consultation responses, along with continued close engagement with stakeholders, with three broad themes of attitudes and education, research, and living with ME/CFS. We aim to publish it at the end of March 2025.

The Department is also currently working with NHS England to develop an e-learning course on ME/CFS for healthcare professionals, with the aim of supporting staff to be able to provide better care and improve patient outcomes.

Additionally, the Government funds research into ME/CFS through the

National Institute for Health and Care Research (NIHR) and the Medical Research Council (MRC), through UK Research and Innovation. In 2020, the NIHR and the MRC came together to fund the world's largest genome-wide association study of ME/CFS. This 3.2 million pounds study, termed DecodeME, 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. Further details of the study are available at the following link:
http://www.decodeme.org.uk

Source: UK House of Commons
Date: December 17, 2024
URL:
https://questions-statements.parliament.uk/written-questions/detail/2024-12-09/18782

[Written Answers]

Fibromyalgia: Research

Peter Fortune

To ask the Secretary of State for Science, Innovation and Technology, how much Government funding there was into fibromyalgia research in 2023-24; and which public bodies provided that funding.

Feryal Clark

DSIT funds medical research through UK Research and Innovation (UKRI) and the Department of Health and Social Care funds research through the National Institute for Health and Care Research (NIHR).

UKRI's Medical Research Council (MRC) supports the best scientific research to improve human health, with work ranging from molecular level science to public health medicine. MRC plays a key role in funding underpinning research which may not be attributable to a specific disease but will benefit medical research more generally. As part of this, UKRI funds research on immunology which is relevant to all of these diseases and will not be categorised per disease.

UKRI did not commit any funding specifically for fibromyalgia research in 2023 and 2024 to date. NIHR has not allocated any funds concerning fibromyalgia disease during F/Y 2023-24.

Source: UK House of Commons
Date: December 19, 2024
URL:
https://questions-statements.parliament.uk/written-questions/detail/2024-12-16/20200
Ref: http://www.me-net.combidom.com/meweb/web1.4.htm#westminster

[Written Answers]

Chronic Fatigue Syndrome: Health Services

Tessa Munt

To ask the Secretary of State for Health and Social Care, whether his Department plans to publish the findings of the consultation entitled Improving the experiences of people with ME/CFS: interim delivery plan, published on 9 August 2023.

Andrew Gwynne

We are committed to improving the care and support for people with myalgic encephalomyelitis (ME/CFS), also known as chronic fatigue syndrome. We recognise how devastating the symptoms can be, and the significant impact they can have on patients and their families.

We published a summary report of the responses to the 2023 consultation on the interim delivery plan on 19 December 2024. The responses to that consultation, along with continued close engagement with stakeholders, will inform the development of the final ME/CFS delivery plan, which we aim to publish by the end of March 2025. The plan will focus on boosting research, improving attitudes and education, and bettering the lives of people with this debilitating disease.

The report is available at the following link:
https://www.gov.uk/government/consultations/improving-the-experiences-of-people-with-mecfs-interim-delivery-plan/outcome/improving-the-experiences-of-people-with-mecfs-consultation-outcome

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