It’s time to solve ME/CFS: Establishing a strategic approach to ME/CFS and post-infectious disease research funding

ACTION FOR M.E.

ME/CFS (called ME hereafter) is a long-term (chronic), often post-viral, illness that causes symptoms affecting many body systems, most commonly the nervous and immune systems. There are an estimated 1.3 million people in the UK who experience ME or ME-like symptoms with post-exertional malaise, the hallmark symptom of ME.

Despite ME’s high prevalence, little is known about its causes and ultimate cure. Parallels have also recently been drawn between ME and Long Covid with some research indicating that at least 50% of people with long covid have symptoms that directly mirror ME.

There are currently no cures or effective, evidence-based treatments for ME. Biomedical research is urgently needed to understand the disease, develop diagnostic tests and find treatments.

The UK has a world-leading life sciences sector, yet this expertise is not being taken advantage of as research into ME is still critically underfunded, lacks coordination and is not structured in a way to deliver meaningful progress at scale.

A strategic approach to research funding will address these issues and accelerate progress by bringing together researchers, clinicians, industry, and patients, helping to boost pre-competitive research and create an ecosystem of expertise that attracts investment in potential treatments as promising results emerge. Parliamentarians can play a vital role in ensuring this initiative is supported.

The issue: chronic neglect of ME research

ME research in the UK is fragmented, underfunded, and **lacks critical mass.**

20x LESS

For comparison, **the UK spends 20 times less on ME research compared to multiple sclerosis,** despite ME being twice as prevalent.[1]

There are only 10 research groups working on ME in the UK, with most of those researchers treating it as a secondary focus due to funding limitations.

Just three postdoctoral fellows are currently leading their own ME research, making it difficult to develop expertise and attract junior researchers.

Existing world-class resources—such as the Uk Biobank, the CureME Biobank and DecodeME genetic database—**are underutilised in ME research** due to a lack of coordination in biomedical research.

Long standing failure of existing research stimulus mechanisms to deliver disease-commensurate research investment.

Cost of ME

In 2017 the cost of ME to the economy was calculated to be £3.3 billion per year.[2] Accounting for inflation and some revised incidence figures, a conservative estimate would put the **current cost of ME at £23 billion per year.**

Action for ME’s Big Survey found that **less than 10% of respondents with ME were in full-time employment, education or training[3].**

Productivity losses are also experienced by carers who must give up working hours to look after their loved ones.

the ME association me

ME RESEARCH UK

The solution: a strategic approach to ME and post-infectious research funding

A strategic approach to research funding is urgently needed. An effective way to coordinate this would be through a national ME and post-infectious disease research hub. The proposal is supported by the Government's Delivery Plan on ME Research Working Group and other researchers, charities, clinicians and people with lived experience.

This hub proposal mirrors the successful structure of the Medical Research Council's Mental Health Research Platform. It would establish:

Five regional research hubs, awarded through open competition, each focused on a key research priority.

A national coordinating centre, responsible for integrating research, engaging with industry, and ensuring collaboration with patient groups.

A structured research career pathway, including support for PhD and early-career researchers to build the next generation of ME experts.

A focus on underserved communities, including severely affected patients and those from minority ethnic backgrounds.

Interdisciplinary collaboration, connecting ME research with other post-infection conditions like Long Covid, and Lyme disease.

Research priorities

The hub would focus on researching key patient, carer and clinician-identified research priorities, including:

- **Understanding post-exertional malaise (a hallmark of ME).**
- **Repurposing existing medications and launching clinical trials for new treatments.**
- **Identifying disease mechanisms, genetics, and biomarker discovery.**
- **Exploring the role of infections and immune dysfunction in ME.**
- **Researching severe and very severe ME, which remains critically understudied.**

How you can help

We urge MPs and Peers to:

1. **Learn more about the importance of coordinating ME biomedical research** through the ME research hub by meeting Action for ME.
2. **Call for strategic funding** to build research capacity from a very low level.
3. **Table written and oral questions** on the merits of establishing a strategic approach to research funding.
4. **Advocate for ME research in policy discussions,** ensuring it is included in government health and research strategies.
5. **Champion interdisciplinary approaches** that integrate ME research with Long Covid and other post-infectious conditions.

Please contact us via
actionforme@connectpa.co.uk
to arrange a meeting or if you would like any further information.

Learn more about our hub proposal:
https://psp-me.co.uk/campaign-strategic-approach-mecfs-research/

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[1] ME Research UK, 2023. Available at: https://www.meresearch.org.uk/parliamentary-question-on-me-cfs-research-funding/
[2] 20/20 Health. *Counting the Cost: CFS/ME (2017)*. Available at: https://2020health.org/publication/counting-the-cost/
[3] Action for ME. *Big Survey (2020)*. Available at: https://www.action-forme.org.uk/uploads/images/2020/02/Big-Survey-Impact-of-ME.pdf