FACE M.E.

PARLIAMENTARY BRIEFING: ENDING THE M.E. RESEARCH FUNDING CRISIS

The "Left in the Dark" campaign | Prepared by Face M.E.

"Too ill to be seen. Too many to ignore."

Face M.E. is a grassroots, patient-led collective uniting the UK Myalgic Encephalomyelitis (M.E.) community to demand equitable biomedical research funding and urgent government accountability. Working alongside Team GB Olympian Beth Dobbin, we are calling on Parliamentarians across all parties to end decades of systemic neglect and bring over a million British citizens out of the dark.

Campaign hub: faceme.org.uk/campaign

Open letter to the Prime Minister: actionnetwork.org/petitions/left-in-the-dark-end-the-me-research-funding-crisis

MP support tracker: faceme.org.uk/mp-tracker

Contact email: faceme.org.uk@gmail.com

1. THE SCALE OF THE CRISIS

Zero Approved Treatments: Despite the scale of suffering, there are still no approved diagnostic tests and no effective, curative treatments available on the NHS.

Source: NHS England & NICE Guideline [NG206]: there is currently no cure and no specific licensed medicine to treat the underlying disease.

1.35 Million+ Affected: Over 1.35 million people across the UK live with Myalgic Encephalomyelitis (M.E.), a complex, multi-system chronic illness.

Source: 2025 joint estimate by The ME Association and Action for M.E. (using University of Edinburgh and ONS data), which includes people with Long Covid meeting ME/CFS criteria.

Devastating Workforce Impact: 70% of people with M.E. are completely unable to work in employed roles due to the severity of their illness.

Source: The ME Association UK Parliamentary Evidence, 2025.

£1 per person, per year: The average UK public investment in ME research.

Source: Face M.E. calculation based on average annual ME/CFS research spend by NIHR (National Institute for Health and Care Research) and UKRI/MRC (UK Research and Innovation / Medical Research Council) over 3 financial years (2023/24–2025/26) and 1.35m UK prevalence.

£24bn Annual Economic Drain: Leaving M.E. untreated costs the UK economy and public purse an estimated £24 billion every year.

Source: Face M.E. calculation scaling the 2017 Counting the Cost report for inflation and 2025 UK prevalence data.

Chronic Underfunding: For decades, M.E. research has received only a tiny fraction of the public investment allocated to comparable chronic conditions with similar disease burdens.

Annual UK government research funding per patient (2023/24–2025/26 average)

Myalgic Encephalomyelitis (ME) receives £1 per patient, per year; Parkinson's Disease receives £39.



Source: UKRI and NIHR funding datasets (2023/24–2025/26 average), excluding overseas aid (ODA), based on an estimated UK patient population of 1.35 million.

2. WHY NOW: BUILDING PARLIAMENTARY MOMENTUM

Public and parliamentary pressure has reached a critical turning point. Team GB Olympian Beth Dobbin recently shared her own reality of living with severe M.E. in an open letter to the Prime Minister on 21 October, followed by a landmark letter on 12 November backed by more than 500 fellow athletes.

With Beth Dobbin meeting the Secretary of State for Health and Social Care to press for urgent reform, MPs have an immediate opportunity to turn national awareness into decisive parliamentary action.

3. OUR THREE CORE DEMANDS

While recent government contributions are welcome, they fall far short of what is needed to match the scale of this crisis. We call on the Government to deliver on three concrete demands:

1. **Finish the Science:** Immediately close the **£15 million funding gap** for *Sequence ME*, the landmark UK genetic study essential for unlocking diagnostic biomarkers and targeted therapeutics.
2. **Fund What Patients Actually Need:** Deliver dedicated, ring-fenced public investment directly into the official **M.E. Priority Setting Partnership (PSP)** research goals—the top priorities agreed upon by patients, carers, and clinicians.
3. **Enforce Accountability:** Implement a binding **national biomedical roadmap** with annual targets and clear ministerial accountability to pull the UK out of decades of institutional neglect.

4. HOW YOU CAN HELP: ACTION CHECKLIST FOR MPS

1. **Sign the open PM letter and join our MP support tracker.** Add your name to our open letter to the Prime Minister (actionnetwork.org) and email faceme.org.uk@gmail.com to confirm your backing so we can proudly feature you on our public MP support tracker: faceme.org.uk/mp-tracker
2. **Write to Cabinet Ministers.** Write directly to the **Secretary of State for Health and Social Care** and the **Secretary of State for Science, Innovation and Technology** urging them to close the £15 million sequencing funding gap, ring-fence funding for the M.E. PSP priorities, and commit to a binding biomedical roadmap.
3. **Table a Parliamentary Question (PQ).** Keep pressure on Ministers on the Parliamentary record by tabling a written or oral question (see ready-to-use templates below).
4. **Attend the handover of our open letter to the PM and short vigil (date TBC).** Join patients, carers, and advocates outside Downing Street, Whitehall for our upcoming open letter handover and short vigil (final date to be confirmed with signed-up MPs).

5. SAMPLE PARLIAMENTARY QUESTIONS (READY TO TABLE)

QUESTION 1 (DEPARTMENT OF HEALTH AND SOCIAL CARE)

To ask the Secretary of State for Health and Social Care, what steps their Department is taking to close the £15 million funding gap for the Sequence ME and Long Covid research programme, and what plans they have to establish a binding national biomedical research roadmap with annual targets for Myalgic Encephalomyelitis.

QUESTION 2 (DEPARTMENT FOR SCIENCE, INNOVATION AND TECHNOLOGY)

To ask the Secretary of State for Science, Innovation and Technology, whether they will allocate ring-fenced public research funding to address the top research priorities identified by the M.E. Priority Setting Partnership.

Get in touch

To confirm your support for the MP Tracker, request further information, or coordinate a brief 15-minute online meeting with local constituents living with M.E., please contact our team:

- **Email:** faceme.org.uk@gmail.com
- **Website:** faceme.org.uk
- **Social media:** @facemeuk