Invest in ME Research

Research

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Tessa Munt MP
House of Commons
London
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15 November 2025

Dear Ms Munt,

Re: Government Support for People with Myalgic Encephalomyelitis (ME) — Westminster Hall Debate, 19 November 2025

Invest in ME Research has only just become aware of your forthcoming Westminster Hall debate on government support for people with ME on 19 November 2025.
We welcome this opportunity to raise awareness of the challenges faced by people living with ME and provide you with a broader view of the issues, drawn from two decades of experience.

Founded in 2005 and registered as a charity in 2006, Invest in ME Research is a UK charity dedicated to funding and facilitating biomedical research into ME and improving patient care and education. We will be celebrating our 20-year anniversary as a registered charity in 2026.

Over two decades, we have worked closely with patients, clinicians and researchers to raise awareness, fund pioneering research and establish international collaborations that have advanced the understanding of this complex condition.
Our volunteer-run charity has achieved more for biomedical ME research than many larger organisations. We fund the only clinical trial for ME currently underway at the Quadram Institute in Norwich Research Park and funded the first fellows dedicated to ME research at this centre of excellence for ME, including the Invest in ME Research Ian Gibson Fellowship and the LunaNova Fellowship. Additionally, we have funded multiple PhDs and facilitated extensive European and international collaboration over two decades.

The charity arranges an annual CPD-accredited international ME conference week that attracts researchers, clinicians and patients from around the world, including NIH and CDC.

The developments and issues of the past two decades were recently summarised in our charity's presentation at the international symposium organised in Belgrade, Serbia by the Institute for Cardiovascular Diseases "Dedinje" [1].
Despite decades of scientific progress in many areas, biomedical research and patient support for ME have made slow progress. This is due to structural failures including chronic underfunding of research, absence of coordinated investment in diagnostics and multi-centre cohorts, stigma, and lack of established research career paths.
This enduring neglect has created a self-reinforcing cycle: inadequate funding produces limited research and no treatments, reinforcing stigma and hampering clinician and researcher engagement, which in turn justifies continued low investment. The Department of Health and Social Care (DHSC)'s

recent initiative on ME exemplifies this inaction—years lost with no substantive outcomes despite repeated calls and proposals from Invest in ME Research.

Invest in ME Research was belatedly invited to join the DHSC working group, and we promptly submitted proposals for a rapid change of direction to make progress. Regrettably, all our proposals were ignored [2].

We consider the DHSC initiative an utter failure due to its poorly thought-out objectives, limited impact, lack of meaningful intent to rapidly progress research into ME, and inadequate support measures. Three more years of patients' lives have been wasted. Participation in a working group is meaningless if proposals (ours, and also from experts in our networks) are ignored and no concrete, time-bound progress follows; the existence of an 'action plan' alone does not constitute genuine action or measurable outcomes.

While government funding claims to build ME research infrastructure, it largely duplicates existing networks already established and funded by Invest in ME Research and partners. Rather than creating meaningful new capacity, this approach reboots coordination efforts at significant cost and with delays, repeating work our charity has been successfully undertaking. This inefficiency exemplifies the misdirection of limited public funds and the lack of strategic recognition of effective existing structures. The government's PRIME initiative represents a fraction of what is required and largely duplicates pre-existing structures established by our charity, structures that are already achieving collaborative projects, delaying rather than accelerating progress. Rather than building on the existing European ME Research Group (EMERG) and related collaborative networks, the creation of parallel structures risks delaying progress and repeating past inefficiencies, without providing tangible benefits to patients.

We have emphasised that collaboration across Europe is the clearest, most rapid route forward. Invest in ME Research has already established European networks for ME, including the European ME Research Group (EMERG) and the Young EMERG network for early-career researchers across Europe. These networks are chaired from the Norwich Centre of Excellence, which provides the scientific infrastructure and coordination needed to support collaborative research and accelerate progress for patients across Europe. Additionally, the European ME Alliance (EMEA) facilitates collaboration among patient organisations across the continent. Together, these structures foster sharing of knowledge and coordinate multi-country research essential for robust biomarker validation and translational clinical trials. They all come together at our annual international ME conference week.

As we noted in our DHSC submissions, to compare the inadequate attention to ME in the UK, the Dutch government has already embarked on a 10 year, 28 million Euro programme of research into ME. Just last week the German government has unveiled plans to invest 500 million Euros in post-infectious disease research over ten years, which will inevitably include ME as part of that research programme. Meanwhile, successive UK governments fail to prioritise research into ME and patients, and their carers continue to pay the price. Recent UK-funded initiatives, including the HERITAGE study, focus on service delivery rather than biomedical discovery. They are unlikely to yield diagnostics, biomarkers, or treatments in the short term, and presenting such studies as 'progress' risks misleading patients and the public while the core scientific barriers remain unaddressed. Presenting such limited studies as progress risks misleading the public and people with ME yet again, while failing to address the core scientific barriers that keep patients without effective care.

It is important also to note that Invest in ME Research made comprehensive submissions to the UK parliamentary debate on ME in 2019, outlining urgent actions needed. Unfortunately, despite these efforts, no significant changes have taken place, and the situation for people with ME continues unchanged [3].

Instead of Investing in ME Research, the UK continues with inaction for ME.

We emphasise that the charity's groundwork in creating current, effective European networks of researchers, clinicians and young researchers should be fully utilised and not reinvented, as this wastes precious time. We have seen this happen too many times already.
We have no confidence that the current government plans will deliver meaningful change, nor do we believe any of the planned measures will result in rapid improvements.

We respectfully request that during the debate you emphasise the urgent need for government action that genuinely reflects the needs of the ME community, including:

- Support for the continuation of the Centre of Excellence for ME at Norwich Research Park, currently funded by our charity. Government backing would be vital to sustain and expand this strategic biomedical research hub focused on fundamental science, biomarker discovery, and treatment development. Training healthcare professionals alone cannot solve the core problem while effective therapies remain unavailable, which depends entirely on strategic research, as performed at Norwich. A meaningful strategy requires long-term, adequate investment in ME research that moves beyond small, symbolic awards and instead builds a workforce capable of delivering breakthroughs. Without sustained government support, vital progress made at Norwich could slow or stall, undermining one of the UK's very few biomedical ME research programmes working toward therapeutic development, and the UK risks losing the scientific momentum built entirely through charitable investment.
- Commitment to funding a coordinated strategy to break the systemic neglect cycle through deliberate capacity building — fellowships, protected posts, multi-centre studies and long-term investment.
- Support, utilisation and expansion of the European collaborative networks that we have established and which function already, rather than reinventing structures and wasting time; Europe offers the critical mass required for meaningful progress. Reinventing structures already functioning across Europe wastes time and funding, whereas adopting these established networks would immediately expand the UK's research capability and accelerate progress. Our aim is for rapid progress, not a continuation of the slow, drawn-out processes that have typified UK policy on ME and delivered no meaningful outcomes.
- Recognition of ME as a valid disabling condition in all disability benefit claims and assessments, enabling people with ME and their carers to access necessary financial support and greatly reducing the enormous stress, uncertainty, harmful discrimination, and stigma they currently face. Recognising ME as a disabling condition is not complex. The real problem is persistent institutional failure to acknowledge the profound functional impairment experienced by people with ME, leaving them repeatedly denied or doubted regarding the basic financial support they are entitled to.
- Transparency in government plans affecting patients, which has to date been insufficient—Invest in ME Research was excluded from Department of Health and Social Care planning efforts until very late and only included after repeated demands from the patient community. Transparency is essential for accountability and rebuilding trust.

We would be pleased to provide you with further information at any time, and to facilitate a visit by you and other MPs to the Centre of Excellence for ME at Norwich Research Park, at your convenience, to assist you in representing the voices of those affected by ME.

Thank you for your attention and leadership on this vital issue.
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Yours sincerely,

Chairman Invest in ME Research

References and Information:

1. Presentation Institute for Cardiovascular Diseases “Dedinje”, Serbia
   https://investinme.org/video/serbia2025/Serbia IiMER presentation 2025.mp4
2. Submissions to DHSC Interim Plan Initiative https://investinme.org/ukcrc.shtml
3. 2019 Parliamentary Debate https://investinme.org/parliamentdebate2019
4. Submissions to DHSC / UKCRC Delivery Plan https://investinme.org/ukcrc.shtml
5. UK Centre of Excellence status https://tinyurl.com/ukcentre
6. Quadram Institute Research into ME https://quadram.ac.uk/targets/me-cfs/
7. European ME Alliance Pan-European Survey on ME
   https://www.europeanmealliance.org/emea-pan-european-survey-pr-uk.shtml