Invest in ME Research

Invest in ME
Research
Charity number 1153730

PO Box 561, Eastleigh SO50 0GQ, Hampshire, UK

***Tel*: 02380 643736   07759 349743**

email: info@investinme.org   web: www.investinme.org

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20 Years of Invest in ME Research

Why Has Progress Been So Slow?

The Potential of European and International Collaboration in Advancing ME Biomedical Research and Patient Care

The Need for European Collaboration in ME Research
Leveraging Existing Networks for Accelerated Progress

Invest in ME Research - November 2025

Slide 1 - Introduction: Why So Little Progress?

We probably all know the historical issues surrounding ME - the research gaps, the treatment shortfalls and the persistent misperception of the disease.
It is patients who must live with the consequences: ignorance, misinformation, apathy and stigma.

Other speakers will describe the current problems people with ME still endure.
Rather than repeat that, I want to ask: **why, after decades of scientific progress in many areas, does ME still have no diagnostic test, no treatment, and little meaningful support?**
And why do we believe that European collaboration offers the clearest, most rapid route forward, given continued governmental failure to address patients' needs promptly and effectively?

Slide 2 - Invest in ME Research: Twenty Years of Determination

Invest in ME Research (IiMER) is a UK charity that will reach its 20th anniversary in 2026.
In that time the charity has worked continuously, entirely voluntarily, to facilitate coordinated biomedical research into ME.
Despite being small and volunteer-run, with no salaried staff, IiMER has achieved more for biomedical ME research than some larger organisations.
It has funded multiple PhDs and fellowships, supported diverse research projects, backed a clinical trial, and developed collaborative initiatives that governments have ignored.
Our purpose is simple: to facilitate discovery of the causes of ME and to develop effective treatments.

Slide 3 - The Same Situation, Twenty Years On

From the seminar flyer:

> "*Despite its increasing prevalence and debilitating nature, it remains largely unfamiliar to the public and many medical professionals. Understanding of its aetiology and pathophysiology is limited, diagnostic criteria are inconsistent, and guidelines for diagnosis and treatment are inadequate and outdated.*"

A comparison of research papers from 2006 and today shows the same conclusions: the mechanisms of ME remain unknown, clinical management is inadequate, and research is underdeveloped.

This was apparent as far back as the UK Chief Medical Officer's report of 2002, and the landscape described today would have been familiar in 2006 when IiMER held its first conference.
Twenty years on we are therefore still asking: **why has ME research made so little progress?**
Apart from the recent 10-year research programme in the Netherlands, and promising developments in Austria, very little has changed.
That is why we argue that collaboration - especially across Europe - is the way forward.

Slide 4 - Why So Little Progress? The Structural Barriers

Why? Not because ME is uniquely difficult. The real barriers are structural:

- Chronic underfunding, producing small studies and little replication.
- No sustained investment to standardise diagnostics or build multi-centre cohorts.
- Stigma that fills the void left by scientific inaction.
- The absence of research career paths, leaving capacity small.

All of these problems point to the same root cause: **a lack of intent to prioritise ME.**

Slide 5 - The Root Cause: A Self-Reinforcing Cycle

All these barriers stem from one origin: a lack of intent to fund and prioritise ME research.
When a disease is not a priority it receives inadequate funding;
that underinvestment constrains research, which produces no treatments.
No treatments reinforce perceptions that ME is untreatable - or not real - which breeds stigma and discourages researchers and clinicians.
Weak capacity is then used to justify continued low investment.
The result is a perfect storm: a self-reinforcing cycle that reproduces neglect.

This cycle has been recognised repeatedly, yet no concerted strategy has been put in place to break it.
Occasional reviews or "delivery plans" have created the appearance of progress without addressing the underlying problem: a failure of intent, coordination and accountability.
Nowhere is this clearer than in the UK.

Slide 6 - Institutional Apathy: The UK Delivery Plan Example

Government departments and national bodies have repeatedly demonstrated passive acceptance of the status quo.
The UK Government's Delivery Plan is a prime example: it took two to three years and achieved nothing substantive - no infrastructure, no clear strategy, no meaningful investment, no accountability.
And yet Invest in ME Research predicted this result from the outset when we were first invited to participate and proposed rapid solutions – but few listened and nobody acted.
Another three years wasted for patients.
The status quo has been tolerated rather than challenged. And patients were fooled again
The appearance of action has been used to hide inaction.
That is strategic indecision.

Slide 7 - What Must Change: Funding and Capacity

If ME research is ever to progress, fundamental gaps must be addressed. Researchers need career paths, multi-centre studies, biobanks and translational programmes - possibly housed in Centres of Excellence. Two things are fundamental:

1. **Sustained, coordinated strategy with adequate biomedical funding** - real programmes, not piecemeal grants.

2. **Deliberate capacity building** - fellowships, protected posts, multi-centre studies and long-term commitments.
   These must be deliberate efforts, not left to chance.

Slide 8 - Our Call for Today's Seminar: Use What We Have Built

For twenty years we have built collaborative structures that governments have failed to consider or have only talked about. Our model encourages researchers and clinicians to share knowledge and data across borders. The strongest route to progress is through Europe. We have deliberately brought researchers from outside the field into these networks. European links now connect scientists, clinicians and early-career researchers, supported by annual CPD-accredited colloquiums that unite researchers, clinicians and patient groups. We must use these networks and build on them rather than wait for governments to act or waste time reinventing existing structures.
Augment what has started - it is the fastest and most cost-effective route for European nations.

Slide 9 - Develop Europe-Wide Frameworks: EMEA, EMERG, EMECC, Young EMERG

Develop European groups as a framework for advocacy, research and clinical care:

- **European ME Alliance (EMEA)** - a federation of patient organisations advocating across Europe.
- **European ME Research Group (EMERG)** - enabling researchers to collaborate on joint projects.
- **European ME Clinicians Council (EMECC)** – to build a network of clinicians who share knowledge and influence practice.
- **Young EMERG** - supporting early-career researchers entering the field.

These networks, amplified by events such as IiMER's annual Colloquiums, create a powerful resource for international biomedical collaboration.

Slide 10 - Multi-Country Research: Essential for Modern Biomedical Science

Multi-country research provides larger and more diverse cohorts, stronger biomarker validation and faster translation to clinical trials. Techniques such as AI, systems biology, genomics and metabolomics need large shared datasets. No single country can generate these alone; Europe can. This scale is essential for robust discovery and for delivering personalised-medicine approaches to ME.

Slide 11 - The Opportunity in 2026

This approach can work. 2026 offers an opportunity to launch a European multi-country ME project that consolidates twenty years of groundwork.
EMERG is preparing a pan-European bid that, if funded, would create the foundation for sustained, collaborative research across many nations - the logical next step after voluntary, patient-led efforts.

Slide 12 - Conclusion: Commitment Now

The takeaway is simple: progress in ME research will come more rapidly through European collaboration, using structures, networks and momentum that already exist.
Commitment from funders and policymakers is critical.
European collaboration is not optional - it is the fastest, most reliable route to meaningful progress for patients. The structures are in place; the need is undeniable. The next step is commitment from funders and policymakers.

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Email: info@investinme.org