ME RESEARCH UK

25

YEARS

2000–2025

# ANNUAL REPORT

## 2024 - 2025

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ME Research UK

SC036942

# ME Research UK

## Contents

# ME Research UK

## Reference and Administrative Details

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|---|---|
| **Charity name** | ME Research UK |
| **Charity registration number** | SC036942 |
| **Trustees** | Jonathan P J Davies, Chair<br>Mrs Sue Waddle, Vice Chair<br>Mrs Jan McKendrick, Secretary<br>Prof Faisel Khan<br>Dr Eleanor Roberts<br>Joe Welton<br>Mrs Lesley Carr (assumed as Trustee 22 January 2025) |
| **Founding Patron** | Roger Jefcoate CBE DL |
| **Patron** | The Countess of Mar |
| **Honorary Presidents** | Robert D McRae<br>Dr Vance A Spence |
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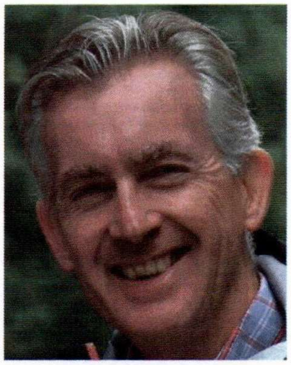
| **Auditor** | Morris and Young, Chartered Accountants<br>6 Atholl Crescent<br>Perth<br>PH1 5JN |

# ME Research UK

## Trustees' Report

### Introduction by the Chair



It gives me great pleasure to present our latest Annual Report and Accounts, which reflect a year of continued progress in our mission of Informing, Influencing and Investing in research into ME worldwide.

Since the inception of the Charity, we have invested over £5m in 78 research projects (including a Fellowship and four PhD-level research studies in 12 countries and remain, by some margin in terms of projects, the largest charity funder of biomedical research into ME in the world (outside North America). 2025 saw 6 new research grants and one Fellowship awarded, totalling £866,000, to both existing and new ME researchers.

Our work is only possible with the continued support of all those who donate funds to us. We are truly grateful to all of our supporters for the faith they place in us and in the work we do. Our total income from voluntary donations (including Gift Aid) was £433,000 in the year, the highest it has ever been. With bequests and legacies of £361,000 also received in the year, we are confident in continuing our work on your behalf and we remain committed to putting every penny to the best possible use. Thank you for your invaluable support - we could not exist without you.

Our current global investment in research stands at £1.8m, represented by 16 ongoing research studies, a Fellowship and 3 PhD level research projects. We continue to deliver on our commitment to supporting and encouraging both young and established researchers into the field of ME research.

The final publication of the Government's ME/CFS Delivery Plan this year was a significant, but not unexpected, disappointment. It contained no tangible commitment or funding to boost research in the UK, but has strengthened our determination to make a positive difference. Our desire to increase the pace and value of funding we provide to rigorous biomedical research remains undimmed and we will continue to work towards our vision to bring to an end the suffering caused by ME.

A final word of thanks to our dedicated staff team without whom none of what we do would be possible. On behalf of the Board, I thank them for their commitment and the value they bring.

Jonathan Davies

Chair of Board of Charity Trustees

# ME Research UK

## Trustees' Report

The Trustees present their report along with the financial statements of the charity for the period 1st November 2024 to 31st October 2025 - see Note 1 to the accounts. The financial statements have been prepared in accordance with the accounting policies set out in Note 1 to the accounts and comply with the charity's Constitution dated 3rd June 2019; the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended); and the requirements of the Office of the Scottish Charity Regulator (OSCR).

### Our Vision and Mission

Our vision is to end the suffering caused by ME/CFS by investing in high quality, scientific (biomedical) research into the causes, consequences and treatment(s) of the disease. Only through biomedical research will the disease be understood, accepted and real change to the lived experience of those with the disease become a reality.

In particular, we

- invest globally in high quality biomedical research into ME/CFS globally which we believe has the potential to further the understanding of the disease;
- inform the science community, civic society and those affected by the disease by taking a leading role in interpreting, analysing and commenting on published biomedical research into ME/CFS; and
- influence the biomedical research and funding agenda by working proactively and collaboratively with other organisations.

We exist solely to inform, influence and invest in biomedical research and, to date, we have invested over £5 million in biomedical research worldwide on 72 distinct projects and funded 4 PhD-level research studies. In addition, we have, alongside the Daphne Jackson Trust, awarded a 3-year Fellowship to facilitate the return to work of a post-doctoral researcher to ME/CFS research after a career break. The Fellowship is co-funded with the UK's main central funder of research - the National Institute for Health and Care Research.

There is more to do and we are determined to do more. In fact, ME Research UK has funded more specific biomedical ME/CFS research projects than any other charitable organisation in the world outside North America. However, it is vital that more high-quality research is carried out into both the cause(s) of the disease and its effects, with the ultimate aim to discover a treatment or a cure for this most disabling of diseases. ME Research UK's Constitution specifically charges the charity "To advance scientific knowledge by commissioning or funding research into the causes, consequences and treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)".

ME Research UK is dedicated to ensuring that research into ME/CFS reflects the prevalence and seriousness of the disease, and to funding the highest quality of biomedical research possible.

### The Disease

Myalgic encephalomyelitis (ME) is characterised by a range of neurological symptoms and signs, muscle pain with intense physical or mental exhaustion, relapses, and specific cognitive disabilities. Both the World Health Organisation's 'International Classification of Disease' (ICD10 (G93.3) under 'Post-Viral Fatigue Syndrome') and the Systematized Nomenclature of Medicine (SNOMED CT) lists ME as a disorder of the nervous system.

During the 1990s, the term Chronic Fatigue Syndrome (CFS) came into use. As there was (and presently remains) no specific diagnostic test for ME, and, as post-exercise 'fatigue' was one of its prominent symptoms, people with ME began to be diagnosed with CFS. In recent years, however, there has been a growing recognition that the diagnosis 'CFS'- based on a list of vague non-specific symptoms shared with other illnesses - is so broad that it can encompass a range of diverse patient groups.

The National Institute for Health and Care Excellence (NICE) in their 2021 'Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management' guideline (NG206) recognises that "Many people with ME/CFS consider the name 'chronic fatigue syndrome' too broad, simplistic and judgmental." It is to be welcomed that the 2021 NICE guideline refers to the disease as ME/CFS rather than the 2007 guideline label of CFS/ME. This change formed part of ME Research UK's submission to NICE during the consultation process and, increasingly, the media now use ME/CFS or even just ME when describing the disease.

Of course, none of the issues surrounding the name alter the reality of the disease for millions of people, and the lay term 'ME' is still used by patients, patient groups and charities (including ME Research UK) to describe the disease affecting people diagnosed with ME/CFS, including that subgroup of CFS patients with an organic disease, characterised by neurological signs and symptoms.

In 2025, due to the work of ME Research UK-funded researchers, the widely accepted standard prevalence rate for ME/CFS has been updated. It is now estimated - thanks to ME Research UK funded work - that in excess of 400,000 people in the UK have ME/CFS, with about 2.4 times as many women affected as men. The prevalence rate, however, remains incomplete due to limitations in the methodology of studies relating to long COVID and its effects on the numbers of those accepted as having ME/CFS. The charity provided a full critique of the current situation assessing methodology, limitations, and weighting prior to promulgating its fully-justified figures. Others have followed ME Research UK's lead and the figures have been quoted both by the BBC and by the Department for Health & Social Care.

Worldwide, as the German Parliament was informed, the number affected by long COVID is estimated at around 17 to 24 million people. In addition, it is estimated that around 1 to 2 percent of all SARS-CoV-2 infected people (up to 20 percent of all post-COVID sufferers) will meet ME/CFS diagnostic criteria after six months. It must therefore be assumed that the number of people affected by ME/CFS will almost double worldwide. In figures, this would correspond to 10 million new cases.

ME/CFS can affect people of all ages. It is a complex, multi-system, chronic medical condition that has considerable personal, social and economic consequences and a significant impact on a person's quality of life, including their psychological, emotional and social wellbeing.

Everyday life for people with ME/CFS, their family and carers is disrupted and unpredictable. Many people with the condition are unemployed, and less than a fifth work full-time. Approximately 25% are classified as severely affected and are house- or bedbound. The quality of life of people with ME/CFS is lower than that of many people with other severe chronic conditions, including multiple sclerosis and some forms of cancer.

It is not clear what causes ME/CFS. In many cases, symptoms are thought to have been triggered by an infection but the exact cause of the disease remains unknown. Over the years there have been a number of attempts to devise a more sensitive way of diagnosing patients but none have yet been successful. Indeed, NICE identifies clinical and cost-effective diagnostic tests as a key area where they recommend further research be undertaken.

What is certain is that ME/CFS is not a simple post-disease fatigue. It lasts longer and even minimal mental or physical activity can make symptoms worse. NICE records neither a cure nor a treatment for ME/CFS.

There is presently no diagnostic test or single universally accepted diagnostic definition for ME/CFS. People with the condition report delays in diagnosis, and many healthcare professionals lack the confidence and knowledge to recognise, diagnose and manage it. Fatigue associated with other chronic diseases may be erroneously confused with ME/CFS and some practitioners are reluctant to positively diagnose ME/CFS.

Many people with ME/CFS report a lack of belief and acknowledgement from health and social care professionals about their condition and related problems, which may lead them to be dissatisfied with care and to disengage from services. This lack of belief by healthcare professionals and even family members is also recognised by NICE in the 2021 guideline. There are added issues for children and young people when the disease makes school attendance difficult, and bringing families to the attention of educational and social care services.

The four key diagnostic criteria in the NICE 2021 guideline are -

(1) Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.

(2) Post-exertional malaise after activity in which the worsening of symptoms:
  - is often delayed in onset by hours or days;
  - is disproportionate to the activity;
  - has a prolonged recovery time that may last hours, days, weeks.

(3) Unrefreshing sleep or sleep disturbance (or both), which may include:
  - feeling exhausted, feeling flu-like and stiff on waking;
  - broken or shallow sleep, altered sleep pattern or hypersomnia.

(4) Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

On 28 May 2025 the Scottish Government withdrew the Scottish Good Practice Statement (SGPS) on ME/CFS leaving NICE Guideline NG206 as the default clinical guidance on ME/CFS. How his change will track through to the creation of specialist services in Scotland remains to be seen but ME Research UK, through a series of Freedom of Information requests, has been able to publicise what is planned throughout Scotland's 14 NHS Boards.

Given the disease's prevalence and impact, it is widely acknowledged that ME/CFS has faced significant under-investment in biomedical research over many years, both in the UK and overseas. Within the UK specifically, for example, ME/CFS receives comparatively little funding compared to other neurological disorders. MS affects about 100,000 people compared to the c400,000 estimated to have ME/CFS but has received 20 times the funding.

### Department of Health and Social Care

Throughout the year ME Research UK has been involved actively in the Dept for Health and Social Care's 'ME/CFS Delivery Plan' process - from participation in meetings, providing a detailed critique of the draft Delivery Plan during the consultation period, to supporting a research-, charity- and patient group- led research plan. Over 3 years after the process began, in July 2025, the Delivery Plan was published and repeated the 'Problem statements' on research:

(1) There is low capacity and capability among the research community to respond to research needs in this area.

(2) Historically, there has been low awareness of the need and scope for research into ME/CFS across the health and care research landscape.

(3) There has been a relatively low amount of biomedical research funded on ME/CFS, compared with disease burden.

(4) There remains a lack of trust between different stakeholders, including a perception of bias, expressed by patient and carer groups, about prioritisation and the peer-review process when applied to ME/CFS research.

The Plan, however, failed in its ambition to boost research and was certainly not the Plan for future research success which was hoped. It is apparent that the Plan actually adds little new. The central issues facing biomedical research into ME/CFS are actually well known, and have been for decades. These issues were narrated in the 'Inquiry into the status of CFS/M.E. and research into causes and treatment' - the 2006 Gibson report - which cast a critical eye on progress made to that point in implementing the research recommendations of the 2002 'Report of the CFS/ME Working Group' to the Chief Medical Officer. What is to be regretted, given the crucial role of government funders of research, is why there is no obvious or indeed oblique comment on how the (in)actions of central funders may have contributed to the problems being faced within the draft Plan. There has, after all, been a Highlight Notice for ME/CFS since 2003 and the disease has been, according to the MRC "a high priority for MRC for several years". Looking at the four problem statements identified, how many are caused by the lack of funding? How many researchers have chosen not to study ME/CFS due to the paucity of funding opportunities offered, or have abandoned their research after failing to achieve MRC backing? Apart from a few initiatives - e.g. a welcome promotion of drug repurposing - all hopes are built on the results of DecodeME. Most other Plan provisions were on support and guidance as researchers continue to be blamed for inadequate quality and quantity of research applications.

The challenges and potential solutions were raised at a high-level meeting of ME/CFS researchers, charity funders, the Department of Health and Social Care, and UK Research and Innovation/Medical Research Council in September 2024. This, in turn, resulted in a broad-based coalition of researchers, research funding charities, patient representatives and others producing a detailed proposal for a 5-year NIHR/MRC platform grant for a multi-hub, interdisciplinary research strategy for ME/CFS research. This has not been progressed by the Department and failed to be mentioned in the Delivery Plan.

These initiatives and ME Research UK's active participation highlight even more clearly the crucial importance of the work of ME Research UK in funding the highest quality research globally - research which lays the foundation of larger projects, helps inform and inspire early career researchers, and which lays the foundations of improved healthcare professional education and practice.

## 25th Anniversary

2025 marked a milestone in the history of ME Research UK, as this year the charity marked 25 years since its foundation. As an organisation, our dearest wish is that sustained major funding into ME/CFS becomes available, leading to a cure or effective treatment, and ME Research UK could withdraw.

ME Research UK did not celebrate 25 years of work but rather marked the commitment of researchers and supporters and what they have achieved. The charity's original founding document was signed on 20th January 2000, and The ME Research Group for Education and Support (MERGE) was born.

During the year -

- The contribution of ME Research UK to ME research was recognised by the Scottish Parliament via a Motion for International ME Awareness Day which was supported by 70 of the 104 MSPs eligible to sign (an unprecedented proportion) at which Holyrood 'commends ME Research UK on the occasion of 25 years since its foundation; notes that the charity is dedicated to commissioning and funding biomedical research into the causes, consequences and treatment of myalgic encephalomyelitis/chronic fatigue syndrome (ME/ CFS); believes that the disease, which affects at least 20,000 people in Scotland, is often misunderstood, mis-diagnosed and under-diagnosed, and is grievously under-researched; understands that the Perth-based charity has invested over £4.5 million in research with 68 research projects globally, four PhD-level projects and a Fellowship; further understands that, in terms of projects, the Perth-based charity is the largest funder of ME/ CFS outwith North America, that it presently funds projects in Australia, France, Germany, the Netherlands, Sweden, USA and the UK, and is funded entirely by individual donations, and extends its thanks for the work of ME Research UK in informing, influencing and investing in ME research globally'.
- A Civic Reception was granted to the charity by the Provost of Perth and Kinross Provost Xander McDade and Perth and Kinross Council on 12th May at the Civic Hall, Perth. During the event the principal speakers, Deputy Lieutenant Charlie Gallagher, the Provost of Perth and Kinross, and Councillor Michelle Frampton spoke eloquently and with deep understanding of ME, enlightened by their familial experiences of the disease. Deputy Lieutenant Gallagher read from a note from Stephen Leckie, Lord-Lieutenant of Perth and Kinross, which narrated many congratulations on the work the charity had done over the past quarter century and that "Everyone in the county is very proud ..." of the achievements of a small, local charity.

- ME Research UK sponsored the poster competition at the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis October 2025 virtual conference. The competition challenged early career researchers to face the issues inherent in communicating research data in a concise and attractive form for a defined audience. Two awards were funded to recognise different facets of a successful science poster with the aim that the process of designing and writing the poster would provide a real-life challenge to those at the beginning of their research careers.
- In cognisance of the fact that 13th July 2025 marked the 70th anniversary of the outbreak of a disease which was, in a 1956 piece in The Lancet, labelled 'benign myalgic encephalomyelitis', ME Research UK initiated an annual ME Research Day which, in coming years, will recognise and mark the work, challenges, and success of ME researchers globally. The Research Day will be an annual reminder of ME Research UK's role and work.
- Additional efforts were placed into marking International ME Awareness Day with the charity arranging for all four UK nations and, indeed, all four nations capitals, to be united to mark 12th May with the Northern Ireland Assembly's Parliament Buildings, Belfast City Hall, Gateshead Millennium Bridge, Cardiff Castle, Edinburgh, and Aberdeen Council's HQ illuminated in blue in honour of those affected by ME and to raise awareness of the disease. Perth City also joined and, of particular note, the logo of ME Research UK revolved around London's BT Tower (formerly the Post Office Tower) in honour of the 25th Anniversary and 12th May events.
- Highlighting ME Research UK's anniversary, the charity was an active participant at a meeting organised by Hope4ME & Fibromyalgia NI at Northern Ireland's Parliament Buildings. The meeting being attended by MLAs, political representatives, healthcare workers, academics, & educators and the audience heard the Minister of Health Mike Nisbett MLA pledge his determination to help those affected by M.E. in Northern Ireland.
- For a week from 13th July, ME Research UK's social media carried messages from the Founders 'answered' by their 2025 office holder counterparts which anchored the modern charity to its roots and served as an opportunity to once more acknowledge with grateful thanks the contribution of Roger Jeffcoate CBE DL, Dr Vance Spence and Robert McRae.

## ME Research UK - Year in Review

## Achievements and Performance

### A. Investing in Research

*The most significant aspect of our charity and the core of our charitable purposes and aims is the provision of funding for research.*

It is worthwhile recalling that in our free Breakthrough magazine a regular contributor and well-respected ME/CFS commentator highlighted the vital importance of charity funders in ME/CFS research - and, in particular, ME Research UK. Governmental funders are, as he stated, "... fundamentally conservative and when it comes to ME/CFS, sometimes ignorant... Because large amounts of money are at stake -a typical large NIH grant lasts 5 years and runs in the millions of dollars - they also tend to be risk averse. They want something that's worked out." "Contrast that approach with an ME/CFS organisation that just wants answers. An organisation that intimately knows the suffering that ME/CFS imposes." "You're [ME charities] not willing to settle for the status quo. You're willing to take risks. You keep an eagle eye on the emerging research, and when something promising shows you pounce on it - and, in contrast to the federal funders, you do so quickly.