Projects Completed in 2024/25

Project - 23-063

Dr Bo Christer Bertilson, Medect Clinical Trials, Bragée Clinics, Sweden
Proteomic and metabolomic analyses to reveal biomarkers of ME/CFS - a case-control study of blood and spinal fluid
£98,000.00

Dr Bertilson and colleagues are using a technique called mass spectrometry to search for biomarkers of ME/CFS in blood plasma and cerebrospinal fluid samples from people with the disease. The team will use state-of-the-art methods to analyse proteins and metabolites in the samples, with the aim of identifying a profile of these molecules that is characteristic of ME/CFS and can help identify people with the disease. Proteins perform many critical roles in the body, while metabolites are produced during chemical processes. Identifying biomarkers of ME/CFS could improve diagnosis of the disease, as well as highlighting potential new treatment options.

Project -23-064

Prof. Janet Taylor, Edith Cowan University, Australia
Investigation of motoneurone firing behaviour and associations with symptom severity in individuals with myalgic encephalomyelitis/chronic fatigue syndrome
£28,557.00

Reduced muscle strength in people with ME/CFS may be due to problems with the nerves that drive these muscles, specifically those nerves in the spinal cord that supply the muscle fibres and control our movements. Prof. Taylor and her team plan to record the electrical activity of these nerves during muscle contractions, comparing people with ME/CFS and control subjects. They will also look at whether any abnormalities are due to a reduced action of serotonin, a chemical that carries messages between nerves. The findings may help us better understand the muscle problems experienced by people with ME/CFS, and lead to more effective treatments.

Project - 23-066

Prof. Robert Dorey / Prof. Fatima Labeed, University of Surrey, UK
The Electrophysiology of ME/CFS: Development of an Electrical Model for Exploration and Diagnosis
£32,206.50 (50% share of joint grant with the ME Association)

Dr Labeed and colleagues are investigating whether the electrical properties of white blood cells can be used to diagnose ME/CFS. Every cell generates a small electric field across its membrane and on its surface, and these play a role in the cell's function. Previous research reported that the impedance of white blood cells (representing a combination of electrical properties) differed between people with ME/CFS and healthy controls. Dr Labeed is following up these initial findings using a more robust approach using samples from the UK ME/CFS Biobank, in the hope that they have the potential to be used as a routine diagnostic test.

Projects not being completed in 2024-25

None

Impact and Scientific Publications

A widely accepted means by which the work of the charity can be assessed is to gauge the number of scientific publications emanating from specific projects. Since 2000, ME Research UK has awarded or agreed to award 73 specific grants, 4 PhD-level funding and a Fellowship totalling over £5 million, to research institutions in the UK, Austria, Australia, Belgium, Canada, France, Germany, Latvia, Spain, Sweden and the USA. The results of our studies are published as research papers in peer-reviewed scientific journals worldwide and are available to researchers globally.

Ten papers were published by researchers in the charity year 2024/25 (2023/24: four) acknowledging the support of ME Research UK.

- Byrne H, Knight SJ, Josev EK, Scheinberg A, Beare R, Yang JYM, Oldham S, Rowe K, Seal M Hypothalamus Connectivity in Adolescent Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Journal of Neuroscience Research, 2024; 102(10):e25392
- Thapaliya K, Marshall-Gradisnik S, Eaton-Fitch N, Barth M, Inderyas M, Barnden L Hippocampal subfield volume alterations and associations with severity measures in long COVID and ME/CFS: A 7T MRI study
  PLoS One, 2025; 20(1):e0316625
- Clarke KSP, Kingdon CC, Hughes MP, Lacerda EM, Lewis R, Kruchek EJ, Dorey RA, Labeed FH The search for a blood-based biomarker for Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS): from biochemistry to electrophysiology
  Journal of Translational Medicine, 2025; 23(1):149
- Van Campenhout J, Nijs J, Aerts JL, Buntinx Y, Laeremans T, Xiong HY, Wyns A, Hendrix J
  Unravelling the Connection Between Energy Metabolism and Immune Senescence/Exhaustion in Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
  Biomolecules, 2025; 15:357
- Giménez-Orenga K, Martín-Martínez E, Nathanson L, Oltra E
  HERV activation segregates ME/CFS from fibromyalgia while defining a novel nosologic entity
  eLife, 2025; 14:RP104441
- Samms GL, Ponting CP
  Unequal access to diagnosis of myalgic encephalomyelitis in England
  BMC Public Health, 2025; 25(1):1417
- Arcos-Burgos M, Arcos-Holzinger M, Matsronardi C, Isaza-Ruget MA, Vélez JI, Lewis DP, Patel H, Lidbury BA
  Neurodevelopment Genes Encoding Olduvai Domains Link Myalgic Encephalomyelitis to Neuropsychiatric Disorders
  Diagnostics, 2025; 15(12):1542
- Samms GL, Ponting CP
  Defining a high-quality myalgic encephalomyelitis/chronic fatigue syndrome cohort in UK Biobank
  NIHR Open Research, 2025; 05:39

- Beentjes SV, Miralles Méharon A, Kaczmarczyk J, Cassar A, Samms GL, Hejazi NS, Khamseh A, Ponting CP
  Replicated blood-based biomarkers for myalgic encephalomyelitis not explicable by inactivity
  EMBO Mol Med, 2025; 17(7):1868-91
- Nuzzo JL, Taylor JL, Latella C
  Muscle strength, muscle endurance, voluntary activation, and perception of effort in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): an overview
  Fatigue: Biomedicine, Health & Behavior, 2026; 14(1):42-60

Key Findings of ME Research UK researchers within the year

- Changes in connectivity in the hypothalamus were reported in adolescents with ME/CFS. The hypothalamus is a part of the brain responsible for controlling a wide range of processes in the body. (Project 15-040)
- People with ME/CFS and those with long COVID had larger volumes of several areas of the hippocampus, compared with healthy control subjects. The hippocampus is a brain structure involved in memory and learning. (Project 21-057)
- Human endogenous retrovirus (HERV) profiles could accurately distinguish between women with ME/CFS, those with fibromyalgia and healthy control subjects. These "HERV fingerprints" could therefore be valuable in the diagnosis of both conditions. (Project 20-054)
- Using hospital data, 0.25% of men and 0.92% of women in the UK are now estimated to have a diagnosis of post-viral fatigue - the diagnosis most closely matching ME/CFS. This suggests that 403,922 people in the UK have a diagnosis of post-viral fatigue. (Project 22-PhD002)

Prevalence rate for ME drawn from deCodeME redefined prevalence in UK and become de facto standard figure replacing NICE. Through a series of articles ME Research UK examined critically existing prevalence estimates and promulgated a new research-based figure of "at least 400,000" which is backed by ME Research-UK funded researcher evidence. This has now become a standard figure quoted by HM Government and the media.

- Variants in a number of genes were found to be significantly associated with ME/CFS.
  These genes are involved in several processes in the brain, including the generation of new neurons, and have been linked with the development of neurological conditions. (Project 15-042)
- Individuals with ME/CFS were shown to have reduced muscle strength, reduced muscle endurance and greater perceived effort during muscle endurance tasks.

It is also telling the number of ME Research UK-funded researchers who are asked to speak on research topics. Such invitations cement ME Research UK's reputation and demonstrate the charity's ability to fund the highest quality researchers.

- May 2025's Norges ME-Forening conference and ME/CFS Research Foundation's Conference were addressed by Prof. Carmen Scheibenbogen and Assoc Professor Robert Wüst.
- May 2025's 17th Invest in ME Research International ME Conference held near Cambridge, UK and 14th International Biomedical Colloquium were addressed by Prof Simon Carding.

- October 2025's IACFS/ME virtual Conference was addressed by Professors Leonard Jason, Carmen Scheibenbogen and Dr Luis Nacul.

The Trustees were heartened by the impact that PhD-level researchers have begun to have in their scientific field which bodes well for their careers but also the future of ME research.

PHD - 002 University of Edinburgh, UK

Experimental investigation of genetic risk factors for ME/CFS revealed by the DecodeME project.

- 2 first-author papers published
  Samms GL, Ponting CP. Defining a High-Quality Myalgic Encephalomyelitis/Chronic Fatigue Syndrome cohort in UK Biobank. NIHR Open Res. 2025 Apr 28;5:39.
  Samms GL, Ponting CP. Unequal access to diagnosis of myalgic encephalomyelitis in England. BMC Public Health. 2025 Apr 22;25(1):1417.
- 1 co-authored paper published
  Beentjes SV, Miralles Méharon A, Kaczmarczyk J, Cassar A, Samms GL, Hejazi NS, Khamseh A, Ponting CP. Replicated blood-based biomarkers for myalgic encephalomyelitis not explicable by inactivity. EMBO Mol Med. 2025 Jul;17(7):1868-1891.
- a further paper accepted for publication;
- an author on the DecodeME genetics pre-print;
- nominated to be one of '300 faces of Edinburgh Medical School'.

PHD - 003 La Trobe University, Australia

Cause-effect relationships in the mitochondrial energy inefficiency in ME/CFS

- Attended and presented on research findings at Young EMERG Symposium For Promoting the Advancement of Research Knowledge in ME (SPARK ME) and 14th International Biomedical Research into ME Colloquium
- Book Chapters
  Mitochondrial Measures in Primary Cells Isolated from Patients with ME/CFS. Authors Allan CY, Katsaros T, Missailidis D, Fisher PR, Annesley SJ in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Methods and Protocols pp203-223 (21 pages) Humana Press:

  Real-Time Measurement of Mitochondrial Function and Glycolysis in Lymphoblastoid Cell Lines. Authors Katsaros T, Missailidis D, Annesley SJ in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) pp173-202 (30 pages)

PHD - 004 Vrije Universiteit Brussel, Belgium

Mitochondrial dysfunction in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): are autonomic phenotypes necessary to clear conflicting results?

- Conference attendances/presentations: Young EMERG + 14th International Biomedical Research into ME Colloquium 2025 with poster presentation on both

- Publications: Van Campenhout, J., Buntinx, Y., Xiong, H.-Y., Wyns, A., Polli, A., Nijs, J., Aerts, J. L., Laeremans, T., & Hendrix, J. (2025). Unravelling the Connection Between Energy Metabolism and Immune Senescence/Exhaustion in Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Biomolecules, 15(3), 357. https://doi.org/10.3390/biom15030357
- Awards: Best Oral Presentation Award (3rd Belgian Pain Society Young Researchers Day 2025)

PHD - 005 Leicester University, UK

Impaired selective attention as a cognitive and neurophysiological markers of ME/CFS

- Attended European Conference on Visual Perception in Mainz, Germany in August 2025.

B. Informing

During 2024/25, the charity continued its role as an independent, science-centred provider of high-quality information and education for key decision-makers, healthcare professionals and those affected directly or indirectly by ME/CFS. In addition to the capacity to provide speakers for external events - to discuss ME Research UK's role, its achievements and to provide insight into current research and the research landscape for ME/CFS - ME Research UK also produces printed literature (leaflets and Breakthrough magazine) and embraces the opportunities afforded by new means of communication to remain relevant and at the forefront of research funding.

Our 'Breakthrough' magazine is provided free of charge to all who request it and is normally dispatched on a biannual basis, in both hard and electronic form. The magazine not only informs the reader of the charity's newly funded research but also describes and interprets the results of ME Research UK projects.

Breakthrough also reports non-ME Research UK published studies that are presented in a form which aims to ensure that readers have a holistic perspective of worldwide research and of findings which may be relevant to them. The magazine is also available online ensuring as wide a readership as possible without any barriers to access. It is often cited as being especially useful to people with ME/CFS when speaking to GPs, nurses and other healthcare professionals about their symptoms. To expand its breadth and bring a new voice to our communications, the Trustees contracted with Cort Johnston, the highly regarded writer and creator of the influential Health Rising blog, to contribute articles to Breakthrough and the charity's website. The international view and research sectoral review adds significantly to the scope of ME Research UK's output.

Our Facebook page (MEResearchUK) strives to balance postings relating to fundraising activities of our active supporters with a more scientific focus with summaries of the most important worldwide research into ME/CFS and news of ME Research UK funded projects. In this way, those affected by ME/CFS can be kept abreast of recent developments. This, it is believed, results in a lively but informative realm that is both engaging and educational. Where possible, postings link back to the charity's main website thus driving traffic to one of our central resources and providing a route by which the casual visitor could become more engaged with our work and our cause. Since its launch in July 2012, our Facebook page has amassed 20,930 (14,293 in previous period) followers - an increase of 46% over the charity year (15.8% in previous period) - and is viewed regularly worldwide. It has steadily increased the audience for postings, created a community of regular commentators and provides a platform from which we can connect to supporters both old and new. In fact, over the year, there were over 153,000 content interactions - an increase of 156% year-on-year.

ME Research UK's active X (Twitter) account further drives the successful dissemination of our research news and it will act as an additional avenue to engage more fully with potential donors and create a new community of supporters. With 5,603 followers (2023/24 - 5,249), representing an increase of 6.7% (28.3% in previous period) the facility has proved to be a useful, extra avenue for engagement with the ME community. In August 2023, the charity launched an ME Research UK - Researcher Zone X/twitter account to cater for the distinct needs of researchers. This feed provides links to new research, funding opportunities, meetings, conferences and the like as charity seeks to raise its profile amongst researchers at all stages in their careers. At year end, it had 282 followers (2024/25 - 231), representing an increase of 22.1%.

In addition, due to the impetus of the Science & Written Communications Officer, ME Research UK's Instagram account was reactivated and now has 3,286 followers (2023/24 - 1,415) representing an increase of 132%. Posts were viewed over 435,000 times with a 100% increase in content interactions to 22,200.

A LinkedIn account was also created during October 2024 to widen the scope of distribution of ME Research UK's output. In the last year it has amassed 262 followers (20 in previous year).

Due to the sustained increase in written output, the charity actioned its long-held goal of launching a monthly e-newsletter to supporters with links to the most popular articles produced during the month and providing various ways in which engaged supporters could donate to the work of the charity.

Increasingly, researchers require to be involved in public awareness initiatives as a facet of their work. Conferences, online events, and public interaction at all stages of research provide the opportunity to raise awareness of ME/CFS and of ME Research UK. Funding, especially PhD-level research, provides new avenues for dissemination of ME/CFS information as well as ME Research UK's work through the social media and other efforts of young researchers. It was against this background that the Founders Award was devised.

As disclosed previously, during ME Awareness Week, we arranged for landmarks throughout the UK to be bathed in blue. This proved to be highly effective on social media in raising awareness of ME/CFS but also of the charity with a number of the building owners sharing pictures internally and carrying them on their own social media.

A major item of work being a review of prevalence rates in ME/CFS. The resultant papers identified and critiqued existing prevalence rates and pointed out limitations, restrictions and features which cast doubt on their future use. This highly popular series of papers by our Science Writer and Research Engagement Officer, laid the foundations for an updated stance on prevalence figures based on ME Research UK-funded PhD-level research.

C. Influencing

Highlights of the charity year included -

- widespread media, charity sector and official recognition of an increased prevalence figure for ME/CFS arising from PhD-level research funding from ME Research UK. The research and prevalence figure referenced by Dept for Health & Social Care in the Delivery Plan replacing the NICE guideline's figure and on the BBC.
- ME Research UK supporting calls for creation of internationally recognised and operationalised research criteria for ME. In doing so, it joined leading researchers, clinicians, fellow charities, patients, advocates, and supporters from across the globe.
- the charity being an active participant in the Department for Health and Social Care's ME/CFS Delivery Plan under the auspices of the UK Clinical Research Collaboration's ME/CFS Research Subgroup. This structure being part of the former Secretary of State's initiative and reports directly to the Chair of the UKCRC, and to the ME/CFS Delivery Plan Task and Finish Group. ME Research UK is a participant in the funder-led sub-group 'Building capacity and capability in the research community'.
- ME Research UK attending workshops on Post-Exertional Malaise (PEM), under-served groups and drug repurposing as part of the Research Subgroup.
- through membership of Forward-ME, ME Research UK influencing the grouping's contributions to other areas of the Secretary of State for Health and Social Care's initiative - namely the overarching ME/CFS Delivery Plan Task and Finish Group and the Working Group sub-committees on Attitudes and Education, and Living with ME/CFS.
- Forward-ME is also a partner in DecodeME the world's largest ME/CFS study which seeks, through the recruitment of 25,000 people with ME, to see whether the disease is partly genetic and, if so, help pinpoint what its causes are. The study should help researchers understand the disease and ultimately find treatments. In addition, Forward-ME is also a member of the World ME Alliance.
- increased contact with ME Research UK grant holders and potential funders to raise the profile of the charity.
- collaborating with the ME Association to co-fund a project (Project 24-71) at Brunel University, London.
- through the efforts of the Chair and Vice Chair, discussing with other organisations the research landscape and scope for collaborative working and a more pro-active approach to research project funding.
- funding the poster competition at IACFS/ME October 2025 Conference.
- reaching out and holding meetings with MSPs and MPs on the Delivery Plan and the plight of research funding in the UK.

- creating of a Research Circle. The Circle is aimed (initially) at PhD-level students working on projects funded by ME Research UK charity, and :
  - Creates an online space for students to network and learn about each other's work.
  - Provides an opportunity for skill development through talks given by members of ME Research UK staff, from established researchers in the field, and from other relevant experts.
  - Provides a friendly forum to discuss challenges faced, to practice presentations, and to lay the foundations for future careers.
  - Fulfils ME Research UK's aim to create an environment to encourage, support, and to facilitate the entrance and retention of early-career researchers in the field of ME/CFS research.

Through the funding of PhD-level research, we facilitate the forging of bold, new researchers whose career progression will impact the research field for decades.

Overall, 2025 has seen the charity both deliver and continue its focus on informing, influencing and investing in ME research.

Structure, Governance and Procedures

Governance and Management

At quarterly Trustees' meetings, the Trustees agree the broad strategy and areas of activity for the charity, including consideration of grant making, investment, reserves, risk management, policies and performance. The day-to-day administration of grants and the processing and handling of applications, prior to consideration by the Trustees, is delegated to the Director of Research & Communications.

The Board of Charity Trustees exercise operational planning responsibilities.

Recruitment and Appointment of New Trustees

In terms of the Constitution, new Trustees are appointed by the Board of Charity Trustees acting by a majority decision. Application for appointment as a Charity Trustee is open to any individual aged 16 and over, whose skills, experience and qualifications are in accord with the charity's purposes. Prospective Trustees are required to complete and to sign a written application in such form as the Board of Charity Trustees may decide; completed applications are considered at the next scheduled Board meeting after receipt of the form.

No person, whether natural or legal, has the power to appoint a Trustee to the Board of ME Research UK.

During the charity year 2024/25 ME Research UK welcomed Mrs Lesley Carr as a returning Trustee.

The Board of Charity Trustees welcomes new applications but is acutely aware that applicants must contribute towards the good management of the charity and ought to enhance the capabilities of the Board. The Board of Charity Trustees therefore considers applications against the skill-set required for the proper functioning and evolution of the charity.

Grant Making Policy and Procedures

ME Research UK has established its grant making policy to achieve its objectives for the public benefit. Any private benefit received by researchers, and research institutions and other bodies is purely incidental to the objects of our work. Policies and procedures are reviewed regularly and aim to ensure that research grants are awarded to projects which are scientifically sound, fall within the charity's purposes and have justifiable costings.

The charity actively encourages applications for pilot studies and seed-corn projects concerned with novel aspects of research into ME/CFS.

To support its aims, ME Research UK accepts both formal applications and informal funding queries. Once an application is received core members of the Science Committee undertake an initial assessment to ensure alignment with the call for funding and that the research is in conformity with ME Research UK aims. Thereafter applications are subject to peer review (including review by external experts). The peer review reports are collated and considered by the Science Committee which assesses the application, the peer review results (which include a standardised scoring system), and the charity's research objectives. Any queries are referred to the applicants before the Science Committee arrives at a decision of whether or not to recommend funding to the Board of Charity Trustees. The final decision on whether to fund lies with the full Board.

In the current year, a number of grant applications were unsuccessful either that, upon peer review and Science Committee input, they were deemed to fall out-with ME Research UK's charitable objectives or that their research methodology or submitted expenses did not meet the requisite standards. Through careful scrutiny of applications - the scientific basis of the submission, the itemised costs - ME Research UK strives to ensure proper and rigorous safeguards for the stewardship of funds under its control.

The 2020 Science Committee Plan was put into effect aiming to streamline the awards process; capture key data; focus the applicants' proposals; introduce application deadlines and key time indicators. The alterations further professionalise the charity's operations and provide the structure to allow it to operate effectively in best interests of its supporters. Upon reviewing the implementation of the plan, the Science Committee consider the changes to have made a positive impact on their work and also for researchers as they provide certainty as to requirements and timescales. Further improvements are required as the Science Committee workload increases in volume and complexity and additional resources will be required. The additional experience and insight of the Research and Science Lead will aid greatly the work of the Committee.

ME Research UK's Standard Grant Conditions provide that all payments of research funding are dependent upon satisfactory proof of research progress. Longer term projects i.e. those in excess of 1 year, are subject to regular (normally 6-monthly) progress reports. The charity therefore ensures that grant monies which have been given are utilised in line with the charity's purposes and that progress merits payment of further instalments of financial assistance.

ME Research UK endorses the position of the Association of Medical Research Charities as regards university funding, and ME Research UK-sponsored projects are conducted in accordance with the principles outlined in the Declaration of Helsinki, and approved by local research ethics committees as appropriate.

On PhD level research funding, applications must be made via the Institution concerned to ensure charity funds are protected. The charity funds the research and so the proposal progresses through the normal stages in our review process.

ME Research UK does not agree to fund research without having sufficient funds available to satisfy its liabilities.

Grant Making Objectives

Through funding studies at recognised Institutions worldwide, ME Research UK-funded projects enrich the scientific literature of ME/CFS and have the ultimate aim of helping those affected directly or indirectly by ME/CFS and those who may develop ME/CFS in the future. The research we fund helps lay the foundation for further research in an area that is under-represented in scientific research and where replicated and larger scale studies are rare. ME Research UK believes that, by providing albeit small scale funding to research projects, momentum will build and lead ultimately to large scale research through the involvement of major governmental and private philanthropic bodies. Once the mechanisms of the disease are understood, more effective treatment and ultimately hopefully a cure will follow.

ME Research UK, through its website, publications, attendance at conferences and contacts worldwide, invites applications for research grants. Having the name of the charity noted in the 'Funding Acknowledgment' section of scientific papers is an important way of bringing ME Research UK to the attention of other scientists. In the current year, all the projects accepted for funding were the result of our 'Call for Funding Applications' which went to researchers across the world. Full applications received are peer reviewed by independent researchers with specialist knowledge of the area, subject to the funding requested.

ME Research UK only funds projects at established institutions - such as universities, research centres and NHS hospitals (or equivalent overseas) - to ensure that, in the case of non-compliance with the terms of the research award, charity funds are protected and recoverable. Research grant instalments are normally paid only upon receipt of regular progress reports, which are reviewed against the requirements of the prevailing research award by the Research & Communications Director.

By careful, structured and objective consideration of applications and a prudent approach to payment of research monies, ME Research UK ensures high standards of care of the funds entrusted to it. Details of the application process, together with relevant forms are available on the charity's website - www.meresearch.org.uk

Monitoring Achievement

Research is assessed by the completion of approved research projects within the planned timescale for the project and of publication of the results in peer-reviewed journals. Longer-term consequences of the research are more difficult to assess but published papers build a critical mass of information in the scientific literature. In addition, our funding lays the foundation for future work by allowing researchers to acquire pilot data on which to base applications to larger, often governmental, funding bodies.