# ME Research UK

Scotland · Charity number SC036942

## Details

| | |
|---|---|
| **Status** | Active |
| **Legal form** | SCIO (Scottish Charitable Incorporated Organisation) |
| **Registered** | 2005-10-06 |
| **Register** | View on the OSCR register |

## Contact

| | |
|---|---|
| **Address** | Morris & Young<br>6 Atholl Crescent<br>Perth<br>PH1 5JN |
| **Website** | www.meresearch.org.uk |

## Activities

**Activities:** 'It makes grants, donations or gifts to organisations','It carries out activities or services itself'

**Purposes:** 'the advancement of education','the advancement of health','the advancement of the arts, heritage, culture or science'

**What the charity does:** To fundraise for and to fund biomedical research into the causes, consequences and treatments for ME/CFS. Charity provides information on research findings as well as information on the disease and the importance of research. The aims are achieved by providing research grants and provision of information via social media and print.

**Beneficiaries:** 'No specific group, or for the benefit of the community'

**Objectives:** To advance scientific knowledge by commissioning or funding research into the causes, consequences and treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) or any other related illnesses, and to publish or cause to be published the results of any such research. To advance public education and awareness of the causes, consequences and treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) or any other related illnesses, and of the need for research into the condition, by producing printed or electronic information, funding or hosting scientific meetings, and acting as a key information resource for researchers, medical practitioners, healthcare professionals and the general public.

## Geography

- **Main operating location:** Perth And Kinross
- **Geographical spread:** UK and overseas

## Finances

| Period end | Income | Expenditure | Assets | Employees |
|---|---|---|---|---|
| 2025-10-31 | £877,131 | £1,078,262 | - | 6 |
| 2024-10-31 | £364,816 | £511,226 | - | 5 |
| 2023-10-31 | £516,571 | £1,218,726 | - | 5 |
| 2022-10-31 | £754,257 | £608,081 | - | 4 |
| 2021-10-31 | £612,152 | £713,330 | - | 3 |

**ME Research UK**

Scotland - Charity number SC036942

# Accounts

You fund small pilot studies that give researchers the data they need to approach the big boys. How effective that approach is has been borne out in the many prominent ME/CFS researchers (David Systrom, Bhupesh Prusty, Chris Armstrong, Leighton Barnden, Amy Proal) and scores of young researchers who have been able to keep their ME/CFS work alive via small pilot grants." Of these, ME Research UK has funded 3 of the 5 exemplars - Bhupesh Prusty, Leigh Barnden and Amy Proal.

This puts our work in context - hence through the provision of funds, we aim to -

- Be an accessible source of finance for scientifically sound research from researchers (normally) at the beginning of their careers.
- Fund projects, the results of which produce findings to enrich the research-world's understanding of ME/CFS.
- Generate data for larger studies or to build upon for applications to central funding bodies e.g. United Kingdom Research and Innovation/Medical Research Council.
- Encourage new researchers into ME/CFS research.

ME Research UK's charitable activities in the current period resulted in a further investment of £866,328.80 (2023/24: £349,693.50) covering 6 ME/CFS research projects in 4 countries (Australia, Latvia, Belgium and UK) plus a Fellowship and including an offer to fund of £153,624.30 made before 31st October 2025.

This level of commitment is consistent with the charity's objectives and is judged to be manageable within the charity's overall financial position. The policy to never agree to fund projects unless funds are available engenders trust between the researchers and the charity and has proven to be a sound financial principle in the most trying of circumstances.

A total of 27 (2023/24: 28) outline research proposals were received in the year and were reviewed with 4 applications which were carried over from the previous year. These included a project jointly funded with the ME Association, and our first Daphne Jackson Trust Fellowship (jointly funded with the NIHR/MRC).

The size and complexity of the applications mean additional scrutiny is required in order to ensure charity resources are expended wisely and that the tangible benefits to the research field and to people with ME are capable of being ascertained and quantified.

ME Research UK is heartened by the geographic spread of applications for funding received within the year,the diverse range of research topics and the number of applications themselves.

The number of applications bodes well for progress in research in 2025/26 and for the reputation and future evolution of the charity beyond the current year.

In August 2025, ME Research UK in conjunction with the Daphne Jackson Trust, awarded a Fellowship. The aim being to further deepen the pool of ME researchers and research in the UK by enabling post-doctoral researchers to return to their profession after a hiatus through health or other issues.

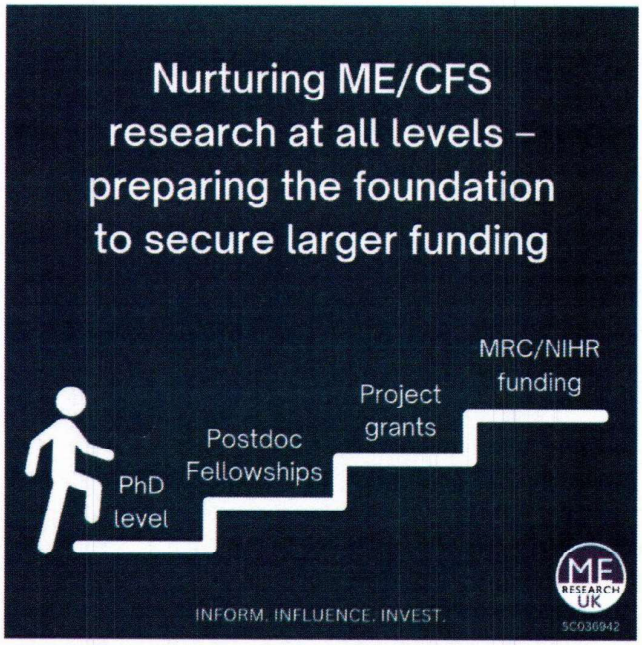
## ME Research UK

## Trustees' Report

**From PhD-level research, post-doctoral fellowships and to project funding, ME Research UK is the only UK charity with laser-like focus on research through the various stages of research globally. With these initiatives, ME Research UK has now funded over £5m of high-quality ME research since its inception in 2000.**

**Uniquely, step-by-step ME Research UK is helping to build the research infrastructure which has been absent for decades.**

**ME Research UK - Delivering Research: Delivering Results.**




ME Research UK wishes to thank the members of the Science Committee (including volunteer peer reviewers) for their dedication throughout the year. Due to the additional resources available (for example from The Gordon Parish Charitable Trust and The Fred and Joan Davies Bequest), the charity has attracted an increased number of high-quality applications from notable sources globally and for sums which demand additional scrutiny. Also, the increased knowledgebase of the disease and tools/methods available to researchers mean a high degree of skill and knowledge is required by Science Committee members and peer reviewers. Plans to streamline the review progress have been implemented with the result that applicants, and Science Committee members have a set schedule of work and are able to concentrate on progressing applications swiftly with the high degree of rigor for which the charity is renowned.

Maintaining the capacity within the Science Committee and access to appropriate peer reviewers remains an area of focus for the organisation in order to ensure the level of scrutiny which the charity prides itself upon is maintained.

With the substantial funds available from recent legacies largely invested in research, the charity is excited with the potential new findings which the investments may provide. The Trustees have decided to concentrate charity income next year on funding a PhD level research award, a Fellowship, and such high-quality research projects annually as funds permit. Vigilant to the challenges surrounding funding, the charity recruited a Donor Relations Officer in February 2025 whose role is to maximise the charity's fundraising potential.

In summary, ME Research UK has 16 ongoing studies, including 6 newly funded projects and 3 PhD-level research projects, and these represent more than £2 million currently invested in ME/CFS research globally. The research for which we have recently awarded funding covers a number of areas of interest, including 2 studies looking at immune abnormalities, 2 investigating genetic factors, and 2 looking at biomarkers and diagnosis. The total value of awards given since 2000 is now more than £5 million.

**New Research Projects in 2024/25**

**Project - 24-069**

Sarah Annesley, La Trobe University, Australia
Do MicroRNAs regulate platelet activation and associated metabolic dysfunction in women with ME/CFS?
£211,624

Dr Annesley's new study is looking at microRNA profiles and their impact on platelet function and energy production in women with ME/CFS. Dr Annesley explains, "Our early research has found that certain microRNAs are altered in people with ME/CFS - and some of these changes are in microRNAs that control the expression of proteins related to energy production and platelet function. In this new project, we'll study blood samples from women with ME/CFS and compare them to healthy controls to look for differences in microRNA profiles. We'll also test whether these changes in microRNAs can actually cause changes in platelet activity and energy production using cellular models. If our hypothesis is correct, it could open the door to new treatment possibilities - including therapies based on microRNAs, which are already being explored for other illnesses."

**Project - 24-070**

Bhupesh Prusty, Riga Stradins University, Latvia
Dissecting the mechanism of immunoglobulin-mediated alterations in ME/CFS using single-cells to organoids
£210,000

Prof. Bhupesh Prusty is investigating the role of autoimmunity in ME/CFS. Following on from his previous work, Prof. Prusty will look at the mechanisms through which immunoglobulins from ME/CFS patients can cause dysfunction of the mitochondria (which are responsible for generating energy in cells). As well as providing a better understanding of the role of autoimmunity in ME/CFS, the findings may also help in the design or selection of suitable treatments for the disease.

### Project - 24-071a

Funded by the Gordon Parish Charitable Trust
Andrea Polli, Vrije Universiteit Brussel, Belgium

Unravelling immune exhaustion, immune senescence, and their contribution to Myalgic Encephalomyelitis / Chronic Fatigue Syndrome
£130,830

### Project 24-071b

Funded by the Gordon Parish Charitable Trust
Lode Godderis, Katholieke Universiteit Leuven, Belgium
Unravelling immune exhaustion, immune senescence, and their contribution to Myalgic Encephalomyelitis / Chronic Fatigue Syndrome
£18,000

This study will explore whether the immune system in people with ME/CFS is exhausted by prolonged activation (so called immune exhaustion) or whether it is weaker and vulnerable (so called immune senescence). In both cases, the cells of the immune system are likely dysfunctional and cannot really use energy to function. Therefore, the researchers will also study how these cells produce and use energy, and how that links to immune exhaustion and senescence.

### Project 24-072

Joint funding with the ME Association
Jacqueline Cliff, Brunel University London, UK
The electrophysiology of ME/CFS: advancing the electrical model of PBMCs for aetiology and diagnosis
£76,989.50

This study builds on a previous 12-month study exploring electrical differences in blood cells from people with ME/CFS, which showed that two biomarkers have potential for distinguishing ME/CFS patients from other groups. This next phase will refine and expand the initial work, testing a larger, more diverse group of patients, and improving how samples are prepared and testing. As well as giving us deeper insights into the biology of ME/CFS, the researchers hope the findings will move us closer to a reliable and low-cost diagnostic test.

### New Fellowships in 2024/25

### Fellowship 24-FEL001

Daphne Jackson Trust Fellowship - joint funding with the MRC
Alkisti Manousaki, University of Leicester, UK
Decoding the female bias in ME/CFS at the molecular and cellular ultrastructural level
£61,605.51

In partnership with the Daphne Jackson Trust and Medical Research Council, this fellowship was awarded to Dr Alkisti Manousaki for a project investigating the genetic and cellular clues that may explain why ME/CFS affects more women than men. Dr Manousaki's research will test the idea that, in ME/CFS, X chromosome inactivation in women is not being maintained correctly. This could lead to abnormal levels of certain X-linked genes, disrupting immune balance and energy production in cells. She explains, "Understanding the molecular differences in how ME/CFS affects men and women could be key to unlocking its underlying biology. By combining advanced genetic analysis with cutting-edge imaging, I hope to identify the mechanisms driving symptoms and point the way towards earlier diagnosis and more targeted therapies."

**New PhD Projects in 2024/25**

None

**Ongoing Projects in 2024/25**

*Initiated in previous financial years, and payable (subject to progress) in 2025/2026 - Sums due represent total funding commitment.*

***Research studies***

**Project - 18-047**

Jarred Younger, University of Alabama at Birmingham, USA
Tracking peripheral immune cell infiltration of the brain in ME
$134,516.70 (£113,900.68 at date of conversion to US$)

The central hypothesis behind Prof. Younger's project is that activated immune cells infiltrate the brain of ME/CFS patients causing neuroinflammation and symptoms such as fatigue, pain sensitivity, cognitive problems and sleep disturbances.

The team plans to track radio-labelled peripheral immune cells using positron emission scanning to see whether they do indeed break the blood-brain barrier and infiltrate the brain. The project will be carried out in 15 women with ME/CFS and 10 age-matched healthy control women, who will be scanned at 24 hours and then 96 hours following injection of the labelled cells. As well as advancing our understanding of the pathogenesis of ME/CFS and the role of the immune system, the results of this study may indicate whether neuroinflammation is a worthwhile target for treatment of the illness, and even help in establishing a diagnostic test that can distinguish between patients and healthy control subjects.

**Project -21-055**

James Allison, Newcastle University, UK
EluCidATe: Exploring pain and autonomic dysfunction in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis and Temporomandibular disorders
£13,576

Widespread pain is a problem for people with ME/CFS and impacts on everyday activities. In particular, a group of musculoskeletal conditions affecting the muscles that move the jaw, temporomandibular disorders (TMD), are more common in ME/CFS and cause pain in the face and jaws. The grant holder's research suggests that one reason for the link between ME/CFS and TMD may be that they have a similar underlying problem affecting the autonomic nervous system (ANS), which controls many unconscious activities such as breathing and circulation. The ANS is known to work less well in ME/CFS and this is worse still when TMD is also present. To investigate the contribution of the ANS to painful symptoms, the researchers will examine brain responses to, and subjective experience of experimentally induced pain in four groups of people: 1) ME/CFS only; 2) ME/CFS who also have TMD; 3) TMD only; and 4) Healthy participants with no ME/CFS and no TMD.

To examine brain responses, the researchers will use electroencephalography which measures electrical activity from the scalp. Examining the brain's response to painful pressure applied to different body regions (finger and jaw) in each of these groups will help understand how pain differs in ME/CFS to in other people, and where in the brain these differences are located. They will also investigate whether they can "calm" the ANS using non-invasive stimulation of the vagus nerve (part of the ANS) and measure the effect this has on both brain activity and levels of pain. The study will inform future treatments for ME/CFS by identifying where in the brain differences in response to pain occur, what part the ANS plays, and by understanding why some people might differ in their response to treatment.

**Project -22-059**

Amy Proal, PolyBio Research Foundation, Medford, MA, USA
Use of advanced metagenomic technologies for the identification of viruses in ICC-diagnosed ME/CFS patient tissue and nerve biopsy samples
£162,350

It is possible that polio-type and related viruses connected to ME/CFS do not "clear" from patients after acute infection, but remain in a persistent state. If that is the case, it is important to search for such viruses in samples beyond just the blood. That is because the viruses most connected to ME/CFS - especially the polio-type enteroviruses and herpesviruses - can infect nerves and "hide" in tissue. New computer-based technologies have been developed to identify viruses in human samples, including novel viruses that earlier techniques might have missed. The goal of this project is to use these technologies to search for viruses in two types of samples collected from ME/CFS patients: 1) Tissue/nerve samples obtained from the ankle via punch biopsy, which contain tissue and pain-associated nerves called C fibres; and 2) Stomach tissue/nerve samples obtained via endoscopy. The investigators will compare any viruses identified in the ME/CFS samples to those in similar samples obtained from healthy people.

**Project -22-060**

Simon Carding, Quadram Institute, Norwich, UK
Gut eukaryotic viruses as a player in ME/CFS
£123,874

Disturbances of the gut microbiome are seen in numerous human diseases including ME/CFS, where many patients also suffer from gut disorders. To date, most gut microbiome studies, including those on ME/CFS, focused on bacteria, ignoring or excluding viruses (the virome). However, viruses living or gaining access to the body via the gut have long been associated with ME/CFS. Gut virome studies have identified striking alterations in virus type and/or numbers in patients with colon cancer, inflammatory bowel disease, diabetes and Parkinson's disease, with evidence suggesting this may also be true for ME/CFS. These studies in ME/CFS have focused on specific virus families, but excluded others with more pathogenic potential. The investigators plan a comprehensive analysis of the intestinal virome of ME/CFS patients enrolled in a clinical trial microbiota transplantation therapy (MRT). The study aims to: 1) Define the virome of ME/CFS patients and identify "signature viruses" which can be distinguished as a new biomarker of disease; and 2) Establish the impact of MRT in those patients who respond positively to such treatment, by looking at any loss of identified "signature viruses", as well as evidence of reactivation of latent viruses.

**Project -23-061**

Dr Eliana Lacerda & Prof. Geraldine Cambridge, London School of Hygiene and Tropical Medicine & UCL, UK
Antibody Discovery using Novel Microarray of Functional Proteins in patients with Myalgic Encephalomyelitis/Chronic Fatigue syndrome: a pilot study
£63,899.00

One potential explanation for many of the features of ME/CFS is that the body's immune system is attacking damaged proteins, some of which are involved in generating energy. These proteins may be damaged by an excess of toxic molecules (reactive oxygen species). An immune response is characterised by the production of antibodies, and Dr Lacerda and Prof. Cambridge plan to analyse the pattern of antibodies in samples from patients with moderate and severe ME/CFS (from the UK ME/CFS Biobank), linking them to changes in specific proteins. Their results may form the basis of new diagnostic tools for the disease, including stratification of patients based on severity.

**Project -23-062**

Dr Zack Shan, University of the Sunshine Coast, Australia
Non-invasive MR imaging of chronic neuroinflammation in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)
£415,737.00

Dr Shan and his colleagues are conducting the world's first controlled study directly assessing neuroinflammation in the brains of people with ME/CFS. Neuroinflammation occurs when the brain's immune system is activated, and this is believed to play an important role in ME/CFS. The team's advanced imaging techniques mean they can now analyse several aspects of this, including microglia and astrocytes (the immune cells of the brain), the lymphatic system, and various neurometabolites. Their results will provide evidence of whether neuroinflammation is a factor in ME/CFS, which could point to specific treatments.

**Project -23-065**

Prof. François-Jérôme Authier, Henri Mondor University Hospital, France
Neurocognitive impairment in Myalgic Encephalomyelitis (ME): Neuropsychological evaluation and functional brain imaging study - COGNIME 2022
£129,900.00

Cognitive problems (affecting memory, concentration, reading, etc.) are a common, disabling symptom of ME/CFS, and Prof. Authier and his team are investigating how these abnormalities are related to functional changes in the brain. The group will carry out a comprehensive neuropsychological evaluation and functional brain imaging in patients with ME/CFS, in order to look at the correlations between them. In particular, they are exploring whether a specific pattern of brain hypometabolism (seen in many neurodegenerative diseases) may be used as a biomarker for ME/CFS, and whether patients can be stratified according to the severity of impairment.

**Project - 24-067**

Leighton Barnden, Griffith University, Australia
A multimodal longitudinal 7 Tesla MRI study to investigate brain changes and disease progression of ME/CFS patients
£217,487

Prof. Barnden and colleagues have previously identified a number of abnormalities in the brains of people with ME/CFS and long COVID. In this new study, the group plans to use 7-Tesla MRI to track the progression of these brain abnormalities - as well as their association with clinical symptoms - in 40 people with ME/CFS over the course of 3 years. They will also assess 40 healthy individuals over the same time, as a control group. The parameters will include cortical volume, thickness and white matter; networks of brain activation and functional connectivity; myelin and iron dysregulation; myelin and axonal integrity; and levels of various neurochemicals linked to neuroinflammation in the brain.

**Project - 24-068**

Rob Wüst, Vrije University Amsterdam, the Netherlands
Skeletal muscle microclots and microvascular pathophysiology in ME/CFS
£100,000

Symptoms affecting the muscles are one of the key features of ME/CFS. Muscle pain, weakness and fatigue cause significant suffering, and can severely limit individuals' day-to-day activities and quality of life.

Dr Wüst and colleagues aim to collect skeletal muscle biopsy samples and venous blood samples, before and after the induction of post-exertional malaise, from 25 people with ME/CFS, as well as from patients with long COVID and healthy control subjects. Immunofluorescence techniques will be used to identify and assess the location of microclots in the muscle and in blood samples, and to correlate these with the presence of clinical symptoms. Electron microscopy will also be performed to assess the structure of the capillaries and mitochondria in the skeletal muscle fibres. A third aim is to look for markers in the blood that indicate muscle tissue stress, and to determine whether these correlate with abnormalities in muscle tissue structure.

**Offered but not yet accepted**

**Project - 24-073**

*Funded by E M Thompson*

Chris Ponting, University of Edinburgh, UK
Creating an accurate biomarker panel for myalgic encephalomyelitis
£153,624.30

In recent unpublished research, the researchers discovered hundreds of protein, lipid and cellular blood traits that differ significantly between ME cases and controls. Importantly, 115 traits were replicated, and each was significant for both female and male cohorts. The aims of this new study are to replicate these previous associations in a new cohort, and to define a restricted set of blood molecules that accurately predicts an ME diagnosis. They aim to develop a blood trait model that can distinguish between ME/CFS cases and controls, and the findings may also aid in patient stratification.

**PhD-level research projects**

**22 -PHD - 002**

Chris Ponting, University of Edinburgh, UK
Experimental investigation of genetic risk factors for ME/CFS revealed by the DecodeME project
£92,193.68

DecodeME is a genome-wide association study (GWAS) which aims to look for locations on the genome with DNA changes that are significantly different between ME/CFS patients and healthy control subjects, and which may therefore be associated with an increased ME/CFS risk. The aim of this PhD project will be to identify which specific genes are involved, what types of cell are affected by those genes, and how those changes may lead to alterations in cellular function in people with ME/CFS. Firstly, the researchers will identify which dysfunctional genes highlighted by the GWAS are most likely to contribute to the risk of ME/CFS. Then they will investigate the impact of these genetic changes in more detail by looking at their effects on the function of the cells involved.

**22 - PHD - 003**

Sarah Annesley, La Trobe University, Australia
Cause-effect relationships in the mitochondrial energy inefficiency in ME/CFS
£66,363

The investigators have previously identified key changes in the way that ME/CFS cells make energy, specifically a decrease in energy production efficiency and activation of a major stress-sensing protein (TORC1). This combination of changes can accurately distinguish ME/CFS patients from healthy controls. The aim of this new study is to look at the interaction between these changes, and determine which event comes first and potentially causes the other defects. This will identify which proteins or processes could potentially be targeted for treatment, while understanding this cause-and-effect relationship may also help in predicting the effects of these treatments.

**23 - PHD - 004**

Prof. Jo Nijs, Vrije Universiteit Brussel, Belgium
Mitochondrial dysfunction in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): are autonomic phenotypes necessary to clear conflicting results?
£174,459.00

Prof. Nijs and colleagues are investigating the relationship between two features of ME/CFS thought to contribute to its symptoms. Dysfunction of the mitochondria (responsible for energy production in cells) may be an important factor in the disease, while there is also evidence of abnormalities in the autonomic nervous system (which controls heart rate, circulation, etc.). This PhD project will compare mitochondrial function between groups of ME/CFS patients divided according to the autonomic symptoms they experience. As well as understanding the disease process better, subgrouping patients could help improve diagnosis and selecting treatments.

**23 - PHD - 005**

Douglas Barrett, Leicester University, UK
Impaired selective attention as a cognitive and neurophysiological markers of ME/CFS
£81,966.00

Individuals with ME/CFS often report visual overload, difficulties filtering relevant from irrelevant visual information, and fatigue during visual search. Despite the prevalence of these symptoms, little is known about the way ME/CFS impacts sufferers' ability to perceive and prioritise objects and events in the visual scene. This studentship will provide a detailed description of the impact of ME/CFS on perceptual and cognitive processes that are essential for everyday visual function and develop novel diagnostic markers of the syndrome and its severity. The work addresses an urgent clinical need to identify and evaluate objective measures of sensory and cognitive impairment in ME/CFS, which will aid diagnosis and the evaluation of treatment outcomes.