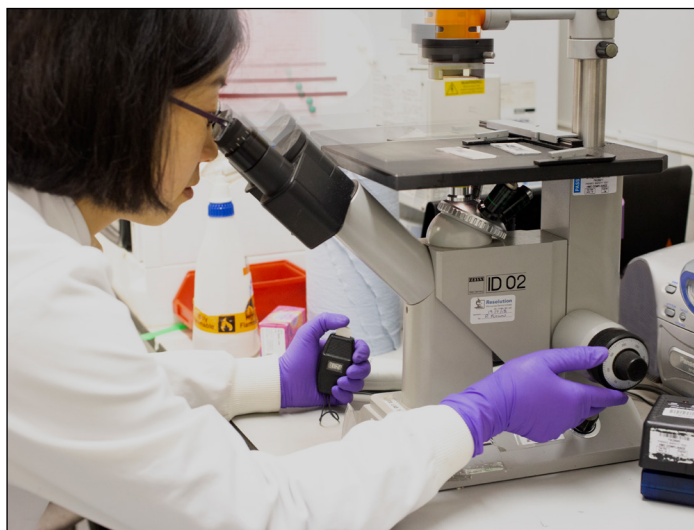


RAMSAY RESEARCH FUND

The ME Association has always regarded the promotion and funding of biomedical research to be a key priority and we have invested more than £1million in recent years. In 2019/20 we announced an additional £200,000 in three new studies.

We fund research through the Ramsay Research Fund (RRF) which was named after Dr Melvin Ramsay who brought the neurological disease M.E. (myalgic encephalopathy/encephalomyelitis) to the attention of the medical profession in 1955.

Dr Ramsay also helped establish the ME Association which was founded in 1978 and he remained closely involved with the charity until his death in 1990.



What sort of research do we fund?

We invest only in biomedical research studies and infrastructure projects that will help lead to:

- A better understanding of underlying disease mechanisms,
- The development of reliable diagnostic tests for use in surgeries and clinics,
- Safe and effective forms of treatment.



ME/CFS is a complex multisystem disease with symptoms that cut across several medical boundaries – genetics, endocrinology, immunology, muscle pathology, and neurology in particular – so research into the underlying cause of ME/CFS is rather like piecing together a complex medical jigsaw puzzle.

We actively seek researchers who will examine these underlying disease mechanisms. This must be our top priority if we are to obtain a better understanding of this disease and discover effective forms of treatment.

- We have also provided funding from general funds for selected studies that analyse patient survey evidence relating to illness management approaches and that critically review the so-called biopsychosocial model.

These studies have been led by Dr Keith Geraghty from the University of Manchester.

Additional information:

For more information about M.E. and the recent advances in research and understanding, please refer to our other **FREE** factsheets below:

[What you need to know about M.E.](#)

[The M.E. Research Summary](#)

ME Association Index of Published Research

- This is an A-Z index of the most important research studies, selected key documents and articles, that have been published on ME/CFS.
- It provides links to PubMed or to Journals, is updated monthly and is available as a free download.
- You can find the latest version of the Index in the [Research section](#) of our website.

Index of ME/CFS Published Research

An A-Z index of the most important published research

RAMSAY RESEARCH FUND

below: Researcher separating plasma at the ME Biobank, by Yas Crawford www.yascrawford.com

Why is it so important that we raise money for research?

We believe that a key part of our role is to offer hope to the estimated 265,000 people with M.E. in the UK who desperately want to return to a normal way of life, and one of the best ways to achieve this goal is to fund high quality biomedical research. M.E. research is appallingly underfunded compared to other serious medical conditions and we do as much as we can to address this imbalance.

We also advocate for more funding from other sources e.g. the Medical Research Council (MRC) through active membership of the CFS/ME Research Collaborative (CMRC). Medical research is very expensive – so finding the underlying cause of M.E. and effective forms of treatment isn't going to be easy. But that has not and will not prevent us from trying!

How you can help

Please help us to build on our success and continue to expand our vital work. One day we will find the cause of M.E. and have an effective form of treatment. And with your help, that day could come much sooner.



If you would like to help the Ramsay Research Fund invest in even more biomedical research, please donate now:

- with either a [single online donation](#) via JustGiving,
- by cheque (made payable to: The ME Association Ramsay Research Fund) to: **The ME Association, 7 Apollo Office Court, Radclive Road, Gawcott, Bucks MK18 4DF,**
- by card donation over the phone to our head office (01280 818964).

To fundraise for the Ramsay Research Fund, you can create your own [JustGiving campaign](#).



Research Investments

The ME Biobank at the Royal Free Hospital in London

The ME Association Ramsay Research Fund covers all the basic running costs of the ME Biobank and Dr Charles Shepherd is Chair of the Biobank Steering Group.



The Biobank was launched in August 2011 following extensive consultation with professionals and patient representatives. To date the Ramsay Research Fund has invested c.£380,000 in the M.E. Biobank which will cover running costs until 2021 when we hope the project will be self-sustaining.

This bioresource, which aims to enhance research into M.E. in relation to pathophysiology, biomarkers and therapeutic approaches, now has international acclaim with samples being used by research groups in various parts of the world.

Blood samples are collected from volunteers with very carefully diagnosed M.E. (Canadian and Fukuda diagnostic criteria) in designated locations. They are then rapidly transported to the Royal Free Hospital in London – where the ME Biobank forms part of the University College London Biobank.

RAMSAY RESEARCH FUND



The UK M.E. Biobank

The patient cohort comprises 314 ME/CFS (236 mild/moderate and 78 severe); 37 chronic fatigue (non-ME/CFS); 69 multiple sclerosis (MS); and 133 healthy controls.

Blood samples are aliquoted (separated) into serum, plasma, peripheral blood mononuclear cells (PBMC), red blood cells/granulocyte pellet, whole blood, and RNA (totalling 33,442 aliquots).

The samples are then processed into different components and stored before being released to researchers whose research proposals have gone through rigorous ethical approval and peer review.

An extensive clinical dataset (700 clinical and socio-demographic variables) enables comprehensive phenotyping (sub-grouping). Potential re-use is conditional on ethical approval.

Making these samples and the clinical data available to other researchers increases the chances of achieving much-needed breakthroughs in the aetiology and treatment of ME/CFS, in the most cost-effective manner.

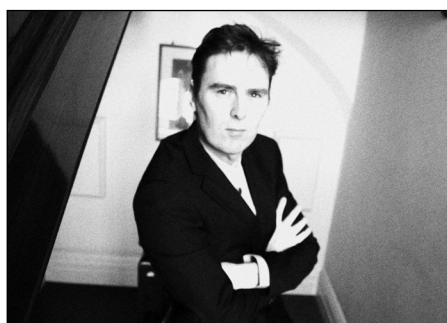
The list of [current collaborators](#) and their stories can be found on the M.E. Biobank website.

From the very beginning, the ME Association Ramsay Research Fund has provided significant funding for this essential project, and because we see real value in this initiative, we continue to support it as a major investor.

This is the only such project in the UK aimed at the study of M.E. and the supply of samples to outside researchers. Additional funding has been granted to the M.E. Biobank until 2021. This will allow all patient samples to be refreshed and for an increase in the total number of samples collected.

It is hoped that by 2022 the M.E. Biobank will be self-sustaining. Currently, it is providing vital samples and clinical data to more than ten research-teams in universities around the world.

Latest RRF investment = £100,000 (2020-21)



Current research studies

1. Dr Keith Geraghty (pictured above), University of Manchester

This study will centre around a national patient survey that will determine the factors affecting diagnosis and highlight any issues that may relate to delays in the diagnostic process.



It is very important that people presenting with symptoms are reviewed in a timely manner and are accurately diagnosed. We hope that the analysed data when published will lead to improvements in the current process that will benefit future generations.

RRF investment = £25,000 (2020/2021)

2. Dr Karl Morten et al., Universities of Oxford and Newcastle

Recently preliminary investigations at 3 independent laboratories highlighted that there may be an anomaly present in the blood plasma of people with ME/CFS that is adversely affecting mitochondrial performance in healthy cells.

Dr Morten and his team will attempt to determine if this anomaly can be isolated and identified. They will be working closely with Dr Pawel Zalewski from Nicolaus Copernicus University, in Poland and using samples from his own work on M.E.

RRF investment = c.£75,000 (2020/2021)

RAMSAY RESEARCH FUND

3. Dr Keith Geraghty, University of Manchester

Critical examination of the theoretical basis that underlies the use of cognitive behaviour therapy (CBT) and graded exercise therapy (GET) in ME/CFS.

This two-year award will challenge and review the theoretical basis and clinical application of CBT and GET in the NHS. The aim of the study is to better understand why clinical trials are reporting seemingly different effects than are demonstrated in patient surveys and clinical outcomes.

**RRF investment = £25,000
(2019/2020)**

4. Dr Karl Morten et al., Universities of Oxford and Newcastle

Examining metabolites in ME/CFS. Scientists from Oxford and Newcastle are spending 12 months analysing nearly 300 blood samples from the UK ME/CFS Biobank to look for small molecular clues known as metabolites.

**RRF investment = £100,000
(2019/2020)**



5. Dr Luis Nacul et al., LSHTM ME Biobank team and University College London

Examination of immune system status and energy metabolism in ME/CFS. The B- and T-cell main study will examine samples from 100 patients (50 moderate: 50 severe) and 100 controls (50 healthy: 50 MS) using flow cytometry.

This new research will investigate how abnormalities in this part of the immune system are linked with evidence that is now emerging of a disturbance in the way that energy is being produced at a cellular level in ME/CFS.

**RRF investment = c. £50,000
(2019/20)**

Published research

For a complete list of all research that has been published following grants made by the MEA Ramsay Research Fund, and to view our popular research summaries, please visit the [Research section](#) of our website.

1. Professor Elisa Oltra et al., University of Valencia, Assessing diagnostic value of microRNAs from PMBCs and EVs in ME/CFS

Prof. Oltra's team analysed the levels of microRNA's in PBMC's and EV's in the blood of people with severe ME/CFS, and compared them to healthy controls, to see if they could identify a diagnostic biomarker.

They found decreased levels of Creatine Phosphokinase and differences in the number and size of Extracellular Vesicles. 27 miRNA's were also found to be significantly different.

Further studies are needed in order to validate the possibility of these findings being used as diagnostic biomarkers.

[Read more...](#)

2. Geraghty et al., University of Manchester, The 'cognitive behavioural model' of chronic fatigue syndrome: Critique of a flawed model

Dr Geraghty led a team of international experts – from Harvard, Berkeley and DePaul Universities in America – and set about reviewing the cognitive behavioural model of ME/CFS; both the theory attached to it and all the evidence said to validate it.

They concluded, "There is little scientific credibility in the claim that psycho-behavioural therapies are a primary treatment for this illness."

[Read more...](#)



RAMSAY RESEARCH FUND

3. Tomas et al., University of Newcastle, Mitochondrial complex activity in permeabilised cells of chronic fatigue syndrome patients using two cell types

"Our results showed no differences in activity of any of the mitochondrial complexes in either cell type..."

"This implies that what we observed in our previous experiment using whole cells (lower mitochondrial respiration in ME/CFS) is caused by abnormalities in the energy production pathways upstream of the mitochondrial complexes..."

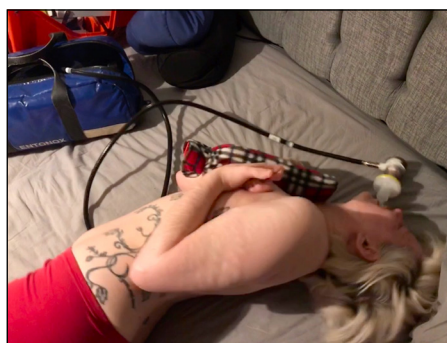
"Ultimately, our results show that future studies wanting to pinpoint the process or processes that are different regarding ATP production by mitochondria in ME/CFS should focus on the parts of the pathways that precede the mitochondrial complexes."

DR CARA TOMAS

[Read more...](#)



Dr Cara Tomas



4. Nijs et al., Vrije Universiteit Brussel, Relationship Between Exercise-induced Oxidative Stress Changes and Parasympathetic Activity in ME/CFS

Oxidative stress has been proposed as a contributor to pain in patients with ME/CFS. During incremental exercise in patients with ME/CFS, oxidative stress enhances sooner, and antioxidant response is delayed.

We explored whether oxidative stress is associated with pain symptoms or pain changes following exercise, and the possible relationships between oxidative stress and parasympathetic vagal nerve activity in patients with ME/CFS versus healthy, inactive controls.

Oxidative stress showed an association with pain symptoms in people with ME/CFS, but no exercise-induced changes in oxidative stress were found. In addition, the change in parasympathetic activity following exercise partially accounted for the change in oxidative stress in healthy controls. More research is required to further explore this link.

[Read More...](#)

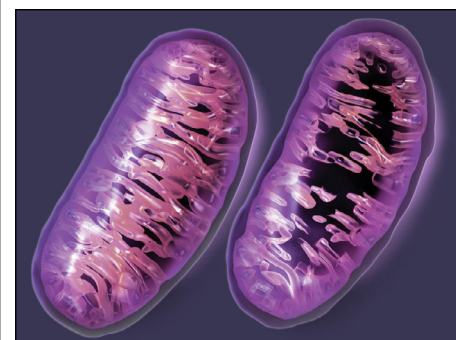
5. Xu, Morten and Huang et al., University of Oxford, A new approach to find biomarkers in CFS/ME by single-cell Raman micro-spectroscopy

Dr Morten and Prof Wei Huang attempted to link mitochondrial dysfunction and ME/CFS pathogenesis by comparing the 'fingerprint' of a cell model containing no mitochondrial DNA to the 'fingerprint' of molecules from the blood cells of ME/CFS patients.

The researchers found that both the cells with no mitochondria and the ME/CFS patients' blood cells had high 'bands' (or markers) associated with phenylalanine-like compounds, whereas the controls did not. Phenylalanine is an amino acid (a building-block employed by the body to make important molecules) readily detectable by Raman. It is used to make many neurotransmitters, such as adrenaline (involved in the fight/flight response for example).

They concluded, "Our results suggest that the increase in cellular phenylalanine may be related to mitochondrial/energetic dysfunction in both systems."

[Read more...](#)



RAMSAY RESEARCH FUND



6. Geraghty et al., University of Manchester, ME/CFS and the biopsychosocial model: a review of patient harm and distress in the medical encounter

Dr Keith Geraghty and Charlotte Blease explain the controversial biopsychosocial (BPS) model that is still applied to ME/CFS.

"We identified seven types of harm or distress experienced by ME/CFS patients, including difficulties getting a speedy and accurate diagnosis, poor care quality, scepticism and hostility, difficulties accessing social support and sickness disability benefits.

"We also identified that ME/CFS patients are directed towards controversial psycho-behavioural therapies (CBT and GET), that emerge from a cognitive-behavioural model that asserts that ME/CFS is perpetuated by patients holding unhelpful illness beliefs and adopting unhelpful behaviours.

"Our review found that this model is often rejected by patients as inaccurate and generates a range of harms, including the propagation of an erroneous view that ME/CFS is easily treated with talk therapy. We

detail how this model impacts socio-cultural perspectives of the illness and generates stigma for ME/CFS sufferers."

DR KEITH GERAGHTY

[Read more...](#)

7. Tomas et al., University of Newcastle, Cellular bioenergetics is impaired in patients with ME/CFS

"For many years, arguments have raged over whether CFS - also known as myalgic encephalomyelitis, or ME - has a physiological or psychological basis.

"But the latest research comparing samples of peripheral blood mononuclear cells (PBMCs) from 52 people with the condition and 35 without has reinforced the case for a biological explanation...

"Results from our experiments showed energy production to be consistently lower in cells taken from ME/CFS patients compared to controls.

"Both the basal rate and the maximal rate of energy production of the control cohort was shown to be double that of the ME/CFS cohort..."

DR CARA TOMAS

[Read more...](#)



Additional research funding

The MEA Ramsay Research Fund provides funding for various other projects, including:

■ The post-mortem tissue research that is carried out by Dr Dominic O'Donovan, neuropathologist at Addenbrooke's Hospital in Cambridge.

Dr Shepherd is a member of the post-mortem research group that co-ordinates this research. For details about donating post-mortem tissue to ME/CFS research please visit the Research section of our website.



■ The analysis of patient evidence from the Forward ME survey of efficacy and safety of CBT and GET in ME/CFS. This was carried out by Professor Helen Dawes et al. at Oxford Brookes University and co-funded with MERUK. It also included preparation of a report that was submitted to NICE guideline committee.

[Read more...](#)

■ Payments that allow open access in Journals to important research papers, e.g. the 2018 PACE trial data reanalysis paper from Wilshire et al.

[Read more...](#)

RAMSAY RESEARCH FUND

How to apply for a research grant

Researchers who are considering a research grant application should first contact our medical adviser Dr Charles Shepherd (via admin@meassociation.org.uk) for an informal discussion.

If you would then like to submit a proposal for consideration, please do so by providing the necessary information on our [research proposition form](#) and returning it to us as soon as possible.

The next stage in the process will require submission of a formal grant application, but this should not be completed until your proposition has received approval. We aim to reply to all propositions within four weeks of receipt.

Grant decisions are based on the guidelines produced by the [Association of Medical Research Charities](#) and we will normally include both an internal and external peer review of all formal grant applications.

How much do we spend on administration?

We make no administration charge. We are very aware that people who give money to research want to see it spent on research – and not swallowed up by administration expenses.

The Ramsay Research Fund is a restricted fund which means that all donations are used exclusively for research activity. We do not employ any extra staff to deal with routine



administration or the research we are funding, and any support that is required is done so voluntarily or is met out of our general funds.

What is our position on animal testing?

The MEA Ramsay Research Fund is not funding any research that involves the use of animals nor do we have any plans (or applications) to fund research that involves the use of animals.

ME Association Clinical and Research Guide

■ The 11th edition is a must-have for anyone who has been affected by – or has an interest in – M.E.

■ Priced at just £9.00 for UK residents, it features a detailed section on clinical evaluation and contains all relevant published research.

■ Written by Dr Charles Shepherd, Hon. Medical Adviser to the ME Association, and Dr Abhijit Chaudhuri, Consultant Neurologist, Essex Centre for Neurosciences, Clinical Issues is reviewed and revised on an annual basis.

■ You can purchase a hard copy from our [website shop](#) or by contacting head office on 01280 818964 (Monday-Friday, 9.30am to 3.00pm).

■ Now available on Kindle!

Download from Amazon for more convenience, making the content in our guide much easier to locate. It also comes complete with links to external resources and all relevant ME Association leaflets.

■ Free copy available for health professionals! We have funds set aside in our medical education budget to provide free hard copies of our clinical and research guide to GPs and allied health professionals.

Just let us have the contact information and we'll send a copy in the post.



Our quarterly magazine
ME Essential
goes out to all members

If you would like to receive it regularly, please phone our office on 01280 818 963 or email: admin@meassociation.org.uk

© ME Association 2020. No part of this publication may be reproduced without the written permission of the ME Association

ME Association: Facebook and Twitter and Instagram

[illegible]