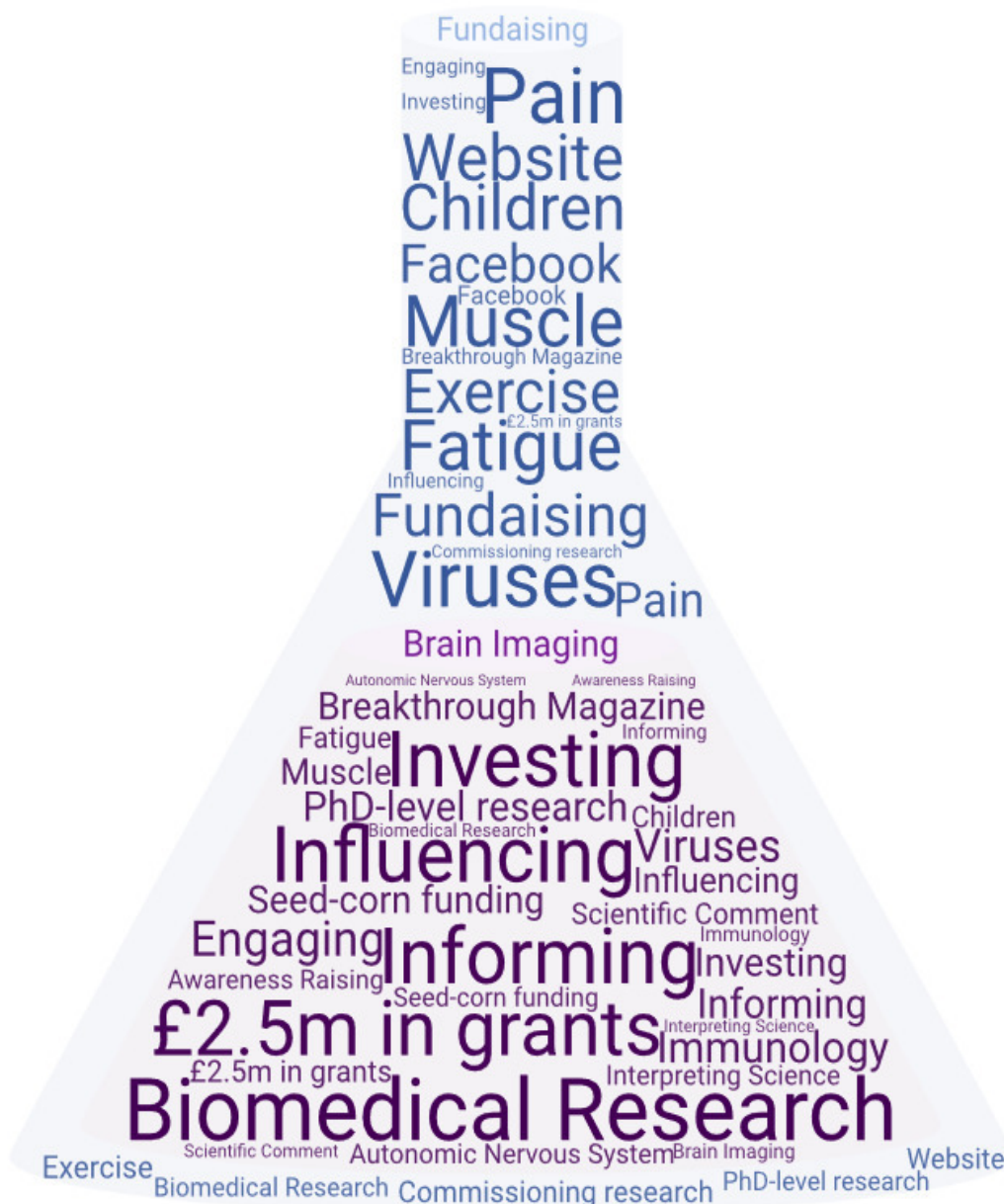




# ANNUAL REPORT & ACCOUNTS 2020/2021

Scottish Charitable Incorporated Organisation Registered Charity No. – SC036942



# ME Research UK

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# ME Research UK

## Reference and Administrative Details

<b>Charity name</b>	ME Research UK
<b>Charity registration number</b>	SC036942
<b>Trustees</b>	Jonathan P J Davies, Chair Mrs Sue Waddle, Vice Chair Mrs Jan McKendrick, Secretary Edward Dunkerley Prof Faisal Khan Mrs Lesley J Carr Dr Eleanor Roberts
<b>Founding Patron</b>	Roger Jefcoate CBE DL
<b>Patron</b>	The Countess of Mar
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# ME Research UK

## Trustees' Report

### Introduction by the Chair



It gives me great pleasure to present our latest Annual Report and Accounts, which reflect further significant progress in delivering our strategy, despite all of the challenges we have faced through the continuing Covid19 pandemic.

We are very fortunate to have a dedicated staff team that have fully adapted to new ways of working over the last twelve months, allowing us to continue our work with no break in service. On behalf of the Board, I thank them for their commitment and the value they bring.

Whilst many fundraising activities have been curtailed or cancelled during the year, we remain extremely grateful to all our supporters – both new and old – for the faith they place in us and in the work we do. Our ability to inform, influence and ultimately invest in biomedical research would not be possible without the commitment and generosity of our benefactors, fundraisers and friends.

We are delighted to have been able to award approximately £600,000 in new research grants this year, with our cumulative research funding now over £2.5m. We enter the new financial year with a healthy balance sheet and substantial pipeline of research grant applications under review and I am confident that the coming year will see us approve further significant grant funding.

We are committed to further encourage both young and established researchers into the field of ME research. We hope to build on the PhD award which is pending with further PhD grant applications currently under review. In May 2021 we launched a call for research applications on the topic of 'Viruses and ME with an indicative commitment of £400,000 and this looks likely to be fully invested by the early part of 2022.

We have no doubt that more research still needs to be done and we are committed to ensuring that we get the greatest impact from donations, through focusing considerable investment in research and in the provision of high quality information on the disease. We welcomed the publication of the new NICE Guideline on 29<sup>th</sup> October 2021 and hope that this will prove a catalyst for far greater demand for high quality research into the causes, consequences and treatment of ME. We will continue to do everything we can to make this a reality.

Our determination to make a positive difference remains undimmed and we will continue to work towards our vision to bring to an end the suffering caused by ME.

Thank you once again to all our friends for your invaluable support.

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 2020 to 31st October 2021 - see Note 1 to the accounts. The financial statements have been prepared in accordance with the accounting policies set out in Note 2 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).

### The Illness

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) list 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 illness 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.

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

NICE records that recent data from the UK Biobank suggests that there are over 250,000 people in England and Wales with ME/CFS, with about 2.4 times as many women affected as men. 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% have severe disease and are housebound 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 illness 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 recommended further research be undertaken.

What is certain is that ME/CFS is not a simple post-illness 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.

## ME Research UK

### Trustees' Report

There is no diagnostic test or universally accepted 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 another chronic disease may be confused with ME/CFS and some practitioners are reluctant to positively diagnose ME/CFS when no other causes are found.

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 if illness makes school attendance difficult, bringing families to the attention of educational and social care services.

One welcome aspect of the 2021 NICE clinical guideline is the weight given to post exertional malaise after activity and this was one of a set of four diagnostic criteria which were established through the guideline development process. This accords with the realities of those with the illness and will aid delineation from other conditions. The four key diagnostic criteria suggested in the 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, along with debilitating fatigue worsened by activity, unrefreshing sleep and/or sleep disturbance, and cognitive difficulties.

Given the illness'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 240,000 estimated to have ME/CFS but has received 20 times the funding.

ME Research UK exists solely to fund biomedical research and, to date, we have invested c£2.5 million in biomedical research world-wide on 58 distinct projects and have funded more specific biomedical research ME/CFS 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 illness and its effects with the ultimate aim to discover a treatment or a cure for this most disabling of illnesses. 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 illness and to funding the highest quality of biomedical research possible.

# ME Research UK

## Trustees' Report

### Objectives

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 illness. Only through biomedical research, will the illness be understood, accepted and real change to the lived experience of those with the illness become a reality.

In particular, we

- **invest** in high quality biomedical research into ME/CFS globally which we believe has the potential to further the understanding of the illness;
- **inform** the science community, civic society and those affected by the illness 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.

### ME Research UK - Year in Review

The impact of Covid-19 continued to have a major impact on the day-to-day operations of the charity for a large part of 2020/21 and the Trustees wish to thank the staff for working so diligently throughout the pandemic and for ensuring that remote working and the added complications of lockdowns and restrictions did not materially affect either supporters or researchers. The Trustees also thank the Science & Engagement Director who demitted office in December 2020 and are grateful for the contribution she made to the organisation – especially to the workings of the Science Committee.

Trustees also extend their gratitude to supporters who, despite the period of economic uncertainty, continued to support our work financially. ME Research UK is not alone in seeing fundraising income drop considerably as events were cancelled as uncertainty as to the lessening of coronavirus restrictions remained. As restrictions loosened, ME Research UK was however fortunate to have been chosen as a supported charity of both Walk for ME and Team Run for ME, and the Celtic Wiseman Perpetual as they continue to raise much appreciated funds. These three initiatives both inspire and involve our supporter-base. Fortunately, activity-based fundraising remains only one part of ME Research UK's fundraising mix.

The charity has also seen interest rates decline on its own investments as rates are held at record lows. This may also affect grant-making trusts from whom the charity may apply for future funding. ME Research UK currently does not receive government, local authority or Lottery grants and so is immune from any restriction on funds from these external bodies.

The charity took the positive decision not to furlough staff and work in informing, influencing and investing in ME research continued despite lockdown.

Thanks largely to the funds provided by legacies, ME Research UK has been able to expand its research commitment and add substantially to the number of research projects curated. This was achieved through the launch of a dedicated global call for research applications in spring 2021; a new PhD funding initiative; and publicising the availability of research funding to active ME research groups worldwide. During a period when researchers' work was looking uncertain, the charity made a commitment to support the ME research-base at a point where other sources of finance were unclear. By pro-actively allowing a 12-month no-cost extension to project award holders the charity aided stability and offered hope to researchers. The delays have, however, impacted the schedules of work and that is reflected in the lower than normal conclusion of research projects.

## **ME Research UK**

### **Trustees' Report**

ME Research UK is pledged to encourage researchers with fresh, novel ideas to become active in ME/CFS research and provide them with the resources to undertake their work. It is at this leading edge that ME Research UK sees its role: to give financial aid and other assistance to biomedical scientists for novel but scientifically sound research projects which would otherwise not be funded. We will continue to support research groups to the stage where they can apply, based on their ME Research UK funded work, to major funding agencies for support. In doing so, we will act collaboratively to achieve these aims. In light of this priority, ME Research UK not only launched a PhD funding program but, in conjunction with Action for ME, has issued a letter of intent to fund a PhD at Kings University, London with funding being provided equally with Action for ME. The application was progressed through a task-specific joint Science Committee in order to ensure that both charities needs for rigour in selecting suitable projects were met and it is anticipated that the award will be made in early 2022.

To coincide with International ME Awareness Day 2021 (12th May), ME Research UK with the financial support of The Gordon Parish Charitable Trust (SCIO Charity no SC045752) announced a £400,000 joint initiative to fund biomedical research into the role of viruses in ME/CFS. We were delighted to have received six high-quality proposals from around the world which are progressing through peer-review and being assessed by our Science Committee. One project – by Dr Prusty (proj 56), has now been awarded funding.

In April 2021, Forward-ME Group's founder and Chair – the Countess of Mar – announced that the time was right for her to step aside from her role as Chair. A new Chair was appointed and a new structure for the Group agreed as it clarified its mission to recognise "... the benefit of being able to speak with a louder voice, Forward-ME was established as a coordinating body to provide a unified and perhaps louder voice for the ME community to reach key influencers and stakeholders – government, medical bodies etc." Since Forward-ME was founded, with a core group of nine ME charities, ME Research UK has been an active voice within the Group. Our Chair serves on the Group's steering committee and the charity contributes to the joint initiatives coordinated by the organisation to the extent permitted within ME Research UK's aims and objectives. The benefits of a coordinated, but not limiting, common voice were demonstrated by the response of Forward-ME to NICE's announcement of a 'pause' to the publication of its new guideline on the diagnosis and treatment of ME/CFS and the measured insistence that the 2021 guideline must be published as soon as possible. This common, agreed, approach was voiced to NICE both in the theme gathering phase and at the roundtable meeting (18th Oct 2021) attended by ME Research UK.

A major feature of ME Research UK's year has been the process leading to publication of the 2021 NICE guideline. The charity alone, and in conjunction with Forward-ME, responded to drafts; participated in the round-table meeting; and produced information to supporters on the procedure and the outcome of the process.

It was expected that after the issue of a draft guideline in November 2020 that publication would follow swiftly upon the closure of the consultation period on the draft which ended late December 2020. However, on 29th March 2021, NICE announced that due to the volume of responses (included amongst these were comments from ME Research UK and Forward-ME) publication would be delayed until 18th August. All stakeholders received a finalised copy of the new guideline a fortnight before publication but on 17th August NICE announced the highly unusual step of 'pausing' publication of the guideline as "In order to have the desired impact, the recommendations must be supported by those who will implement them and NICE will now explore if this support can be achieved." Through Forward-ME, statements and representations were made to NICE and the media briefed. Both ME Research UK and Forward-ME attended NICE's 18th October roundtable discussion with stakeholders, and thereafter, on 20th October 2021, news that the guideline would be published was released by NICE with the new guideline published on 29th October 2021.



# ME Research UK

## Trustees' Report

ME Research UK's comment on the guideline was reported on the BBC's news website; "Today's publication by NICE of its updated 'Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management' clinical guideline marks a significant step in both the acceptance of ME as a physical illness and the recognition of appropriate treatment needs of those affected by the condition."

However, the charity is also acutely aware that publication of the 2021 NICE guideline marks only the beginning of the transformation needed for ME to be more fully understood and, ultimately, for a cure to be found. NICE's recommendations highlighted the need for research into diagnostic criteria and tests, as well as health-outcome measures, but these will not be fulfilled without researchers, healthcare professionals and funders working together to understand the causes of the illness and the effects it has on bodily systems. Research from numerous studies informed the changes to the guideline, but it is clear that further progress depends on increased research and the availability of funding to make this work a reality. This is where ME Research UK stands ready.

### 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.*

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 £577,746 (2020 (£220,787)) in 4 ME research projects in 3 countries, and a letter of intent for a PhD studentship. This represents a 162% increase over last year. This level of commitment is consistent with the charity's objectives and is judged to be more than 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 further 16 (2019/20 - 13) applications were received in the year, of which 5 were not progressed to the full application stage. Of the remaining 11 full applications, 2 were not funded, 1 was funded, and 8 are currently progressing through the external peer review process, after which they will be considered by the Science Committee. The size and complexity of the applications means 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**

### **Trustees' Report**

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 knowledge-base of the illness and tools/methods available to researchers mean a high degree of skill and knowledge is required by Science Committee members and peer-reviewers. Administrative steps have been taken to stream-line the review progress but the charity acknowledges that additional capacity within the science Committee and peer-reviewers will be required to ensure the level of scrutiny which the charity prides itself upon.

The number of applications bodes well for progress in research in 2021/2022 and for the reputation and future evolution of the charity beyond the current year. The applications before us, if funded, would cost £1,009,711 – an increase on last year's total applications (£965,000) – which illustrates the value of a research-centred charity devoted to biomedical research into ME/CFS but also the needs of the research base for increased funding.

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.

In summary, ME Research UK has 6 ongoing studies, 4 newly funded projects, and a proposed PhD studentship and these represent more than £1 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 two studies investigating the potential causes of mitochondrial dysfunction, one that strengthens our involvement with research in the brain, and another that tackles a frequent source of pain in ME/CFS. A common theme is the possibility of discovering a viable biomarker for the illness that has the potential to transform its recognition and treatment. In addition, the new applications we received in response to our call for virus-related studies have great relevance given current interest in post-viral illnesses such as long COVID.

#### **1. New Research Projects in 2020/21**

Contracted for:

##### **Project 55 - 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.

## ME Research UK

### Trustees' Report

The study focuses on pain as a common, debilitating ME/CFS symptom. 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
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 56 - Bhupesh Prusty, Julius-Maximilians-Universität Würzburg, Germany Understanding potential infectious triggers behind mitochondrial dysfunction in ME/CFS £207,100**

ME/CFS is a complex disease with many potential unknown triggers. Recently it has been observed that a large subset of patients who had recovered from SARS-CoV-2 infection are developing ME/CFS-like symptoms and are continuing to have ME/CFS-like clinical conditions even after several months post infection. This has strengthened the idea of infectious origin behind ME/CFS. However, there are no strong experimental evidences to support this. Mounting epidemiological evidences implicate Human herpesvirus 6 (HHV-6), HHV-7 and Epstein-Barr virus (EBV) as three highly probable infectious triggers for ME/CFS. The researchers have recently observed several cellular changes in cells carrying functionally active HHV-6 virus, which overlaps with clinical abnormalities frequently observed in ME/CFS patients. The most convincing changes included dysfunctional mitochondria, and altered mitochondrial glucose metabolism. The researchers' results supported the previously documented notion that mitochondrial dysfunction and changed mitochondrial metabolic signatures might be induced by a soluble factor that can be transferred from cell to cell through serum. Their preliminary studies have detected several possible serum-transferable factors in ME/CFS patients that can originate after an infectious trigger. Preliminary infection experiments with SARS-CoV-2 supports the idea that it may not be the SARS-CoV-2 that directly causes ME/CFS like symptoms. Rather regaining of functional activity by herpesvirus genome, which often remains inactive in a healthy cell, might be a key factor for ME/CFS development.

The researchers aim to identify and characterise some of these serum-transferrable factors using innovative, inter-disciplinary methodologies and ME/CFS patient samples, which will allow them to understand molecular mechanism(s) behind mitochondrial dysfunction in ME/CFS and hopefully help to develop different strategies for therapeutic interventions.

## **ME Research UK**

### **Trustees' Report**

**Project 57. Leighton Barnden, Griffith University, Australia**  
**Investigation of brain stem dysfunction using 7 Tesla MRI in ME/CFS**  
**£151,000**

Impaired concentration and memory, visual and auditory changes, headache and autonomic manifestations, predominate the signs and symptoms of ME/CFS and indicate primary brain involvement.

Over 15 years, the Griffith University team has applied Magnetic Resonance Imaging (MRI) to study the brain in ME/CFS. Initially, they used unorthodox spin-echo MRI sequences which deliver the sensitivity and stability critical for group comparisons with healthy controls. They also performed correlations of MRI levels with severity and autonomic measures (heart rate and blood pressure) and discovered that ME/CFS severity was associated with upregulated white matter myelin independent of anxiety and depression. They also detected abnormal MRI correlations with autonomic measures within the brainstem reticular activation system (RAS), a diffuse network of small interconnected nuclei with important regulatory functions. Both findings implied impaired nerve conduction within the brainstem. In 2019, they used functional MRI to directly confirm deficits in connectivity between RAS nuclei. The RAS regulates the sleep-wake cycle and brain arousal levels, which affect attention, sensory perception, cognitive performance and memory, which are all deficient in ME/CFS and constitute its major symptoms. The RAS is the primary target of this proposal.

Their RAS results, although unique, were limited by conventional 3T MRI imaging. This new ME Research UK-funded study will investigate the brainstem RAS with a higher powered research 7T MRI scanner, repeating the key MRI measurements of the earlier work with increased sensitivity and spatial resolution, but also adding recently developed MRI measurements to identify and characterise new aspects of RAS pathophysiology. Although targeting the brainstem RAS, they will again test for differences throughout the brain in ME/CFS.

To confirm and expand the understanding of RAS dysfunction in ME/CFS the researchers will also test associations of RAS connectivity with extended clinical parameters. Advanced MRI imaging may yield valuable RAS biomarkers of ME/CFS.

**Project 58 - Sarah Annesley, La Trobe University, Australia**  
**Cell type specificity, molecular scope and epigenetic basis for mitochondrial and cellular dysfunction in ME/CFS cells**  
**£198,076**

Previously, the researchers identified a clear and specific defect in immortalised white blood cells (lymphoblasts) from ME/CFS patient namely an inefficient function of the last enzyme involved in production of energy by mitochondria (Complex V). The mitochondria are tiny compartments in cells which are responsible for generating most of the cell's energy. The inefficiency in mitochondrial energy production is accompanied by compensatory increases in the activity of a key regulator (TOR Complex I) of the production of mitochondrial proteins and in the levels and activities of mitochondrial energy-producing proteins. The increased levels of mitochondrial proteins has since been confirmed by another research group in white blood cells. Importantly, the researchers also showed that these abnormalities correlated with clinical markers of symptom severity and are highly specific and sensitive biomarkers of the disease.

## ME Research UK

### Trustees' Report

Whilst identification of changes in blood cells is beneficial due to their accessibility and involvement in immune responses, it is also important to determine if these changes occur in other cells and systems of the body. The next most accessible tissue is the skin. In this project the researchers will determine if the abnormalities in mitochondrial energy production and compensatory upregulation are present in cells from a different tissue, the skin, and if these alterations correlate with clinical measures of the disease. They will also determine if this is associated with alterations in other pathways and proteins and how this regulation is likely to occur through changes at the DNA, RNA and protein level.

The results of this research will expand our knowledge of the underlying defect in energy production in ME/CFS and could lead to the identification of proteins and pathways for the development of therapeutic treatments and the identification of biomarkers of the disease for future development of a specific and sensitive diagnostic test.

#### 2. Completed Projects

a. Reported and Grant Liability Ended:

**Project 50 - Dr Francisco Westermeier, FH Joanneum University of Applied Sciences, Graz, Austria**

**Role of Sirt1/NOS axis in vascular and immune homeostasis: A missing piece in the ME/CFS puzzle?**

**£44,827 (including £1452 additional funding awarded in year 2020/21)**

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), is a complex multisystem disease characterised by cognitive impairment, post-exertional malaise, autonomic dysfunction, chronic pain and persistent exhaustion that is not improved by rest. Although its exact causes are unknown, there is compelling evidence that correlates ME/CFS with heterogenic immunological and metabolic abnormalities such as inflammation and oxidative stress. Despite inflammation and oxidative stress having been linked to endothelial dysfunction in several diseases, that association in terms of potential mechanisms has not been addressed in ME/CFS.

Several clinical studies have shown dysfunction of the endothelium in a subgroup of people with ME/CFS. The endothelium is a layer of cells lining every blood vessel, and is involved in controlling their opening and closing, and hence the amount of blood flowing through them. One of the ways the endothelium controls blood flow is through the release of a chemical called nitric oxide.

Dr Westermeier and his team used samples from the UK ME/CFS Biobank to look at levels of circulating microRNAs, which are molecules that help cells control what proteins they make. They found that levels of five of these microRNAs were increased in people with ME/CFS compared with control subjects. Furthermore, these five microRNAs are all involved in controlling the endothelium, specifically via the pathway that generates nitric oxide.

These microRNAs may therefore provide biomarkers, and help further characterise the mechanisms of endothelial dysfunction in a subgroup of people with ME/CFS.

## **ME Research UK**

### **Trustees' Report**

**Project 52 - Prof. Julia Newton and Victoria Strassheim, Newcastle University, UK  
Voices of the ignored and invisible: The experience of living with severe CFS/ME  
£8,736**

Very little research has been conducted in people with severe ME/CFS, and this is largely because their poor health makes it very difficult for them to engage with research studies. They are often not able to attend for hospital visits, and the procedures may be impossible to carry out or have a detrimental effect on their symptoms. It is therefore important to find ways in which to include this neglected group of patients in research, and this is what Victoria Strassheim has been looking at in a series of studies over the last few years. In this most recent project, which was supported by ME Research UK with funding from the Sophie Miles Bequest and ME North East, five people with severe ME/CFS were interviewed. A detailed analysis of their responses identified three main themes: their lived experience of the illness, challenges to their daily life, and how they manage the condition.

The investigators believe these findings highlight factors that place people at greater risk of developing more severe ME/CFS, and hope that these insights will allow research and healthcare communities to engage more effectively with this overlooked population.

b. Research Complete, Report received and Grants Funds still to be paid:

**Project 48 - Prof. Mercedes Rincon, University of Vermont, Canada  
Exploring a Citrullinated Antibody Signature in ME/CFS  
£14,868.40 over 4 months (US\$17,559.58 at date of conversion to US\$)**

Growing evidence suggests that ME/CFS is an inflammatory disease, and specifically an autoimmune condition where the immune system wrongly identifies the body's own healthy cells as harmful and produces antibodies against them. One potential cause of this autoimmunity is citrullination, which is the modification of a protein to become what the immune system identifies as a foreign protein. This leads to the generation of antibodies against those citrullinated proteins, and the presence of anti-citrullinated antibodies is characteristic of the autoimmune disease, rheumatoid arthritis. Prof. Rincon has previously found evidence for the presence of an autoantibody targeting a citrullinated protein in the blood of patients with ME/CFS, and this was distinct from the antibody found in rheumatoid arthritis patients. Prof. Rincon's study looks to confirm these findings in a larger group of patients and control subjects, using samples from the UK ME/CFS Biobank. These results may help to define ME/CFS as an inflammatory condition and support the use of biological therapies in its management.

Prof Rincon's study was due to end in 2018/2019 and a final report scheduled to be submitted in January 2020. However, this was delayed by Prof. Rincon moving research Institutions, and subsequently by the COVID-19 pandemic meaning the temporary closure of laboratories. The project is complete and a final report received but a final Invoice remains to be issued by the Institution. ME Research UK's Standard Grant Conditions ensure that charity funds are paid only upon receipt of an acceptable Final Report and final Invoice.

## ME Research UK

### Trustees' Report

#### 3. On-Going Projects

*Ongoing projects, initiated in previous financial years, payable (subject to progress) in 2020/2021 – Sums due represent total funding commitment.*

**Project 37 - Prof F Khan, The Institute of Cardiovascular Research, University of Dundee, Dundee, UK**

**A study examining Nrf2 antioxidant gene expression and its role in combatting oxidative stress**

**£72,448.12**

If low Nrf2 levels are found to play a central role in the increased oxidative stress found in ME/CFS patients, stimulation of Nrf2 could become an important treatment strategy, as there are currently no specifically effective treatments for the illness. The findings may also have broader implications for studies of Nrf2-targeted treatments in other conditions characterised by elevated oxidative stress, such as cancer, diabetes and liver disease.

**Project 47 - Prof. 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 49 - Dr Sanjay Kumar, Oxford Brookes University, Oxford, UK**

**Investigating sensory processing and cognitive function in people with ME: a pilot study**

**£29,641**

Although hypersensitivity is not considered a primary factor in the diagnosis of ME/CFS, it is a common finding in people with the condition. The brain has to work hard to process sensory-inputs and filter out what is irrelevant so we can concentrate on what is important at any given moment. The resulting physical and mental overload can lead to poor coordination, dizziness, clumsiness, numbness, tingling and nausea, and may affect individuals' ability to take in information and make decisions.

Dr Sanjay Kumar, Dr Farzaneh Yazdani and colleagues at Oxford Brookes University wish to understand the nature and impact of the sensory problems experienced by people with ME/CFS, and to determine whether they are associated with any functional or electrical changes in the brain. The investigators' hope is that the results of this preliminary work will help in our understanding of the brain mechanisms that underlie the abnormal sensory experiences of people with ME/CFS, and also lead to the development of interventions to help manage these problems.

## ME Research UK

### Trustees' Report

**Project 51 - Prof. Jo Nijs, Vrije Universiteit Brussel; and Dr Lode Godderis, Katholieke Universiteit Leuven, Belgium**

**Unravelling the role of epigenetic modification on the brain derived neurotrophic factor gene and histone de-acetylases for pain and post-exertional malaise in people with myalgic encephalomyelitis / chronic fatigue syndrome**

**£91,499 over 2 years**

Epigenetics looks at genetic changes that can be passed from one generation to the next, not as a result of alterations in the DNA sequence, but instead caused by changes in gene activity and expression (how information from the gene is used to make proteins). There is evidence that epigenetic changes may play a role in the pathophysiology of ME/CFS, including the post-exertional malaise experienced by many people. The investigators' previous research has uncovered the role of central sensitisation in the chronic pain experienced by many people with ME/CFS at rest and/or after exercise. In this new study, they will be investigating further the role of brain-derived neurotrophic factor (BDNF) and histone de-acetylases (HDACs) in the central sensitisation and post-exertional malaise experienced by people with ME/CFS, and particularly the epigenetic changes occurring in the *BDNF* gene and in the genes regulating HDAC expression.

**Project 53 - Prof. Carmen Scheibenbogen, Charité University Medicine Berlin; and Dr Nuno Sepúlveda, London School of Hygiene & Tropical Medicine, London, UK**

**Analysing antibody responses against EBV-derived antigens as putative biomarkers and candidates for molecular mimicry in ME/CFS**

**£51,096.17 over 1 year including additional funding for staff and publications.**

Epstein-Barr virus (EBV) is one of the strongest candidates as a master infection trigger of ME/CFS across different populations. This is based on the fact that almost all adults are silent carriers of the virus, and the virus can produce proteins similar to the ones found in the body. To understand the role of EBV on disease pathogenesis, the investigators have previously evaluated the antibody responses against more than 3,000 EBV-derived proteins, and identified up to twenty candidate antigens whose antibody responses were either increased or decreased in patients compared with healthy controls. These responses were able to distinguish patients from healthy controls, suggesting they have the potential to be used as biomarkers or ME/CFS. They may also have value in discovering disease pathways triggered by EBV infection. In this new study, the investigators will attempt to replicate these findings in samples from the UK ME/CFS Biobank.

**Project 54 - Prof. Elisa Oltra, Catholic University of Valencia, Valencia, Spain**

**Metabolic impact of activated HERVs and associated innate immune response in severe ME: towards disease modelling**

**£76,000 over 30 months - offered in 2019/20 and contracted for in 2020/21**

Human endogenous retroviruses (HERVs) are a family of viruses contained within the human genome and inherited by successive generations. They have been proposed as potential triggers of ME, and the applicants plan to identify HERVs that are overexpressed in a group of 12 women with severe ME compared with a matched group of women with fibromyalgia. These HERV 'fingerprints' could be used for diagnosis or patient subtyping. They also plan to look at the effects of activation of these ME-associated HERVs on nerve and muscle cells in laboratory conditions, to understand their potential impact on the symptoms of the illness. In addition, the identified HERVs will be validated in an extended cohort of 50 ME patients, 25 fibromyalgia patients and 25 healthy control subjects.



## ME Research UK

### Trustees' Report

#### 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 58 specific grants totalling c£2.4million, to research institutions in the UK, Austria, Australia, Belgium, Canada, Germany, 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.

Five papers were published in the charity year 2020/21 (2019/20 - four) acknowledging the support of ME Research UK.

Josev EK, Cole RC, Scheinberg A, Rowe K, Lubitz L, Knight SJ. Health, Wellbeing, and Prognosis of Australian Adolescents with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): A Case-Controlled Follow-Up Study. *Journal of Clinical Medicine*, 2021 August 16; 10(16):3603.

Domingues TD, Grabowska AD, Lee JS, Ameijeiras-Alonso J, Westermeier F, Scheibenbogen C, Cliff JM, Nacul L, Lacerda EM, Mouriño H, Sepúlveda N. Herpesviruses Serology Distinguishes Different Subgroups of Patients From the United Kingdom Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Biobank. *Frontiers in Medicine*, 2021 July 5; 8:686736.

Blauensteiner J, Bertinat R, León LE, Riederer M, Sepúlveda N, Westermeier F. Altered endothelial dysfunction-related miRs in plasma from ME/CFS patients. *Scientific Reports*, 2021 May 19; 11(1):10604.

Strassheim V, Newton JL, Collins T. Experiences of Living with Severe Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. *Healthcare*, 2021; 9(2):168.

Polli A, Ghosh M, Bakusic J, Ickmans K, Monteyne D, Velkeniers B, Bekaert B, Godderis L, Nijs J. DNA Methylation and Brain-Derived Neurotrophic Factor Expression Account for Symptoms and Widespread Hyperalgesia in Patients With Chronic Fatigue Syndrome and Comorbid Fibromyalgia. *Arthritis & Rheumatology*, 2020 November; 72(11):1936–44.

#### B. Informing

During 2020/21, 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.

## **ME Research UK**

### **Trustees' Report**

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 on-line 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 10,201 (9,618 in previous period) 'likes' - an increase of 6% (2019/20 - 15%) from 2019/20 - and is viewed regularly worldwide. It has steadily increased the audience for postings, created a community of regular commentators and provided a new platform from which we can connect to supporters both old and new. ME Research UK's active Twitter account further drives the successful dissemination of our research news and it will act as a further avenue to engage more fully with potential donors and create a new community of supporters. With 2,630 followers, it has proved to be a useful, addition avenue for engagement with the ME community.

As part of the evolution of the charity, ME Research UK continues its brand review to ensure maximum impact of its news and output to ensure supporters and the wider public are aware, trust and engage with the charity. The outcomes have begun to be rolled out and next year will see phase 1 of a Communications Strategy operationalised which will concentrate on the charity's social media output making it more connected, focused and appropriate to identified target audiences.

The charity will further look to contributing to third party publications to reach a mainstream audience – as was demonstrated by authoring a guest article in September 2020's London Police Pensioner Magazine and the BBC news website quote as part of a piece, on the publication of the new NICE guideline.

In order to engage more fully with supporters - old and new - ME Research UK has embarked on a branding exercise with the results feeding into a social media strategy aiming to leverage greater coverage of ME Research UK news and to utilise fully and effectively the charity's output and message.

## **ME Research UK**

### **Trustees' Report**

#### **C. Influencing**

During the period ME Research UK has:

- attended and contributed to the Forward-ME Group meetings. Forward-ME members work collaboratively to improve recognition and understanding of ME/CFS. The focus of the Group is the urgent need for biomedical research; effective diagnosis and appropriate symptom management; and appropriate care and support services for ME/CFS. ME Research UK's Chair sits on the Steering Group.
- contributed to NICE guideline review as a stakeholder and attended roundtable discussions to press for publication of the new guideline - which occurred on 29th October 2021.
- attended and played part in Steering Group meetings of the UK ME/CFS Biobank hosted by the London School of Hygiene and Tropical Medicine. ME Research UK was a financial supporter of the biobank in its formative stages (Projects 29 & 32 - combined investment £76,542). The charity notes that samples for the biobank have been utilised by Prof Khan (Project 37) and Dr Westermeier (Project 50) as part of their current ME Research UK funded projects.
- been in contact with ME Research UK grant holders and potential funders to raise the profile of the charity and begin forging inter-group links to stimulate collaboration.
- through the efforts of the Chair, discussed with other organisations the research landscape and scope for collaborative working and a more pro-active approach to research project funding.
- been invited to and attended ME/CFS stakeholder meetings with other charities working towards implementing assurances given at Scottish Parliament's Petitions Committee to transform ME treatment, education, and research in Scotland.

Overall, 2021 has seen the charity deliver and become more focused 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 Research & Communications Director.

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.

## **ME Research UK**

### **Trustees' Report**

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's 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.

During 2020, the new Science Committee Plan was initiated 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.

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.

## **ME Research UK**

### **Trustees' Report**

On PhD funding, applications must be made via the Institution concerned to ensure charity funds are protected.

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 illness 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.mereseach.org.uk](http://www.mereseach.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. ME Research UK strives to repeat the success of Prof. Julia Newton, Dr Wan Ng and colleagues at Newcastle University who, in 2012, were awarded almost £1 million by the UK's Medical Research Council. Their successful application for funding was under a call for 'Understanding the Mechanisms of CFS/ME' and resulted in funding for two biomedical projects. At the time, Prof. Newton acknowledged ME Research UK for providing "the pilot/seed corn funding for four distinct projects from 2006 to 2011, which have allowed us to accumulate the data on which these successful applications to the MRC were based".

## **ME Research UK**

### **Trustees' Report**

The Trustees monitor closely the feedback from Breakthrough and the data on uptake and use of Facebook and Breakthrough. It would appear that there is a strong demand for impartial, informed scientific comment in the sphere of ME/CFS.

#### **Accounting Matters**

##### **Donated Facilities and Services**

It is estimated that approximately 1661.5 voluntary hours were donated by members i.e. the Trustees of ME Research UK, and 57.5 voluntary hours were donated by others (most notably by peer-reviewers and members of our Science Committee to whom ME Research UK owes a great debt for their insightful input).

The charity continued to take advantage of donation facilities from Microsoft, Google Ads, and the SAGE Foundation. The value of these donations in kind was approximately £40,000 and has been recognised in the accounts - the calculated 'cost' of the advertising of \$54,521.63 (£39,855.52) is included in expenditure on raising funds.

##### **Key Management Personnel Remuneration**

The Trustees consider key management to be the Board of Charity Trustees, in terms of setting strategy and policy and in assessing risk and responsibility for these matters rests with the Board.

No Trustee received any remuneration directly from the charity: other than approved expenses. Details of remuneration and expenses are disclosed in note 10 to the financial statements.

Trustee, Dr Eleanor Roberts is director/proprietrix of Beeline Science Communications Ltd which, due to departure of ME Research UK's Science & Engagement Director, was contracted to provide additional writing capacity aligned to a specific agreed schedule of work to the charity due to pressing need. Dr Roberts was not involved in any decisions regarding the awarding of the contract and appropriate declarations of Conflict of Interest were made.

##### **Financial Review**

The total funds held at the year-end were £1,616,136 (2020: £1,709,009), including £754,779 of restricted funds (2020: £1,180,434). These funds are further explained at note 21.

The charity continues to rely on the generous donations of its supporters - as detailed in Note 3 to the accounts. The amount of charitable activity funded during the period is set out in Note 7 to the accounts, and the charities assets and liabilities are detailed in the Balance Sheet presented on page 30.

Given OSCR's recommendations for limitation of Trustees' liability insurance, our financial policy remains as it has always been, namely that no new projects be initiated until the necessary funds to complete them are secure and in place in the charity's bank accounts. This ensures that, for research project purposes, the charity assets will always be in excess of its liabilities. In this regard, the charity aims to be regarded as a sound partner in any project award and therefore to ensure a high level of trust between funding agencies. For non-restricted funds, the Trustees remain prudent in their outlook.

# **ME Research UK**

## **Trustees' Report**

### **Plans for Future Period**

The need for high quality ME research has been highlighted by the NICE process which stood squarely on the availability and standard of research to allow for the illness to be characterised, understood, and appropriate recommendations made to healthcare professionals. At the core of ME Research UK's work stands the ambition to fund such research - research which has the capacity to alter fundamentally our understanding of the illness and lead ultimately to change in patient outcomes. This has two strands, that the charity is able to offer grants of sufficient size and number to facilitate such research and that applications to ME Research UK are forthcoming from a diverse range of applicants world-wide. To this end, the charity plans to expand its capacity to engage effectively with current supporters and attract new ones on the basis of the work the charity does and thus grow its financial base. This will encompass greater research writing capacity and communications intelligence which, in turn, will advertise the charity's professionalism and funding availability to researchers globally. In addition, the PhD-level research planned, will attract new, young researchers into ME/CFS research and a point where there has never been more activity in the field and when the researchers are choosing which specialism to choose as a career. The next 12 months will see ME Research UK expand its scope and capacity at a time when its portfolio of research has never been so healthy and when its ambitions have never been so high.

### **Risk Management**

The Board of Charity Trustees has considered the major risks to which the charity is exposed and has reviewed those risks and established procedures to manage them. At their meeting on 8th Oct 2021, the Trustees adopted an updated Risk Register and the items recorded therein will remain under scrutiny.

The principle risks faced by the charity lie in continued reliance on the generosity of individual donors for income and, in the case of operational risks, from ineffective grant making and the ability of the charity to make grants, which fulfil its objectives.

It is fully anticipated that opportunities for active fundraising activity by supporters will recover albeit slowly in 2021/22; there will be (and is) increased competition between charities for donations and trust funders will see income squeezed due to anticipated challenges caused by the pandemic. These risks are containable given the financial strength of the charity both in terms of assets and in terms of low running costs.

As scientific research is largely ineligible for funding support from certain bodies, e.g. the National Lottery, and as other bodies, notably companies, prefer to support 'community based projects', ME Research UK must rely mainly on voluntary donations. The charity strives to encourage active fundraising by facilitating giving through multiple on-line platforms; supporting individual and group projects (such as Walk for ME); and by forging strong links with fundraisers. The Trustees will bolster the current fundraising model by expanding marketing activities to ensure the work of the charity and fundraising opportunities are projected as widely as possible.

The operational risk from ineffective research is managed by retaining staff, peer reviewers and Science Committee members who understand the science and research methodologies behind research. The Trustees are aware that biomedical research is expensive and that the grants provided will be insufficient for large-scale research, which is why pilot studies and seed-corn projects concerned with novel aspects of research into ME/CFS are the focus of our work. ME Research UK is open to working cooperatively with other bodies to promote high quality research into ME/CFS.

Through collaboration and skillful targeting of resources, the Trustees ensure that maximum benefit flows from funds invested and that the aims of the charity are fulfilled.

## **ME Research UK**

### **Trustees' Report**

#### **Charity Test**

The Trustees are mindful of the continuing legal duty to fulfil the charity test under the 2005 Act.

It is considered that the charity fulfils the 'public benefit' test both directly, by the provision of research grants to institutions, and also indirectly, through the dissemination of research outcomes, news and analysis to the general public and by the provision of information via our website, Facebook and meetings. Our staff are also available to answer queries from members of the public by both telephone and e-mail. There are no identifiable disbenefits in the acts of the charity or any concerns relating to private benefit.

There are considered to be no restrictive elements in the provision of information in that the Charity's website and Facebook page are freely accessible to the general public without registration and the biannual magazine 'Breakthrough' is provided completely free of charge to any individual or group which requests copies.

Access to grants is via an open grant application system where the merits of the application are judged in a peer-reviewed system based on scientific merit. The results of ME Research UK funded projects are published, enabling the wider scientific community to enjoy the benefits of the results.

Due to the nature of biomedical scientific research, there is necessarily a limited pool of potential recipient institutions; scientific research requires trained staff, appropriate facilities and administrative support. ME Research UK, however, is committed to stimulating new research into ME/CFS; encouraging scientists to enter the field; and increasing the published research base on the illness.

The Trustees keep under review the level of still to be utilised funds, and it ought to be noted that the charity does not undertake to fund research until the funds have been raised and that payment of successful grants is made to the recipient Institution in instalments. In addition, grant requests are impossible to predict, and so funds may accumulate unavoidably until suitable applications come to the charity. The Trustees continue to monitor the situation and have, and will continue to, take all opportunities to source new project opportunities.

#### **Reserves Policy**

Transfers are made from unrestricted funds to ensure that sufficient is held in restricted funds to cover the charity's grant making obligations, and to effect minor adjustments.

The Trustees have also reviewed their Reserves Policy by examining income, expenditure and risk factors prior to implementing the results.

As the Trustees do not commit to funding research projects until the full costs have been raised, the Trustees minimise financial risk. Trustees continue to monitor their Reserves Policy in implementation of OSCR's general advice to Scottish charities. Within Unrestricted Funds, three months' operating expenses (£30,000) are identified as a financial reserve. Surplus funds beyond this level are available for immediate utilisation to fund research.

In recent years, surplus revenues have accumulated as the Trustees seek relevant research projects worldwide and the level of funds held has been augmented by inflow of larger donations from trusts/charities and executry income.

There are no significant doubts as to the charity's ability to continue as a going concern.



# ME Research UK

## Trustees' Report

### Investment Policy

The Trustees adopted an Investment Policy at their meeting in January 2021. This policy is reviewable on an annual basis and this will include a report on investment returns.

Funds arising from investments are insufficient to make a material contribution to charity assets and are incidental to the charity's operation.

ME Research UK is a small charity with limited resources, the majority of which are dedicated to funding research commitments. The timing of payments to settle commitments is outwith the control of the charity.

As the timing of payments to settle research commitments is not within the control of the charity, our policy is to hold the vast majority of charity funds in cash on short-term deposit to be readily available but to seek to maximise the return. Thus, the vast majority of funds held is invested in UK banks and building societies to a) earn a competitive rate of interest on funds until they are required for use and b) to maximise deposit protection under the Financial Services Compensation Scheme.

On cash deposits, interest rates are such that growth in excess of inflation (RPI) is not possible without excessive risk or overly lengthy notice periods. The Trustees aim for a competitive rate given market conditions and need for liquidity.

As charity reserves are held on a longer basis (albeit that the investments can be traded on a daily basis), the Trustees mandated a balanced approach between income and capital growth be adopted. The Trustees wished to maintain the capital value of these Investment Funds at least in line with inflation.

Ideally, the charity's investment objective is for capital growth in excess of inflation (RPI) and a stable, growing income stream. The charity seeks to produce the best financial return within an acceptable level of risk – namely low to medium level of risk. This balances the need to generate income from investments in the short term with the requirement for longer-term growth in the value of the portfolio.

The charity's reserves are held in Charifund and Charibond investments managed actively by M&G.

### Disclosure of information to auditor

Each trustee has taken steps that they ought to have taken as a trustee in order to make themselves aware of any relevant audit information and to establish that the charity's auditor is aware of that information. The trustees confirm that there is no relevant information that they know of and of which they know the auditor is unaware.

The Annual Report was approved by the Trustees of the Charity on 19th April 2022 and signed on its behalf by:

.....

Mrs Jan McKendrick  
Secretary/Trustee

## **ME Research UK**

### **Statement of Trustees' Responsibilities**

The Trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with the United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice) and applicable law and regulations.

The law applicable to charities in Scotland requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of its incoming resources and application of resources, including its income and expenditure, for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charity's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities and Trustee Investment (Scotland) Act 2005, regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the provisions of the Constitution. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

## ME Research UK

### Independent Auditor's Report to the Members of ME Research UK

#### Opinion

We have audited the financial statements of ME Research UK (the 'charity') for the year ended 31 October 2021, which comprise the Statement of Financial Activities, Balance Sheet, Statement of Cash Flows, and Notes to the Financial Statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is United Kingdom Accounting Standards, comprising Charities SORP - FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and applicable law (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 October 2021 and of its results for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

#### Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

#### Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

#### Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

## **ME Research UK**

### **Independent Auditor's Report to the Members of ME Research UK**

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

#### **Matters on which we are required to report by exception**

In the light of our knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report.

We have nothing to report in respect of the following matters where the Charities Accounts (Scotland) Regulation 2006 (as amended) requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

#### **Responsibilities of trustees**

As explained more fully in the Statement of Trustees' Responsibilities [set out on page 24], the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

#### **Auditor's responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decision of users taken on the basis of these financial statements.

#### **Extent to which the audit was considered capable of detecting irregularities, including fraud**

We identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and then design and perform audit procedures responsive to those risks, including obtaining audit evidence that is sufficient and appropriate to provide a basis for our opinion.

## ME Research UK

### Independent Auditor's Report to the Members of ME Research UK

#### Identifying and assessing potential risks related to irregularities

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- the nature of the regulated sector, control environment and understanding of the entity including, but not restricted to, the understanding that the trustees are not remunerated, and the prevalence of fraud in the sector especially in the current uncertain economic environment;
- results of our enquiries of trustees about their own identification and assessment of the risks of irregularities;
- any matters we identified having obtained and reviewed the Charity's documentation of their policies and procedures relating to:
  - identifying, evaluating and complying with laws and regulations and whether they were aware of any instances of non-compliance;
  - detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected or alleged fraud;
  - the internal controls established to mitigate risks of fraud or non-compliance with laws and regulations;
- the matters discussed among the audit engagement team regarding how and where fraud might occur in the financial statements and any potential indicators of fraud.

As a result of these procedures, we considered the opportunities that may exist within the organisation for fraud and identified the greatest potential for fraud in relation to revenue recognition. In common with all audits under ISAs (UK), we are also required to perform specific procedures to respond to the risk of management override.

We also obtained an understanding of the legal and regulatory frameworks that the Charity operates in, focusing on provisions of those laws and regulations that had a direct effect on the determination of material amounts and disclosures in the financial statements. The key laws and regulations we considered in this context included the charity's own constitution, and various charity-specific legislation, including The Charities and Trustee Investment (Scotland) Act 2005.

Our procedures to respond to risks identified included the following:

- reviewing the financial statement disclosures and testing to supporting documentation to assess compliance with provisions of relevant laws and regulations described as having a direct effect on the financial statements;
- enquiring of Trustees concerning actual and potential litigation and claims;
- performing analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud;
- reading minutes of meetings of those charged with governance;
- tested a sample of income for understatement and other relevant audit procedures while consideration was given to revenue recognition;
- tested a sample of expenditure for overstatement and other relevant procedures;

## ME Research UK

### Independent Auditor's Report to the Members of ME Research UK

- in addressing the risk of fraud through management override of controls, testing the appropriateness of journal entries and other adjustments; assessing whether the judgements made in making accounting estimates are indicative of a potential bias; and evaluating the business rationale of any significant transactions that are unusual or outside the normal course of business.

We also communicated relevant identified laws and regulations and potential fraud risks to all engagement team members and remained alert to any indications of fraud or non-compliance with laws and regulations throughout the audit.

Due to the inherent limitations of an audit, there is an unavoidable risk that we may not have detected some material misstatements in the financial statements, even though we have properly planned and performed our audit in accordance with auditing standards. For example, as with any audit, there remained a higher risk of non-detection of irregularities, as these may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal controls. We are not responsible for preventing fraud or non-compliance with laws and regulations and cannot be expected to detect all fraud and non-compliance with laws and regulations.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

#### Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Section 44 (1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and Regulation 10 of the Charities Accounts (Scotland) Regulations 2006 (as amended). Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and its trustees as a body, for our audit work, for this report, or for the opinions we have formed.

.....  
Morris & Young, Statutory Auditor  
Eligible to act as an auditor in terms of section 1212 of the Companies Act 2006  
Chartered Accountants  
6 Atholl Crescent  
PERTH  
PH1 5JN

Date:.....

## ME Research UK

### Statement of Financial Activities for the Year Ended 31 October 2021 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2021 £	Unrestricted funds £	Restricted funds £	Total 2020 £
<b>Income and Endowments from:</b>							
Donations and legacies	3	441,472	152,738	594,210	250,178	475,515	725,693
Other trading activities	4	8,488	-	8,488	7,091	-	7,091
Investment income	5	3,625	5,829	9,454	4,281	7,671	11,952
Total Income		<u>453,585</u>	<u>158,567</u>	<u>612,152</u>	<u>261,550</u>	<u>483,186</u>	<u>744,736</u>
<b>Expenditure on:</b>							
Raising funds	6	(59,099)	(113)	(59,212)	(71,255)	(25)	(71,280)
Charitable activities	7	(70,009)	(584,109)	(654,118)	(105,645)	(220,862)	(326,507)
Total Expenditure		(129,108)	(584,222)	(713,330)	(176,900)	(220,887)	(397,787)
Gain/(loss) on investment assets		8,305	-	8,305	(9,045)	-	(9,045)
Net income/(expenditure)		<u>332,782</u>	<u>(425,655)</u>	<u>(92,873)</u>	<u>75,605</u>	<u>262,299</u>	<u>337,904</u>
Net movement in funds		332,782	(425,655)	(92,873)	75,605	262,299	337,904
<b>Reconciliation of funds</b>							
Total funds brought forward		<u>528,575</u>	<u>1,180,434</u>	<u>1,709,009</u>	<u>452,970</u>	<u>918,135</u>	<u>1,371,105</u>
Total funds carried forward	21	<u><u>861,357</u></u>	<u><u>754,779</u></u>	<u><u>1,616,136</u></u>	<u><u>528,575</u></u>	<u><u>1,180,434</u></u>	<u><u>1,709,009</u></u>

All of the charity's activities derive from continuing operations during the above two periods.

The funds breakdown for 2020 is shown in note 21.

## ME Research UK

### (Registration number: SC036942) Balance Sheet as at 31 October 2021

	Note	2021 £	2020 £
<b>Fixed assets</b>			
Tangible assets	13	2,061	-
Investments	14	<u>47,166</u>	<u>38,861</u>
		<u>49,227</u>	<u>38,861</u>
<b>Current assets</b>			
Stocks	15	1,568	1,825
Debtors	16	201,357	236,481
Cash at bank and in hand	17	<u>2,267,811</u>	<u>1,854,906</u>
		2,470,736	2,093,212
<b>Creditors: Amounts falling due within one year</b>	18	<u>(564,185)</u>	<u>(332,017)</u>
<b>Net current assets</b>		<u>1,906,551</u>	<u>1,761,195</u>
<b>Total assets less current liabilities</b>		1,955,778	1,800,056
<b>Creditors: Amounts falling due after more than one year</b>	19	<u>(339,642)</u>	<u>(91,047)</u>
<b>Net assets</b>		<u>1,616,136</u>	<u>1,709,009</u>
<b>Funds of the charity:</b>			
<b>Restricted income funds</b>			
Restricted funds	21	754,779	1,180,434
<b>Unrestricted income funds</b>			
Unrestricted funds		<u>861,357</u>	<u>528,575</u>
<b>Total funds</b>	21	<u>1,616,136</u>	<u>1,709,009</u>

The financial statements on pages 29 to 46 were approved by the trustees, and authorised for issue on 19 April 2022 and signed on their behalf by:

.....  
Mrs Jan McKendrick  
Secretary/Trustee

.....  
Mrs Lesley J Carr  
Trustee



## ME Research UK

### Statement of Cash Flows for the Year Ended 31 October 2021

	Note	2021 £	2020 £
<b>Cash flows from operating activities</b>			
Net cash (expenditure)/income		(92,873)	337,904
<b>Adjustments to cash flows from non-cash items</b>			
Depreciation	13	1,031	279
Investment income	5	(9,454)	(11,952)
(Gain)/loss on investment assets		<u>(8,305)</u>	<u>9,045</u>
		(109,601)	335,276
<b>Working capital adjustments</b>			
Decrease/(increase) in stocks	15	257	(417)
Decrease/(increase) in debtors	16	35,124	(215,172)
Increase in creditors	18	<u>480,763</u>	<u>166,404</u>
Net cash flows from operating activities		<u>406,543</u>	<u>286,091</u>
<b>Cash flows from investing activities</b>			
Interest receivable and similar income	5	7,802	10,456
Purchase of tangible fixed assets	13	(3,092)	-
Purchase of investments	14	-	(10,000)
Income from dividends	5	<u>1,652</u>	<u>1,496</u>
Net cash flows from investing activities		<u>6,362</u>	<u>1,952</u>
Net increase in cash and cash equivalents		412,905	288,043
Cash and cash equivalents at 1 November		<u>1,854,906</u>	<u>1,566,863</u>
Cash and cash equivalents at 31 October		<u>2,267,811</u>	<u>1,854,906</u>

All of the cash flows are derived from continuing operations during the above two periods.

# ME Research UK

## Notes to the Financial Statements for the Year Ended 31 October 2021

### 1 Charity status

ME Research UK is a Scottish Charitable Incorporated Organisation (SCIO) and is registered with the Office of the Scottish Charity Regulator under Charity Number SC036942.

The address of its registered office is:

The Gateway  
North Methven Street  
PERTH  
PH1 5PP

### 2 Accounting policies

#### Summary of significant accounting policies and key accounting estimates

The principal accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all the years presented, unless otherwise stated.

The financial statements are presented in Sterling (£). The financial statements are rounded to the nearest £1.

#### Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended).

ME Research UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

#### Going concern

At the time of approving the financial statements, the Trustees have a reasonable expectation that the Charity has adequate resources to continue in operational existence for the next 12 months. Thus the Trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

#### Income and endowments

All income is recognised once the charity has entitlement to the income, it is probable that the income will be received and the amount of the income receivable can be measured reliably.

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### ***Donations and legacies***

Donations and legacies are recognised on a receivable basis when receipt is probable and the amount can be reliably measured.

Incoming resources from tax reclaims are included in the statement of financial activities at the same time as the gift to which they relate.

#### ***Investment income***

Investment income is recognised on a receivable basis.

#### ***Other income***

The value of any voluntary help received is not included in the financial statements but is described in the Trustees' Report.

#### **Expenditure**

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

#### ***Raising funds***

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

#### ***Charitable activities***

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

#### ***Grant expenditure***

Grants payable are payments made to third parties in the furtherance of the charitable objectives.

Where the charity gives a grant with conditions for its payment being a specific level of service or output to be provided, the grant has been recognised in the accounts on a prudent basis.

Grants payable without performance conditions are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.

#### ***Grant provisions***

Provisions for grants are made when the intention to make a grant has been communicated to the recipient but there is uncertainty about either the timing of the grant or the amount of grant payable.

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocation property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

#### Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees' meetings and reimbursed expenses.

#### Tangible fixed assets

Individual fixed assets costing £500 or more are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

#### Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Depreciation method and rate
Fixtures and fittings	33% straight line

#### Fixed asset investments

Fixed asset investments, other than programme related investments, are included at market value at the balance sheet date. Realised gains and losses on investments are calculated as the difference between sales proceeds and their market value at the start of the year, or their subsequent cost, and are charged or credited to the Statement of Financial Activities in the period of disposal.

Unrealised gains and losses represent the movement in market values during the year and are credited or charged to the Statement of Financial Activities based on the market value at the year end.

#### Stock

Stock is valued at the lower of cost and estimated selling price less costs to complete and sell, after due regard for obsolete and slow moving stocks. Items donated for resale or distribution are not included in the financial statements until they are sold or distributed.

#### Foreign exchange

Transactions in foreign currencies are recorded at the rate of exchange at the date of the transaction. Monetary assets and liabilities denominated in foreign currencies at the balance sheet date are reported at the rates of exchange prevailing at that date.

#### Fund structure

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity.

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

#### Financial instruments

The charity only has financial assets and liabilities of a kind that would qualify as basic financial instruments which are recognised at their transaction value and subsequently measured at their settlement value.

#### 3 Income from donations and legacies

	Unrestricted funds £	Restricted funds £	Total 2021 £	Unrestricted funds £	Restricted funds £	Total 2020 £
Donations and legacies;						
Donations from companies, trusts and similar proceeds	1,237	-	1,237	421	-	421
Donations from individuals	132,617	85,777	218,394	158,557	168,444	327,001
Legacies	296,300	60,019	356,319	75,667	303,263	378,930
Gift Aid reclaimed	<u>11,318</u>	<u>6,942</u>	<u>18,260</u>	<u>15,533</u>	<u>3,808</u>	<u>19,341</u>
	<u><u>441,472</u></u>	<u><u>152,738</u></u>	<u><u>594,210</u></u>	<u><u>250,178</u></u>	<u><u>475,515</u></u>	<u><u>725,693</u></u>

#### 4 Income from other trading activities

	Unrestricted funds £	Total 2021 £	Unrestricted funds £	Total 2020 £
Trading income;				
Other trading income	<u>8,488</u>	<u>8,488</u>	<u>7,091</u>	<u>7,091</u>
	<u><u>8,488</u></u>	<u><u>8,488</u></u>	<u><u>7,091</u></u>	<u><u>7,091</u></u>

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 5 Investment income

	Unrestricted funds £	Restricted funds £	Total 2021 £	Unrestricted funds £	Restricted funds £	Total 2020 £
Income from dividends; Dividends receivable from other listed investments	1,652	-	1,652	1,496	-	1,496
Interest receivable and similar income; Interest receivable on bank deposits	1,973	5,829	7,802	2,785	7,671	10,456
	<u>3,625</u>	<u>5,829</u>	<u>9,454</u>	<u>4,281</u>	<u>7,671</u>	<u>11,952</u>

#### 6 Expenditure on raising funds

	Unrestricted funds £	Restricted funds £	Total 2021 £	Unrestricted funds £	Restricted funds £	Total 2020 £
Staff costs	6,760	-	6,760	9,984	-	9,984
Communication costs	3,616	-	3,616	2,829	-	2,829
Office and accommodation costs	2,448	-	2,448	2,476	-	2,476
Fundraising costs and fees	3,070	53	3,123	2,785	-	2,785
Advertising	39,856	-	39,856	41,571	-	41,571
Costs of goods sold	3,131	-	3,131	2,989	-	2,989
Other	218	60	278	8,621	25	8,646
	<u>59,099</u>	<u>113</u>	<u>59,212</u>	<u>71,255</u>	<u>25</u>	<u>71,280</u>

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 7 Expenditure on charitable activities

	Unrestricted funds £	Restricted funds £	Total 2021 £	Unrestricted funds £	Restricted funds £	Total 2020 £
Research grant funding	-	577,746	577,746	-	220,787	220,787
Staff costs	48,358	-	48,358	90,198	-	90,198
Accommodation	5,985	-	5,985	5,881	-	5,881
Breakthrough costs	10,075	-	10,075	3,694	-	3,694
Trustee travel and accommodation costs	217	-	217	1,995	-	1,995
Employee travel and accommodation costs	81	-	81	156	-	156
Other	600	6,363	6,963	421	75	496
Advertising	1,093	-	1,093	-	-	-
Governance costs	3,600	-	3,600	3,300	-	3,300
	<u>70,009</u>	<u>584,109</u>	<u>654,118</u>	<u>105,645</u>	<u>220,862</u>	<u>326,507</u>

Other costs include £6,363 (2020: £75) relating to a foreign currency exchange difference. The charity agreed to fund two projects in US Dollars during 2019 and purchased this currency when the funding was contractually agreed. The US Dollars balance held at 31 October 2021 were translated into £ Sterling at the balance sheet date.

#### 8 Analysis of governance and support costs

##### Governance costs

	Unrestricted funds General £	Total 2021 £	General £	Total 2020 £
Audit fee	3,600	3,600	3,300	3,300
	<u>3,600</u>	<u>3,600</u>	<u>3,300</u>	<u>3,300</u>

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 9 Grant-making

Grants payable at 1 November 2020	412,194
Grants paid	(92,853)
New grants committed	577,746
Grants payable at 31 October 2021	897,087

<b>Institution</b>	<b>Title of Project</b>	<b>Grants paid 2021</b>	<b>Grants committed 2021</b>	<b>Payable 2021</b>	<b>2020</b>
University of Dundee	37 Insights into Pathophysiology of CFS/ME	7,846	-	12,473	20,319
University of Alabama at Birmingham	47 Tracking peripheral immune cell infiltration of the brain in ME	-	-	113,901	113,901
University of Vermont College of Medicine	48 Exploring an anti-citrullinated antibody signature in ME/CFS	-	-	14,868	14,868
Oxford Brookes University	49 Investigating sensory processing and cognitive function in people with ME: a pilot study	9,880	-	9,881	19,761
University of Applied Sciences, Graz, Austria	50 Role of Sirt1/NOS axis in vascular and immune homeostasis: A missing piece in the ME/CFS puzzle?	1,452	1,452	22,558	22,558
Universiteit Brussel	51a Unravelling the role of epigenetic modification on the brain derived neurotrophic factor gene and histone de-acetylases for pain and post-exertional malaise in people with myalgic encephalomyelitis / chronic fatigue syndrome	-	-	39,494	39,494
Universiteit Leuven	51b Unravelling the role of epigenetic modification on the brain derived neurotrophic factor gene and histone de-acetylases for pain and post-exertional malaise in people with myalgic encephalomyelitis / chronic fatigue syndrome	17,335	-	34,670	52,005
Carried forward to page 39		36,513	1,452	247,845	282,906



## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

Institution	Title of Project	Grants	Grants	Payable	
		paid	committed	2021	2020
		2021	2021	2021	2020
Continued from page 38		36,513	1,452	247,845	282,906
University of Newcastle	52 Voices of the ignored and invisible: The experience of living with severe CFS/ME	8,736	-	-	8,736
Charité University, Berlin	53 The role of autoantibodies in ME/CFS	24,804	6,542	26,290	44,552
University of Valencia	54 Metabolic impact of activated HERVs and associated innate immune response in severe ME: towards disease modelling	22,800	-	53,200	76,000
University of Newcastle	55 ELUCIDATE: Exploring pain and autonomic dysfunction in ME/CFS and temporomandibular disorders	-	13,576	13,576	-
Universitait Wurzburg	56 Infectious triggers and mitochondrial dysfunction in ME/CFS	-	207,100	207,100	-
Griffith University	57 Investigating brain-stem dysfunction in ME/CFS using 7-Tesla MRI	-	151,000	151,000	-
La Trobe University	58 Cell-type specificity, molecular scope and epigenetic basis for mitochondrial and cellular dysfunction in ME/CFS	-	198,076	198,076	-
		92,853	577,746	897,087	412,194

As stated in the Trustees' Report, each of these projects relate to research which advances the objectives of the charity.

#### 10 Trustees remuneration and expenses

One Trustee was reimbursed for travelling expenses totalling £217.17 during the year (2020: £1,975.58). No Trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 11 Staff costs

The aggregate payroll costs were as follows:

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
<b>Staff costs during the year were:</b>		
Wages and salaries	51,560	91,550
Social security costs	3,558	8,632
	<u>55,118</u>	<u>100,182</u>

The average number of employees (full time equivalent) during the year was:

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Charitable activities	0.9	1.4
Fundraising	0.2	0.2
Governance	0.7	1.0
	<u>1.8</u>	<u>2.6</u>

No employee received emoluments of more than £60,000 during the year.

The total employee remuneration (including taxable benefits and employer's pension contributions) of the key management personnel of the charity was £Nil (2020 - £20,227).

#### 12 Taxation

No corporation tax was charged during the year (2020: £nil). ME Research UK is a registered charity and has been accepted as a charity for tax purposes.

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 13 Tangible fixed assets

	Furniture and equipment £	Total £
<b>Cost</b>		
At 1 November 2020	5,917	5,917
Additions	3,092	3,092
Disposals	(1,117)	(1,117)
At 31 October 2021	<u>7,892</u>	<u>7,892</u>
<b>Depreciation</b>		
At 1 November 2020	5,917	5,917
Charge for the year	1,031	1,031
Eliminated on disposals	(1,117)	(1,117)
At 31 October 2021	<u>5,831</u>	<u>5,831</u>
<b>Net book value</b>		
At 31 October 2021	<u>2,061</u>	<u>2,061</u>
At 31 October 2020	<u>-</u>	<u>-</u>

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 14 Fixed asset investments

##### Other investments

	<b>Listed investments £</b>	<b>Total £</b>
<b>Cost or Valuation</b>		
At 1 November 2020	38,861	38,861
Revaluation	<u>8,305</u>	<u>8,305</u>
At 31 October 2021	<u>47,166</u>	<u>47,166</u>
<b>Net book value</b>		
At 31 October 2021	<u>47,166</u>	<u>47,166</u>
At 31 October 2020	<u>38,861</u>	<u>38,861</u>

The market value of the listed investments at 31 October 2021 was £47,166 (2020 - £38,861).

All investment assets were held in the UK.

#### 15 Stock

	<b>2021 £</b>	<b>2020 £</b>
Stock	<u>1,568</u>	<u>1,825</u>

#### 16 Debtors

	<b>2021 £</b>	<b>2020 £</b>
Other debtors	<u>201,357</u>	<u>236,481</u>

#### 17 Cash and cash equivalents

	<b>2021 £</b>	<b>2020 £</b>
Cash at bank	<u>2,267,811</u>	<u>1,854,906</u>

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 18 Creditors: amounts falling due within one year

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Other creditors	557,443	321,148
Accruals	6,742	10,869
	<u>564,185</u>	<u>332,017</u>

#### 19 Creditors: amounts falling due after one year

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Other creditors	<u>339,642</u>	<u>91,047</u>

#### 20 Obligations under leases and hire purchase contracts

The total value of future minimum lease payments was as follows:

	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Within one year	<u>2,318</u>	<u>2,318</u>

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 21 Funds

	Balance at 1 November 2020 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 October 2021 £
<b>Unrestricted funds</b>					
<i>General</i>					
Unrestricted funds	528,575	453,585	(129,108)	8,305	861,357
<b>Restricted funds</b>					
Restricted funds	<u>1,180,434</u>	<u>158,567</u>	<u>(584,222)</u>	<u>-</u>	<u>754,779</u>
<b>Total funds</b>	<u><u>1,709,009</u></u>	<u><u>612,152</u></u>	<u><u>(713,330)</u></u>	<u><u>8,305</u></u>	<u><u>1,616,136</u></u>
	Balance at 1 November 2019 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 October 2020 £
<b>Unrestricted funds</b>					
<i>General</i>					
Unrestricted funds	452,970	261,550	(176,900)	(9,045)	528,575
<b>Restricted funds</b>					
Restricted funds	<u>918,135</u>	<u>483,186</u>	<u>(220,887)</u>	<u>-</u>	<u>1,180,434</u>
<b>Total funds</b>	<u><u>1,371,105</u></u>	<u><u>744,736</u></u>	<u><u>(397,787)</u></u>	<u><u>(9,045)</u></u>	<u><u>1,709,009</u></u>

The specific purposes for which the funds are to be applied are as follows:

Restricted Funds are for the purpose of grant-making for research projects.

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 22 Analysis of net assets between funds

	<b>Unrestricted Funds</b>	<b>Restricted funds</b>	<b>Total funds 2021</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Tangible fixed assets	2,061	-	2,061
Fixed asset investments	47,166	-	47,166
Current assets	818,818	1,651,918	2,470,736
Current liabilities	(6,688)	(557,497)	(564,185)
Creditors over 1 year	-	(339,642)	(339,642)
<b>Total net assets</b>	<b><u>861,357</u></b>	<b><u>754,779</u></b>	<b><u>1,616,136</u></b>

	<b>Unrestricted funds</b>	<b>Restricted funds</b>	<b>Total funds 2020</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Tangible fixed assets	38,861	-	38,861
Current assets	500,583	1,592,629	2,093,212
Current liabilities	(10,869)	(321,148)	(332,017)
Creditors over 1 year	-	(91,047)	(91,047)
<b>Total net assets</b>	<b><u>528,575</u></b>	<b><u>1,180,434</u></b>	<b><u>1,709,009</u></b>

#### 23 Analysis of net funds

	<b>At 1 November 2020</b>	<b>Financing cash flows</b>	<b>At 31 October 2021</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Cash at bank and in hand	<u>1,854,906</u>	<u>412,905</u>	<u>2,267,811</u>
Net debt	<u>1,854,906</u>	<u>412,905</u>	<u>2,267,811</u>

	<b>At 1 November 2019</b>	<b>Financing cash flows</b>	<b>At 31 October 2020</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Cash at bank and in hand	<u>1,566,863</u>	<u>288,043</u>	<u>1,854,906</u>
Net debt	<u>1,566,863</u>	<u>288,043</u>	<u>1,854,906</u>

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2021

#### 24 Related party transactions

##### Controlling entity

The charity is controlled by the Trustees of the charity.

##### Related party transactions

##### Edward Dunkerley (Trustee)

Vital Hike Limited, a business co-owned by Edward Dunkerley, was paid for consultancy services provided. Amounts paid during the year were £nil (2020 - £4,800) for consultancy services to the above company. At the balance sheet date the amount due to Vital Hike Limited was £nil (2020 - £nil). Vital Hike Limited was selected for their services after a tender process.

The following relationships exist between the Trustees who have served at any time during the year and connected Projects which have been granted funding. The Trustees do not participate in deliberations relating to and do not vote on, decisions affecting the Project with which they are connected. The related parties are:

##### Prof Faisal Khan (Trustee)

##### Insights into Pathophysiology of CFS/ME

The above Project was paid funding of £7,846 during the year (2020 - £nil). £12,473 remains payable at 31 October 2021 (2020 - £20,319). This is recognised in grants payable at the year-end. Prof Khan joined the Board after the decision was made to award this Project a grant and was not involved in the decision to award additional funding.

##### Dr Eleanor Roberts (Trustee)

Beeline Science Communications Ltd, a business owned by Dr Eleanor Roberts, was contracted to provide additional writing capacity aligned to a specific agreed schedule of work to the charity following the departure of ME Research UK's Science & Engagement Director. Amounts paid during the year were £5,070 (2020: £nil). At the balance sheet date the amount due to Beeline Science Communications Ltd was £nil (2020: £nil). Dr Roberts was not involved in any decisions regarding the awarding of the contract.