

ME RESEARCH UK

ANNUAL REPORT & ACCOUNTS 2019/2020



ME Research UK

Contents

Reference and Administrative Details	1
Trustees' Report	2
Chair's Introduction	2
The Illness	3
Objectives	4
Achievements and Performance	6
A. Investing in Research	6
B. Informing	12
C. Influencing	14
Structure, Governance and Procedures	14
Accounting Matters	17
Statement of Trustees' Responsibilities	21
Independent Auditor's Report	22-24
Statement of Financial Activities	25
Balance Sheet	26
Statement of Cash Flows	27
Notes to the Financial Statements	28-42

ME Research UK

Reference and Administrative Details

Charity name	ME Research UK
Charity registration number	SC036942
Trustees	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 (from 6 th March 2020)
Founding Patron	Roger Jefcoate CBE DL
Patron	The Countess of Mar
Honorary Presidents	Robert D McRae Dr Vance A Spence
Chief Executive Officer	Simon Phillips (to 13/03/2020)
Registered Office	The Gateway North Methven Street Perth PH1 5PP
Telephone	01738 451234
Email	contact@meresearch.org.uk
Web	www.meresearch.org.uk
Facebook	MEResearchUK
Twitter	MEResearchUK
Auditor	Morris and Young Chartered Accountants 6 Atholl Crescent Perth PH1 5JN

ME Research UK

Trustees' Report

Introduction by the Chair



It gives me great pleasure to present our latest Annual Report and Accounts 2019/20, which reflect our continued focus on delivering our strategy. The second half of the year has of course been dominated by the global Covid19 pandemic, which has had such a significant impact on all of us.

We have adopted successfully to new ways of working and to accommodate all the restrictions placed on us as individuals and as an organisation. The dedication and commitment of our staff team, in particular, has meant that we have continued to make progress towards achieving our strategic goals and we are also fortunate in the extreme to end our financial year with a healthy balance sheet and an enhanced portfolio of important research projects.

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.

It is now just over twenty years since the formation of our charity and we finish the year tantalisingly close to reaching the milestone of £2 million in cumulative research funding. We have a healthy pipeline of research grant applications under review and I am confident that the coming year will see us approve further significant grant funding.

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 are well funded currently and have ambitious plans for the coming years, which we are determined to achieve.

We are committed to encourage further both young and established researchers into the field of ME research, with a call for PhD funding applications being issued in the year alongside a general call for research applications. We also increased our capacity to proactively engage with the research community and provide the best possible information and insight to all our stakeholders.

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 2019 to 31st October 2020 – see Note 1 to the accounts. The financial statements have been prepared in accordance with the accounting policies set out in Note 1 to the accounts and comply with the charity's Constitution dated 3rd June 2019; the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended); and the requirements of the Office of the Scottish Charity Regulator (OSCR).

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. The World Health Organisation's 'International Classification of Disease' lists ME as a disorder of the nervous system, under 'Post-Viral Fatigue Syndrome'.

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. For this reason, there have been a number of attempts to devise a more sensitive way of diagnosing patients.

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 biomedical illness, neurological signs and symptoms.

The evidence across many studies is that between 120,000 and 240,000 people in the UK have ME/CFS, a prevalence higher than HIV infection or multiple sclerosis. It is twice as commonly reported in women as men. Studies indicate that most people with ME/CFS are unable to work to full capacity, and that a significant number (from 10 to 25%) are effectively house or bed-bound. It is known that ME/CFS affects all social groups and all ages, including children. The course of the illness can be extremely variable; some people improve quite quickly, while many others develop stable chronic illness, and a few experience a severe and debilitating downward course over many years. A report to the Chief Medical Officer of England in 2002 stated that ME/CFS "is a genuine illness and imposes a substantial burden on the health of the UK population. Improvement of health and social care for people affected by the condition is an urgent challenge", and this remains true today. Indeed, as the NICE Clinical Guideline (CG 53) states: "The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions."

Yet, 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£1.9 million in biomedical research world-wide on 54 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 the cause(s) of the illness and its effects in the desire to discovering a treatment or a cure for this most disabling of illnesses.

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, COVID-19 and the Year in Review

2020 has proven to be a year of unprecedented challenges to individuals, organisations and governments. ME Research UK has not been immune from the upheaval caused by the coronavirus pandemic but it is a testament to the hard work of its staff and the staunch support of its friends that the charity's work has not only continued but expanded in 2020.

Thanks largely to the funds provided by legacies and a family trust, ME Research UK launched a global call for research applications in spring 2020 and heralded a new PhD funding initiative. By launching at this time, the charity made a commitment to support the ME research-base at a point where other sources of finance were uncertain. It also allowed a 12-month no-cost extension to current project fundees, as many researchers were unable to work at their Institutions due to coronavirus restrictions. Through these actions, the charity aided stability and offered hope to researchers.

The Trustees welcomed Dr Louise Crozier to the charity (April 2020) in the newly created role of Science & Engagement Director. A feature of this role is to engage pro-actively with researchers worldwide and to facilitate and stimulate research whilst ensuring that ME Research UK's work and research generally is communicated effectively to supporters, researchers and the public.

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 where possible to achieve these aims.

As prudent stewards of ME Research UK's funds and managing their duties as Trustees, the Board has monitored carefully the impact of coronavirus on the charity and its work. Trustees are heartened to note that regular donees have continued to support the charity despite possible uncertainty in their own personal finances. May, traditionally a strong month for fundraising as ME Awareness Week is the focus of many fundraising opportunities e.g. Walk for ME and Tea for ME, saw little fundraising activity. The charity reacted by transforming Tea for ME to Tea with ME to connect families, carers and those with ME/CFS at a difficult time. ME Research UK is not alone in seeing fundraising income dropping considerably as events were cancelled as lockdown hit. It is probable that fundraising activity will be depressed in the coming year as well, but activity-based fundraising remains only one part of ME Research UK's fundraising mix.

ME Research UK

Trustees' Report

The charity is fortunate in the extreme to have benefitted from Estate and family trust income and allied with rigorous financial controls means that the charity is robust financially. Despite a decrease in donation and fundraising income due to the pandemic, ME Research UK has begun to implement its programme of transformative change – building on the sound foundation of the past whilst aspiring to maximise the impact of ME research in the future.

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

ME Research UK is in a strong financial position given executry income and a funding model that means that it does not commit to projects without having funds available to service the liability.

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

For researchers, many of whom are still dislocated from their laboratories, the coronavirus pandemic has presented unique challenges. ME Research UK, through the Science and Engagement Director and Research & Communications Director, has contacted researchers to assure them of the charity's support and indeed, opportunities for further investment in new projects.

To the best of its ability, the charity plans for future growth and to fulfil its mission to inform, influence and invest in ME research.

Covid-19 has had an unexpected impact on the perception and interest in ME/CFS in that it has been estimated that up to 10% people affected by coronavirus have not recovered fully and experience some symptoms akin to those relevant to ME/CFS. These 'long-Covid' experiences have been covered widely in the world's media and their interactions with the medical profession, employers and family/friends has shone a light on the lived reality of those with ME/CFS. The perception of those with long-Covid has however been far more positive than many with ME/CFS have reported historically. The Covid related experiences of a post viral illness has sparked interest in the wider research sphere and the results may, tangentially, throw a light on ME/CFS's causes and expression. ME Research UK stands ready to fund exploration of links with long-Covid sufferers.

The charity year has also seen a number of important advances in the ME research world. From nascent attempts in the US Congress and EU Parliament to oblige dedicated funding for research into ME/CFS and the creation of research centres, to the welcome £3.2m funding of the DecodeME study by the Medical Research Council and National Institute for Health Research in the UK and the research activity caused by Covid-19. DecodeME is a partnership of various bodies including Forward-ME of which ME Research UK is an active member.

In the UK, the All-Party Group on ME/CFS was re-established at Westminster and in the Scottish Parliament, the Petitions Committee obtained assurances of progress in research, education and support from the Scottish Government.

ME Research UK

Trustees' Report

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. 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 £220,787 (2019 (£201,785.08) in four ME research projects. This represents a 10% increase over last year and comprises four additional projects in four countries. The figures include Prof Oltra's award that was granted and offered prior to the charity's reporting year-end but the Institution involved had yet to finalise signing formalities.

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 thirteen (2018/19 - twelve) applications were received in the year, of which five were not progressed to the full application stage. Of the remaining eight applications, five have progressed from outline to full application status. The remaining three outline applications are either presently being considered by the Science Committee or are awaited. 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.

The number of applications bodes well for progress in research in 2020/2021 and for the reputation and future evolution of the charity beyond the current year. The applications before us, if funded, would cost approximately £965,000 (£215,000) - a four-fold increase - which illustrates the necessity of a research-centred charity devoted to biomedical research into ME/CFS but also the need to increase the research base within the scientific community and to provide greater funding through sustainable and expanding fundraising efforts.

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.

ME Research UK

Trustees' Report

1. New Research Projects in 2019/20

(a) Contracted for

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

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

ii. Project 52 - Prof. Julia Newton and Victoria Strassheim, Newcastle University

Voices of the ignored and invisible: The experience of living with severe CFS/ME

£8,736 over 6 months

Approximately a quarter of people with ME/CFS can be categorised as having severe or very severe illness, and may need a wheelchair to get around, or be house- or even bed-bound. Despite the considerable impact of their illness on these individuals' health and wellbeing, their poor quality of life, and the restrictions on their day-to-day activities, very little research has been done on severe and very severe ME/CFS. This is largely because the health burdens on these people makes it very difficult for them to engage with research. In a previous study, the investigators visited five patients with severe ME/CFS, who underwent a number of assessments and took part in a recorded, semi-structured interview. The researchers now plan to analyse these recordings in more detail, to identify patterns in the participants' responses. There are three main goals: to explore the personal experience of individuals with severe ME/CFS; to find themes that may help identify factors placing people at greater risk of experiencing severe and very severe ME/CFS; and to provide a better understanding of this population to enable the research and practice community to engage with them more effectively.

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

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

£44,552 over 1 year

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.

ME Research UK

Trustees' Report

(b) Funding Awarded in 2019/20 but yet to be contracted for

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

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

£76,000 over 30 months

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.

2. Completed Projects

a. Reported and Grant Liability Ended

Project 45 - Prof. Mark Walker, Newcastle University Investigating abnormalities in AMPK activation and mitochondrial function in primary skeletal muscle cell cultures from patients with ME/CFS

£85,517.64 over 33 months

After a change in personnel at the beginning of the study, and a no-cost extension of 9 months, this project ended in December 2019 with a final report submitted in February 2020. The research has yielded three publications, the most recent of which is detailed below. In summary, the researchers have demonstrated that the AMPK activator, compound 991, is able to activate AMPK in muscle cells from patients with ME/CFS, thereby compensating for the impaired AMPK activation they measured previously. AMPK has an important role in regulating energy in the cell. These findings provide the foundation for future clinical trials of pharmacological activation of AMPK in patients with ME/CFS. In addition, metabolic studies have identified PDH/PK as a potential bottleneck limiting glucose metabolism in ME/CFS.

ME Research UK

Trustees' Report

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

Project 48 - Prof. Mercedes Rincon, University of Vermont
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 with a final report submitted in January 2020. However, this has been delayed by Prof. Rincon moving research Institutions, and subsequently by the COVID-19 pandemic meaning the temporary closure of laboratories. The assays have been completed and the results are (as at 31st Oct 2020) being analysed, with a report anticipated before end of 2020. ME Research UK's Standard Grant Conditions ensure that charity funds are paid only upon receipt of an acceptable Final Report.

2. On-Going Projects

Ongoing projects, initiated in previous financial years, payable (subject to progress) in 2019/20 – Sums due represent total funding commitment.

a. 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-targetted treatments in other conditions characterised by elevated oxidative stress, such as cancer, diabetes and liver disease.

ME Research UK

Trustees' Report

b. 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.

c. 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

d. 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?

£43,375

Inflammation is part of the body's defence mechanism and healing process, involving an increase in blood flow to an injured area, and the migration of protective immune cells into the tissue to combat infection and repair damage. Sometimes inflammation can persist for longer than required, or be triggered unnecessarily, and this may itself cause damage. Inflammation has been implicated in a number of conditions affecting the cardiovascular system, specifically its impact on the function of the endothelium. One of the ways the endothelium controls blood flow is through the release of nitric oxide. However, while it is essential in normal endothelial function (and is also involved in the central nervous system), too much can be damaging and lead to prolonged inflammation. Dr Westermeier is exploring this complicated relationship in more detail by looking at whether the cellular mechanisms that control nitric oxide production are altered in ME/CFS. Using blood samples obtained from the UK ME/CFS Biobank, he will assess levels of nitric oxide and the proteins involved in its production (Sirt1, eNOS and Arg1). He will also investigate whether this is altered in endothelial cells that have been exposed to blood plasma from people with ME/CFS. The researchers hope their findings will throw new light onto the role of these complex mechanisms in ME/CFS, and possibly identify new biomarkers of endothelial dysfunction in the illness.

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 54 specific grants totalling c£1.9 million, 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.

Four papers were published in the charity year 2019/20 (2018/19 - six) acknowledging the support of ME Research UK.

a. IgG stimulated β 2 adrenergic receptor activation is attenuated in patients with ME/CFS

Jelka Hartwig, Franziska Sotzny, Sandra Bauer, Harald Heidecke, Gabriela Riemekasten, Duska Dragun, Christian Meisel, Claudia Dames, Patricia Grabowski, Carmen Scheibenbogen

Brain, Behavior, & Immunity - Health, 2020 March; 3:100047

The key finding of this study is that, in a subgroup of ME/CFS patients with increased autoantibody levels, the activation of adrenergic receptors by immunoglobulin is lower than normal. This suggests that many of the symptoms of the illness - such as immune activation and autonomic abnormalities - may be mediated or made worse by dysfunction of these receptors. The authors suggest that targeting of the adrenergic system may therefore have potential as a treatment for ME/CFS.

b. Does motor cortex engagement during movement preparation differentially inhibit nociceptive processing in patients with chronic whiplash associated disorders, chronic fatigue syndrome and healthy controls? An experimental study

Lisa Goudman, André Mouraux, Liesbeth Daenen, Jo Nijs, Patrick Cras, Nathalie Roussel, Maarten Moens, Dorine Lenoir, Iris Coppieters, Eva Huysmans, Margot De Kooning

Journal of Clinical Medicine, 2020 May 18; 9(5):1520

Preparing for movement is associated with inhibition of nociception - the body's sensory response to harmful or painful stimuli. In this study, the extent of this inhibition was similar in patients with ME/CFS, those with chronic whiplash-associated disorders, and healthy control subjects. The results therefore do not support the idea that this mechanism is impaired in these patient groups.

ME Research UK

Trustees' Report

c. The effect of myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS) severity on cellular bioenergetic function

Cara Tomas, Joanna L Elson, Victoria Strassheim, Julia L Newton, Mark Walker

PLoS One, 2020 April 10; 15(4):e0231136

Researchers at Newcastle University have been trying to determine the cause of the severe fatigue and post-exertional malaise experienced by patients with ME/CFS. Notable findings include a reduction in cellular ATP (energy) levels in ME/CFS patients, and potential issues with AMPK signalling (responsible for regulating energy levels in cells). In this latest study, the authors re-analysed some of the findings from their previous work, separating the ME/CFS patients into two groups: moderately affected (housebound) and severely affected (bedbound). The investigators found that mitochondrial function was reduced by a similar extent in both the moderately and severely affected ME/CFS patients (compared with the healthy control subjects). The most severely affected patients also had reduced glycolysis levels, while the moderately affected patients did not. The findings show a mitochondrial defect in both moderately and severely affected ME/CFS patients, suggesting that the post-exertional malaise and fatigue seen in ME/CFS may be caused by a defect in - or related to - one of the metabolic pathways such as glycolysis or OXPHOS.

d. Substrate utilisation of cultured skeletal muscle cells in patients with CFS

Cara Tomas, Joanna L Elson, Julia L Newton, Mark Walker

Scientific Reports, 2020 October 26; 10(1):18232

The Newcastle team has also been looking more closely at how skeletal muscle cells produce energy from the different fuel sources (or substrates) available, and how this differs between people with ME/CFS and healthy individuals. Importantly, they have built on previous work by using cultured muscle cells rather than the white blood cells used in some of the earlier experiments. The cells of the body - including muscle cells - produce energy by breaking down glucose (a sugar that we get from our food) and converting it into the molecule ATP, which is used to transport energy for use within the cell. There are four steps to this process: glycolysis, pyruvate oxidation, the citric acid cycle and oxidative phosphorylation (OXPHOS). In this study, skeletal muscle cells from people with ME/CFS had a reduced ability to use glucose as a fuel to produce energy via OXPHOS, while they were able to use galactose and fatty acids normally, and glycolysis was also normal. This impairment in energy production may underlie the muscle fatigue that is characteristic of the illness, and the results help narrow down where in the metabolic pathway the abnormality occurs.

B. Informing

During 2019/20, 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. Unfortunately, the spring lockdown prevented the magazine being issued in a paper format instead joining back issues in being fully accessible in electronic format instead. The most important elements being carried forward and incorporated into an expanded autumn issue which was released 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 idea 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 as 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 the charity, 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 will add significantly to the scope of ME Research UK's output.

Our Facebook page (MERResearchUK) strives to balance, on the one hand, postings relating to fundraising activities of our active supporters 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 9,618 (2019 – 8,335) 'likes' - an increase of 15% (19%) 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 1,599 followers, it has proved to be a useful, additional avenue for engagement with the ME community. In addition, our Science & Engagement Director initiated a new twitter feed aimed at the research community with content relevant to their needs.

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 identify target audiences.

The charity will further look to contributing to third party publications to reach a mainstream audience – as was demonstrated most recently by authoring a guest article in September 2020's London Police Pensioner Magazine. It was also heartening to be referenced for research in the Royal Society of Photographer's October 2020 special online publication on Invisible Illnesses (part 1).

In order to engage more fully with supporters – old and new – ME Research UK has embarked on a branding exercise with the results of which 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 Countess of Mar's Forward-ME Group meetings in the Houses of Parliament. Forward-ME is a group of 10 UK charities, led by the Countess of Mar, who work collaboratively to improve recognition and understanding of myalgic encephalomyelitis (M.E.) and chronic fatigue syndrome (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 M.E. and CFS.
- 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 represented at the CFS/ME Research Collaborative's Conference in Bristol by Trustee, Dr Eleanor Roberts.
- been in contact with ME Research UK grant holders and potential funders to forge raise the profile of the charity and begin forging inter-group links to stimulate collaboration via the Science & Engagement Director. In addition, the Director has attended meetings of CureME Biobank steering group meetings, Forward-ME Group, IACFS/ME and Fatigatio e.V. Conferences together with CDC ME/CFS Stakeholder and Engagement Communication Call and BMJ webinar on Long Covid.
- 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 fact-finding meeting with other charities working towards a new research strategy in Scotland in conjunction with the Chief Scientist Office and Clinical Priorities, Scotland.

Overall, 2020 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 and risk management policies and performance. The day-to-day administration of grants and the processing and handling of applications, prior to consideration by the Trustees, is delegated to the Director of Research & Communications.

The Board of Charity Trustees delegated operational planning and day-to-day management of the charity to the Chief Executive Officer and post March 2020 the Board resumed operational planning responsibilities.

The performance of the CEO was overseen by the Board of Charity Trustees through reports and briefings presented by him at quarterly board meetings, and as part of the planning and budgeting process. In absence of CEO, the Chair liaises with individual Directors.

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 require to complete and to sign a written application in such form as the Board of Charity Trustees may decide and completed applications are considered at the next scheduled Board meeting after receipt of the form.

ME Research UK

Trustees' Report

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

The Board having identified the need for additional science capacity on the Board, undertook an open process of recruitment and were delighted to appointed Dr Eleanor Roberts as a science-focused Trustee in March 2020.

At year-end, the charity is considering a further two applications for Trusteeship.

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. After assessment by members of our own Science Committee, utilising a Standardised scoring system to facilitate consistent decision-making, all applications are subject to Peer Review (including review by external experts). 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 and ME Research UK strives to ensure proper and rigorous safeguards for the stewardship of funds under its control.

A new Science Committee Plan was initiated within the current reporting year 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.

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) review. 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.

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

ME Research UK

Trustees' Report

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 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. The peer review reports are then collated and forwarded to the Science Committee which assesses the application, the peer review results (which include a standardised scoring system), and the charity's research objectives to arrive at a decision.

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.mereseearch.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".

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.

ME Research UK

Trustees' Report

Accounting Matters

Donated Facilities and Services

It is estimated that approximately 1,360 voluntary hours were donated by members i.e. the Trustees of ME Research UK, and 114 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 and Google Ads. The former allowing IT upgrades which permitted the charity to initiate remote working when Covid 19 restrictions were introduced and the latter allowing the charity to advertise free via Google searches. The value of these donations in kind was approximately £42,652 and has been recognised in the accounts - the calculated 'cost' of the advertising of \$53,420 (£41,571) 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 to March 2020 the Chief Executive Officer in terms of directing and operating the charity on a day-to-day basis. Since the departure of the CEO, key management functions rest solely with the Board of Charity Trustees.

The remuneration of the Chief Executive Officer was reviewed annually.

No Trustee received any remuneration directly from the charity: other than approved expenses. Details of remuneration and expenses are disclosed in note 9 to the financial statements.

Trustee, Edward Dunkerley is a Director of Vital Hike Limited, which was engaged by ME Research UK to undertake branding consultations. Mr Dunkerley was not involved in any decisions regarding the awarding of these contracts and appropriate declarations of Conflict of Interest were made.

Financial Review

The total funds held at the year-end were £1,709,009 (2019: £1,371,105), including £1,180,434 of restricted funds (2019: £918,135). These funds are further explained at note 20.

The charity continues to rely on the generous donations of its supporters - as detailed in Note 2 to the accounts. The amount of charitable activity funded during the period is set out in Note 6 to the accounts, and the charities assets and liabilities are detailed in the Balance Sheet presented in page 26.

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

Post Year-end Information

It is anticipated that on 18th August 2021, a new NICE guideline replaces the current, much criticised and outdated, 2007 'Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management' document. This replacement firmly refutes any notion of a psychological cause of the disease or a bio-psychosocial approach to the continued expression of the condition. It recasts the options available to healthcare professionals in their approach to, and treatment of, those affected by ME/CFS. In particular, it alters the diagnostic criteria used by GPs and rejects Graded Exercise Therapy as a 'treatment'. The changes will affect the perception of the illness and will trigger the re-evaluation of guidance and practices within the UK's devolved NHSs and world-wide.

As an active stakeholder, ME Research UK fed into the evidence-based process to influence the guidance's content and the charity, both in its own name and through Forward-ME, made initial submissions to NICE and also commented on the draft guidance during the November/December 2020 consultation period.

The advances made through biomedical research in understanding the illness focused the guideline review process on the realities of ME/CFS as a physical illness and also led directly to the re-evaluation (and eventual rejection) of Graded Exercise Therapy as a 'treatment' for the illness. Likewise, Cognitive Behavioural Therapy is now to be regarded only as a symptom coping tool and not a treatment. The positive re-evaluation of the illness will have a direct impact upon the attitude and acceptance of ME/CFS amongst GPs, other healthcare professionals, educators, central funding agencies and the Royal Colleges.

It is telling that NICE demanded research-led evidence when calling for submissions on the content of the guideline. This led ME Research UK to co-fund the 2019 Oxford Brookes University study entitled "Evaluation of a survey exploring the experiences of adults and children with ME/CFS who have participated in CBT and GET interventional programmes" and quantified and highlighted the harms often caused by GET and the ineffectual nature of CBT as a 'treatment'.

The progress which is being made in the recognition and in the study of ME/CFS is being based on sound biomedical research and this is a vindication of the work that ME Research UK has been undertaking in the past 20 years.

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 in April 2020, 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 be muted in 2020/21; there will be increased competition between charities for donations and trust funders will see income squeezed due to anticipated challenges cause 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. Progress in this regard was not possible in 2020 due to coronavirus restrictions where most fundraising activities were cancelled or postponed. 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.

ME Research UK

Trustees' Report

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

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 un-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 the aforementioned family trust and executry income.

ME Research UK

Trustees' Report

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

Investment Policy

The Trustees adopted an Investment Policy at their meeting in January 2020. 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 out with 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 16 April 2021 and signed on its behalf by:

.....
Mr Jonathan P J Davies
Chairman

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 2020, 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 2020 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

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charity's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

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.

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.

ME Research UK

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

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 21], 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 decisions of users taken on the basis of these financial statements.

As part of an audit in accordance with ISAs (UK), we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.

ME Research UK

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

- Conclude on the appropriateness of the trustees use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charity to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.
- Obtain sufficient appropriate audit evidence regarding the financial information of the entities or business activities within the charity to express an opinion on the financial statements. We are responsible for the direction, supervision and performance of the charity audit. We remain solely responsible for our audit opinion.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

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

10 May 2021

ME Research UK

Statement of Financial Activities for the Year Ended 31 October 2020 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2020 £	Total 2019 £
Income and Endowments from:					
Donations and legacies	2	250,178	475,515	725,693	1,191,028
Other trading activities	3	7,091	-	7,091	7,319
Investment income	4	4,281	7,671	11,952	6,396
Total Income		<u>261,550</u>	<u>483,186</u>	<u>744,736</u>	<u>1,204,743</u>
Expenditure on:					
Raising funds	5	(71,255)	(25)	(71,280)	(44,177)
Charitable activities	6	(105,645)	(220,862)	(326,507)	(280,838)
Total Expenditure		<u>(176,900)</u>	<u>(220,887)</u>	<u>(397,787)</u>	<u>(325,015)</u>
(Loss)/gain on investment assets		<u>(9,045)</u>	-	<u>(9,045)</u>	<u>1,249</u>
Net income		<u>75,605</u>	<u>262,299</u>	<u>337,904</u>	<u>880,977</u>
Net movement in funds		<u>75,605</u>	<u>262,299</u>	<u>337,904</u>	<u>880,977</u>
Reconciliation of funds					
Total funds brought forward		<u>452,970</u>	<u>918,135</u>	<u>1,371,105</u>	<u>490,128</u>
Total funds carried forward	20	<u>528,575</u>	<u>1,180,434</u>	<u>1,709,009</u>	<u>1,371,105</u>

All of the charity's activities derive from continuing operations during the above two periods.
The funds breakdown for 2019 is shown in note 20.

ME Research UK

(Registration number: SC036942) Balance Sheet as at 31 October 2020

	Note	2020 £	2019 £
Fixed assets			
Tangible assets	12	-	279
Investments	13	<u>38,861</u>	<u>37,906</u>
		<u>38,861</u>	<u>38,185</u>
Current assets			
Stocks	14	1,825	1,408
Debtors	15	236,481	21,309
Cash at bank and in hand	16	<u>1,854,906</u>	<u>1,566,863</u>
		2,093,212	1,589,580
Creditors: Amounts falling due within one year	17	<u>(332,017)</u>	<u>(132,879)</u>
Net current assets		<u>1,761,195</u>	<u>1,456,701</u>
Total assets less current liabilities		1,800,056	1,494,886
Creditors: Amounts falling due after more than one year	18	<u>(91,047)</u>	<u>(123,781)</u>
Net assets		<u>1,709,009</u>	<u>1,371,105</u>
Funds of the charity:			
Restricted income funds			
Restricted funds		1,180,434	918,135
Unrestricted income funds			
Unrestricted funds		<u>528,575</u>	<u>452,970</u>
Total funds	20	<u>1,709,009</u>	<u>1,371,105</u>

The financial statements on pages 25 to 42 were approved by the Trustees, and authorised for issue on 16 April 2021 and signed on their behalf by:

.....
Mr Jonathan P J Davies
Chair/Trustee

.....
Mrs Sue Waddle
Vice Chair/Trustee

ME Research UK

Statement of Cash Flows for the Year Ended 31 October 2020

	Note	2020 £	2019 £
Cash flows from operating activities			
Net cash income		337,904	880,977
Adjustments to cash flows from non-cash items			
Depreciation		279	278
Investment income	4	(11,952)	(6,396)
Gain on investment assets	13	9,045	(1,249)
		335,276	873,610
Working capital adjustments			
Increase in stocks	14	(417)	(215)
(Increase)/decrease in debtors	15	(215,172)	8,389
Increase in creditors	17, 18	166,404	64,574
Net cash flows from operating activities		286,091	946,358
Cash flows from investing activities			
Interest receivable and similar income	4	10,456	5,067
Purchase of investments	13	(10,000)	-
Income from dividends	4	1,496	1,329
Net cash flows from investing activities		1,952	6,396
Net increase in cash and cash equivalents		288,043	952,754
Cash and cash equivalents at 1 November		1,566,863	614,109
Cash and cash equivalents at 31 October		1,854,906	1,566,863

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 2020

1 Accounting policies

General Information

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.

Registered Office:

The Gateway
North Methven Street
Perth
PH1 5PP

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.

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.

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

Other income

The value of any voluntary help received is not included in the financial statement 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.

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, allocating 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 trustee's 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.

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

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 Trustee's discretion in furtherance of the objectives of the Charity.

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.

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

2 Income from donations and legacies

	Unrestricted funds			Unrestricted funds		
	General £	Restricted funds £	Total 2020 £	General £	Restricted funds £	Total 2019 £
Donations and legacies;						
Donations from companies, trusts and similar proceeds	421	-	421	749	-	749
Donations from individuals	158,557	168,444	327,001	172,115	206,108	378,223
Legacies	75,667	303,263	378,930	33,164	756,115	789,279
Gift Aid reclaimed	15,533	3,808	19,341	17,787	4,990	22,777
	<u>250,178</u>	<u>475,515</u>	<u>725,693</u>	<u>223,815</u>	<u>967,213</u>	<u>1,191,028</u>

3 Income from other trading activities

	Unrestricted funds		Unrestricted funds	
	General £	Total 2020 £	General £	Total 2019 £
Trading income;				
Other trading income	7,091	7,091	7,319	7,319
	<u>7,091</u>	<u>7,091</u>	<u>7,319</u>	<u>7,319</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

4 Investment income

	Unrestricted funds	Restricted funds	Total 2020	Total 2019
	General £	£	£	£
Income from dividends;				
Dividends receivable from other listed investments	1,496	-	1,496	1,329
Interest receivable and similar income;				
Interest receivable on bank deposits	2,785	7,671	10,456	5,067
	4,281	7,671	11,952	6,396
	4,281	7,671	11,952	6,396

Interest receivable on bank deposits of £2,394 during 2019 was Restricted. Other investment income totalling £4,002 was Unrestricted.

5 Expenditure on raising funds

	Unrestricted funds	Restricted funds	Total 2020	Total 2019
	£	£	£	£
Staff costs	9,984	-	9,984	17,926
Communication costs	2,829	-	2,829	2,971
Office and accommodation costs	2,476	-	2,476	2,942
Fundraising costs and fees	2,785	-	2,785	3,324
Advertising	41,571	-	41,571	13,901
Costs of goods sold	2,989	-	2,989	2,383
Other	8,621	25	8,646	730
	71,255	25	71,280	44,177
	71,255	25	71,280	44,177

'Other' costs of £64 during 2019 were Restricted. Other expenditure on raising funds during 2019 totalling £44,113 was Unrestricted.

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

6 Expenditure on charitable activities

	Unrestricted funds £	Restricted funds £	Total 2020 £	Total 2019 £
Research grant funding		220,787	220,787	167,406
Staff costs	90,198	-	90,198	81,188
Accommodation	5,881	-	5,881	5,826
Breakthrough costs	3,694	-	3,694	6,065
Trustee travel and accommodation costs	1,995	-	1,995	3,404
Employee travel and accommodation costs	156	-	156	1,783
Governance costs	3,300	-	3,300	3,900
Other	421	75	496	11,266
	<u>105,645</u>	<u>220,862</u>	<u>326,507</u>	<u>280,838</u>

Research grant funding of £165,885 during 2019 was Restricted. Other costs of £11,226 during 2019 was Restricted. Other expenditure on charitable activities during 2019 totalling £103,687 was Unrestricted.

Other costs include £75 (2019 - £11,266) 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 2020 were translated into £ Sterling at the balance sheet date.

Research grant funding

	Total 2020 £	Total 2019 £
Grant funding	220,787	201,785
Cancelled research project	-	(35,900)
	<u>220,787</u>	<u>165,855</u>

Previously approved grant funding of £35,900 was cancelled in 2019 following notification from the prospective researcher that they had been unable to recruit the required specialist staff. No cancelled projects in 2020.

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

7 Analysis of governance and support costs

Governance costs

	Unrestricted funds £	Total 2020 £	Total 2019 £
Audit fee	3,300	3,300	3,300
Legal fees	-	-	600
	<u>3,300</u>	<u>3,300</u>	<u>3,900</u>

Governance costs of £3,900 during 2019 were Unrestricted.

8 Grant-making

Grants payable at 1 November 2019	250,610
Grants paid	(59,203)
New grants committed/withdrawn	220,787
Grants payable at 31 October 2020	<u>412,194</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

Grants paid and payable

Institution		Title of project	Grants	Grants	Payable	
			paid	committed/ withdrawn	2020	2019
			2020	2020	2020	2019
University of Dundee	37	Insights into Pathophysiology of CFS/ME	-	-	20,319	20,319
University of Newcastle	45	Investigating abnormalities in AMPK activation	28,506	-	-	28,506
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	-	19,761	29,641
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?	20,817	-	22,558	43,375
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	-	52,005	52,005	-
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	-	44,552	44,552	-
University of Valencia	54	Metabolic impact of activated HERVs and associated innate immune response in severe ME: towards disease modelling	-	76,000	76,000	-
			<u>59,203</u>	<u>220,787</u>	<u>412,194</u>	<u>250,610</u>

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

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

9 Trustees remuneration and expenses

Three Trustees were reimbursed for travelling expenses totalling £1,975.58 during the year (2019 - £3,296.86). No Trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

10 Staff costs

The aggregate payroll costs were as follows:

	2020	2019
	£	£
Staff costs during the year were:		
Wages and salaries	91,550	90,098
Social security costs	8,632	9,016
	<u>100,182</u>	<u>99,114</u>
	2020	2019
	No	No
Charitable activities	1.4	1.1
Fundraising	0.2	0.4
Governance	1	1.1
	<u>2.6</u>	<u>2.6</u>

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

The total remuneration (including taxable benefits and employer's pension contributions) of the key management personnel for the year was £20,227 (2019 - £58,256).

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

11 Taxation

No corporation tax was charged during the year (2019: £nil). ME Research UK is a registered charity and has been accepted as a charity for tax purposes.

12 Tangible fixed assets

	Furniture and equipment	Total
	£	£
Cost		
At 1 November 2019	5,917	5,917
At 31 October 2020	<u>5,917</u>	<u>5,917</u>
Depreciation		
At 1 November 2019	5,638	5,638
Charge for the year	279	279
At 31 October 2020	<u>5,917</u>	<u>5,917</u>
Net book value		
At 31 October 2020	<u>-</u>	<u>-</u>
At 31 October 2019	<u>279</u>	<u>279</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

13 Fixed asset investments

Other investments

	Listed investments £	Total £
Cost or Valuation		
Cost brought forward	37,906	37,906
Additions	10,000	10,000
Revaluation	(9,045)	(9,045)
At 31 October 2020	<u>38,861</u>	<u>38,861</u>
Net book value		
At 31 October 2020	<u>38,861</u>	<u>38,861</u>
At 31 October 2019	<u>37,906</u>	<u>37,906</u>

The market value of the listed investments at 31 October 2020 was £38,861 (2019 - £37,906).

All investment assets were held in the UK.

14 Stock

	2020 £	2019 £
Stock	<u>1,825</u>	<u>1,408</u>

15 Debtors

	2020 £	2019 £
Other debtors	<u>236,481</u>	<u>21,309</u>

16 Cash and cash equivalents

	2020 £	2019 £
Cash at bank	<u>1,854,906</u>	<u>1,566,863</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

17 Creditors: amounts falling due within one year

	2020	2019
	£	£
Other creditors	321,148	126,830
Accruals	10,869	6,049
	<u>332,017</u>	<u>132,879</u>

18 Creditors: amounts falling due after one year

	2020	2019
	£	£
Other creditors	<u>91,047</u>	<u>123,781</u>

19 Obligations under leases and hire purchase contracts

	2020	2019
	£	£
Land and buildings		
Within one year	<u>2,318</u>	<u>2,222</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

20 Funds

	Balance at 1 November 2019 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 October 2020 £
Unrestricted funds					
<i>General</i>					
Unrestricted funds	452,970	261,550	(176,900)	(9,045)	528,575
Restricted funds					
Restricted funds	<u>918,135</u>	<u>483,186</u>	<u>(220,887)</u>	<u>-</u>	<u>1,180,434</u>
Total funds	<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>
	Balance at 1 November 2018 £	Incoming resources £	Resources expended £	Other recognised gains/(losses) £	Balance at 31 October 2019 £
Unrestricted funds					
<i>General</i>					
Unrestricted funds	364,385	235,136	(147,800)	1,249	452,970
Restricted funds					
Restricted funds	<u>125,743</u>	<u>969,607</u>	<u>(177,215)</u>	<u>-</u>	<u>918,135</u>
Total funds	<u><u>490,128</u></u>	<u><u>1,204,743</u></u>	<u><u>(325,015)</u></u>	<u><u>1,249</u></u>	<u><u>1,371,105</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 2020

21 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds 2020	Unrestricted funds	Restricted funds	Total funds 2019
	£	£	£	£	£	£
Tangible fixed assets	-	-	-	279	-	279
Fixed asset investments	38,861	-	38,861	37,906	-	37,906
Current assets	500,583	1,592,629	2,093,212	420,834	1,168,746	1,589,580
Current liabilities	(10,869)	(321,148)	(332,017)	(6,049)	(126,380)	(132,879)
Creditors over 1 year	-	(91,047)	(91,047)	-	(123,781)	(123,781)
Total net assets	<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>

22 Analysis of net funds

	At 1 November 2019 £	Cash flow £	At 31 October 2020 £
Cash at bank and in hand	1,566,863	288,043	1,854,906
	<u>1,566,863</u>	<u>288,043</u>	<u>1,854,906</u>
	At 1 November 2018 £	Cash flow £	At 31 October 2019 £
Cash at bank and in hand	614,109	952,754	1,566,863
	<u>614,109</u>	<u>952,754</u>	<u>1,566,863</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2020

23 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 £4,800 (2019 - £nil) for consultancy services to the above company. At the balance sheet date the amount due to Vital Hike Limited was £nil (2019 - £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 £nil during the year (2019 - £28,039). £20,319 remains payable at 31 October 2020 (2019 - £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.