

ME Research UK

Annual Report and Accounts 2018 – 2019

Scottish Charitable Incorporated Organisation – Charity no SC036942

ME Research UK

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ME Research UK

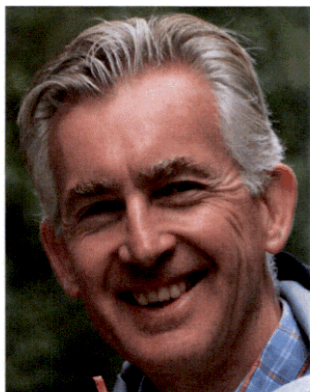
Reference and Administrative Details

Charity name	ME Research UK
Charity registration number	SC036942
Trustees	Jonathan P J Davies, Chair (Secretary to 09/04/2019 and Chair thereafter) Mrs Sue Waddle, Vice Chair Mrs Jan Mckendrick, Secretary (from 09/04/2019) Edward Dunkerley Prof Faisal Khan Mrs Lesley J Carr Dr Vance A Spence (Chairman to 09/04/2019 - retired from Board)
Founding Patron	Roger Jefcoate CBE DL
Patron	The Countess of Mar
Honorary Presidents	Robert D McRae Dr Vance A Spence (from 09/04/2019)
Chief Executive Officer	Simon Phillips (to 13/03/2020)
Registered Office	The Gateway North Methven Street Perth PH1 5PP
Telephone	01738 451234
Email	meruk@pkavs.org.uk
Web	www.mereseearch.org.uk
Facebook	MEReseearchUK
Twitter	MEReseearchUK
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, which cover a year of significant activity for the organisation. We have reviewed and refreshed our strategy for the next five years and have set ourselves some ambitious targets, which we believe we can deliver with the continued commitment of our Board of Trustees, staff team and volunteers.

We remain extremely grateful to all our supporters – both new and old – for the faith they place in us and in the work we do. Our ability to inform, influence and ultimately invest in biomedical research would not be possible without the commitment and generosity of our benefactors, fundraisers and friends.

We are also indebted to Dr Vance Spence, who retired from the Board at our AGM in April 2019. Vance was a founding Trustee and Chairman of ME Research UK for eighteen years and his leadership was fundamental to the success of our organisation. Although Vance has stepped down from the Board, he remains an active member of ME Research UK's Science Committee and we continue to benefit from his knowledge, skill and dedication.

As we enter our twentieth year, our determination and focus remain undimmed. 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 very fortunate to be well funded currently and have ambitious plans for the coming years, which we are determined to achieve.

We have now committed to further encourage both young and established researchers into the field of ME research, with a first call for PhD funding applications being issued in early 2020 alongside a general call for research applications. We are also increasing our capacity to proactively engage with the research community and provide the best possible information and insight to all of our stakeholders.

Our determination to make a positive difference remains undimmed and we will continue to work towards our vision of a world where ME is fully understood and everyone has access to effective treatment.

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

Jonathan Davies

Interim 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 2018 to 31st October 2019 – 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 over £1.6 million in biomedical research world-wide on 50 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 hope of eventually discovering a cure.

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 that we can.

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..

Plans for future periods

Despite the backdrop of economic uncertainty, ME Research UK has been fortunate in the extreme to record a substantial rise in annual income primarily due to the effect of large bequests. The first, from a family trust, the second from an Estate. The Estate funds will be received over a number financial years but allied with the family trust, have enabled the charity to consider transformative change in its operations whilst retaining both scientific rigor and strict financial controls. The funds will enable an increase in the number and size of projects funded but also make a reality plans to offer PhD's and to pro-actively engage with researchers world-wide to facilitate and stimulate research. It is anticipated that in the charity year 2019/2020 our plans will begin to be implemented.

ME Research UK's key goals are to increase applications for grant funding in the new fiscal year, to ensure the charity retains its financial stability and to invest in fundraising initiatives to increase the number of supporters of the charity and resources available to fund research.

Through PhD awards and grant funding, ME Research UK will 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, on the basis of their ME Research UK funded work, to major funding agencies for support.

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

Trustees' Report

ME Research UK's charitable activities in the current period permitted funding of a further £201,785.08 representing 4 projects in 3 countries. This level of commitment is consistent with the charity's objectives and is judged to be manageable within the charity's overall financial position.

ME Research UK is heartened by the geographic spread of applications for funding world-wide received within the year; the diverse range of research topics and the number of applications themselves. During the charity year, twelve applications were received of which seven were not progressed to the full application stage. One application passed through all stages of our process from outline proposal to Letter of Award whilst three applications have moved from outline to full application status. The remaining outline application is presently being considered by the Science Committee. The number of applications bodes well for progress in research in 2019/2020 and for the reputation and future evolution of the charity beyond the current year. The applications before us, if funded, would cost in excess of £215,000 - 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.

Such is ME Research UK's geographic reach, that we were one of only six organisations (alongside such bodies as the UK's Medical Research Council, the US National Institutes of Health and the Open Medicine Foundation), to be recognised as an international funder of ME/CFS research in a Report to Australia's National Health and Medical Research Council's CEO by the Australian ME/CFS Advisory Committee.

i. New projects - funding awarded in 2018/19

Project no. 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.

ME Research UK

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Project no. 48

Prof. Mercedes Rincon, University of Vermont, USA

Exploring a Citrullinated Antibody Signature in ME/CFS

£14,868.40 (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 plans 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.

Project No 49

Dr Sanjay Kumar, Oxford Brookes University, Oxford, UK

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

£29,641

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

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

ME Research UK

Trustees' Report

Project 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.

ii. On-Going Projects

Ongoing projects, initiated in previous financial years, payable (subject to progress) in 2018/19 – Sums due represent total funding commitment.

Project 37

Prof F Khan, The Institute of Cardiovascular Research, University of Dundee, Dundee, UK

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

£72,448.12

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

Project 45

Dr Mark Walker, Institute of Cellular Medicine, Newcastle University, Newcastle, UK

Investigating abnormalities in AMPK activation

£85,517.64

The project uses specific AMPK activators (used in the treatment of other diseases such as diabetes) to explore the mechanism through which AMPK is activated pharmacologically, but is not activated by muscle contraction. The researchers will also examine the function of the mitochondria (the powerhouses of the cell) in ME/CFS patients and healthy control subjects. These results may help to determine whether pharmacological activation of AMPK could improve muscle function in ME/CFS, and could help identify potential new targets for treatment.

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iii. Completed Projects

Projects completed, contract fulfilling and financial commitment settled.

Project 42

Prof Brett Lidbury, The John Curtin School of Medical Research, The Australian National University, Acton, Australia

Two dimensional (2D) sequencing and machine learning to maximise genetic marker

detection in a clinically well-defined ME cohort for enhanced diagnosis.

£49,724

The aim of this study was to apply two-dimensional sequencing of pooled DNA to identify changes across the genome that are associated with ME/CFS. The group has completed its initial analysis, but needs to do some further work using additional samples from another ME/CFS cohort and a control cohort in order to interpret their findings more fully.

Project 44

Dr Madlen Löbel & Prof. Carmen Scheibenbogen, Institute of Medical Immunology, Charité University Medicine Berlin, Berlin, Germany

£70,460

The aim of this study was to identify patients with elevated levels of $\beta 2$ adrenergic receptor autoantibodies and those without, and compare a wide range of clinical and immunological measures between the two groups. This analysis is complete, publications are currently in preparation and further research is also being planned in light of the findings.

iv. Relinquished Grant

Project 46

Prof Yiannakou, University Hospital of North Durham, Durham, UK

Exploring the Association Between CFS and IBS Through Immune and Microbiome Analysis: a feasibility study.

£35,900.00

Due to NHS staffing issues and despite efforts to reconstitute the grant, Prof Yiannakou decided the study was unviable. It is to be regretted that the project could not proceed as both ME/CFS and IBS are often reported to occur after an infection, and they are also both associated with abnormal activation of the immune system, as indicated by raised levels of various cytokines and immune cells. The similarities between ME/CFS and IBS suggest that the two conditions may be part of a spectrum of illness, with shared pathophysiological changes in response to infection. Prof. Yiannakou suggested that, if the two conditions are linked in this way, then 'patients with ME/CFS alone would have mucosal immune and microbiome changes that are similar to, though less pronounced, than patients with both ME/CFS and IBS'.

ME Research UK

Trustees' Report

Impact and Scientific Publications

A widely accepted means by which the work of the charity can be assessed is to gauge the number of scientific publications emanating from specific projects. Since 2000, ME Research UK has awarded or agreed to award 50 specific grants totaling over £1.6 million, to research institutions in the UK, Austria, Australia, Belgium, Canada, Germany, Sweden, and the USA. The results of our studies are published as research papers in peer-reviewed scientific journals world-wide and are available to researchers globally.

Six papers were published in the charity year 2018/19 acknowledging the support of ME Research UK.

- Lacerda EM, Mudie K, Kingdon CC, Butterworth JD, O'Boyle S, Nacul L

The UK ME/CFS Biobank: A Disease-Specific Biobank for Advancing Clinical Research Into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Frontiers in Neurology, 2018 Dec 4;9:1026

- Polli A, Van Oosterwijck J, Meeus M, Lambrecht L, Nijs J, Ickmans K

Exercise-induced hyperalgesia, complement system and elastase activation in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - a secondary analysis of experimental comparative studies

Scandinavian Journal of Pain, 2019 Jan 28;19(1):183–192

- Tomas C, Brown AE, Newton JL, Elson JL

Mitochondrial complex activity in permeabilised cells of chronic fatigue syndrome patients using two cell types

PeerJ, 2019 Mar 1;7:e6500

- Bouquet J, Li T, Gardy JL, Kang X, Stevens S, Stevens J, VanNess M, Snell C, Potts J, Miller RR, Morshed M, McCabe M, Parker S, Uyaguari M, Tang P, Steiner T, Chan WS, De Souza AM, Mattman A, Patrick DM, Chiu CY. Whole blood human transcriptome and virome analysis of ME/CFS patients experiencing post-exertional malaise following cardiopulmonary exercise testing. *PLoS One*, 2019 March 21; 14(3):e0212193.

- Josev EK, Malpas CB, Seal ML, Scheinberg A, Lubitz L, Rowe K, Knight SJ

Resting-state functional connectivity, cognition, and fatigue in response to cognitive exertion: a novel study in adolescents with chronic fatigue syndrome

Brain Imaging and Behavior, 2019 May 17; Epub ahead of print

- Blomberg J, Rizwan M, Böhlin-Wiener A, Elfaitouri A, Julin P, Zachrisson O, Rosén A, Gottfries CG

Antibodies to Human Herpesviruses in Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Patients

Frontiers in Immunology, 2019 Aug 14;10:1946

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B. Informing

During 2018/19, 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 provision of speakers for external events - to discuss ME Research UK's role, its achievements and to provide insight into current research and the research landscape for ME/CFS, ME Research UK also produces printed literature (leaflets and Breakthrough magazine) and embraces the opportunities afforded by new means of communication to remain relevant and at the forefront of research funding.

Our 'Breakthrough' magazine is provided free of charge to all who request it and is dispatched on a biannual basis. It not only informs the reader of the charity's newly funded research but also describes and interprets the results of ME Research UK projects completed in the past. Breakthrough also reports other published studies which are presented in a form which aims to ensure that readers have a holistic idea of world-wide 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.

Our Facebook page (MEResearchUK) strives to balance, on the one hand, postings relating to fundraising activities of our active supporters with summaries of the most important world-wide 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 which 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 8335 (7000) 'likes' - an increase of 19% from 2017-18 - and is viewed regularly world-wide. 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. It is hoped that the newly more active twitter account will further drive the successful dissemination of our research news and that it will act as a further avenue to engage more fully with potential donors and create a new community of supporters. With over 1,000 followers, it has proved to be a useful, addition avenue for engagement with the ME community.

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.

- Our CEO represented ME Research UK at the Royal College of General Practitioners' Annual Primary Care Conference & Exhibition in Liverpool, October 2019.

- Co-funded (in conjunction with the ME Association) a survey and an analysis of the results thereof entitled "Exploring the experiences of adults and children with ME/CFS who have participated in CBT and GET interventional programme" by Professor Helen Dawes and her team at Oxford Brookes University. The results from the 2274 responses were well received by the Chairman of the NICE Guideline Development Group and will, we trust, be helpful to the Group as they develop the highly anticipated new NICE guideline for ME/CFS due in 2020. In particular, the incidence of harm and effectiveness of these interventions, provided a real-life snapshot of the lived experiences of those affected by ME/CFS. The guideline is of critical importance as it forms the basis of how GPs diagnose and treat those with ME/CFS and, in particular, the provisions as to the use of Cognitive Behavioural Therapy and Graded Exercise Therapy (CBT & GET) will be awaited eagerly by the ME community. Recommendations in NICE will also inform other UK and foreign health care systems on the diagnosis and 'treatment' of ME/CFS.

Due to the short-time frame in the initiation and design of the survey there was insufficient opportunity for ME Research UK to assess the project through our normal peer-review process and therefore we do not categorise this nevertheless valid work as one of our research projects despite its importance and professional standards.

- 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.

- CEO alone or in conjunction with our Research & Communications Director, met with Prof Julia Newton (Newcastle University), Prof Y Yiannakou (University Hospital of North Durham), Dr Chris Ponting (Edinburgh University and Vice Chair of UK CFS/ME Research Collaborative) and with Professor David Crossman, Chief Scientist Office (part of the Health and Wellbeing Directorate of the Scottish Government.) and Dr Alan McNair (Senior Research Manager, Experimental and Translational Research, Precision Medicine, NRS Networks, Research Units, Charity Collaborations).

- to discuss the research landscape and scope for collaborative working and a more pro-active approach to research project funding.

- 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.

- Provided background information and research outlines to all MPs in relation to the historic debate in the House of Commons in January 2019.

- Hon Patron and CEO held a number of Skype calls with Prof Ron Davis (Stamford University, USA) and Dr Øystein Fluge (University of Bergen, Norway) discussing current current research and the wider ME research environment.

ME Research UK

Trustees' Report

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 delegates operational planning and day-to-day management of the charity to the Chief Executive Officer, supported by the charity's staff.

The performance of the CEO is 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.

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.

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

The Board of Charity Trustees 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. The Board may set up a working group to recruit new Trustees who may be sought by open advertisement.

As part of the process of renewal and revitalisation of the charity, the Trustees identified the need for additional science capacity within the Board and undertook an open process of recruitment. This entailed both on- and off-line advertising and the outcome will be known in the next charity year.

Trustees also report the retirement of founding Trustee Dr Vance Spence, who held, with distinction, the position of Chairman since the inception of the charity in 2000. The Board's thanks are insufficient to express the charity's debt to Dr Spence as its instigator, guiding light and inspiration but were delighted when Dr Spence accepted the position of joint Hon President alongside other Founding Trustee, Bob McRae.

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.

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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.

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.

Grant Making Objectives

Through funding studies at recognised Institutions world-wide, 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 which 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.meresearch.org.uk

ME Research UK

Trustees' Report

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. Also, 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 2 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.

Accounting Matters

Donated Facilities and Services

It is estimated that approximately 1,770 voluntary hours were donated by members i.e. the Trustees of ME Research UK, and 54 voluntary hours were donated by others.

Google Ads (formerly Google Adwords) enables the charity to advertise free via Google searches. The value of this donation in kind is approximately \$17,740 (£14,349) and has been recognised in the accounts, along with the calculated 'cost' of this advertising of \$17,186 (£13,901), 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 the Chief Executive Officer in terms of directing and operating the charity on a day to day basis.

The remuneration of the Chief Executive Officer is reviewed annually.

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

Financial Review

The total funds held at the year-end were £1,371,105 (2018: £490,128), including £918,135 of restricted funds (2018: £125,743). These funds are further explained at note 19.

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 23.

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

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 2019 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.

As scientific research is largely ineligible for funding support from certain bodies, e.g. the National Lottery, and as other bodies, notably companies, prefer to support 'community based projects', ME Research UK must rely mainly on voluntary donations. The charity strives to encourage active fundraising by facilitating giving through multiple on-line platforms; supporting individual and group projects (such as Walk for ME); and by forging strong links with fundraisers. The re-establishment and nurturing of the Ambassadors scheme will be a feature of 2019/20. The Trustees will bolster the current fundraising model by expanding marketing activities to ensure the work of the charity and fundraising opportunities are projected as widely as possible.

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

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

Charity Test

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

It is considered that the charity fulfills 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.

ME Research UK

Trustees' Report

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. Also, grant requests are impossible to predict, and so funds may, unavoidably, accumulate 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 been 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.

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 April 2019. This policy is reviewable on an annual basis and this will include a report on investment returns.

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

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

As the timing of payments to settle research commitments is outwith 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.

ME Research UK

Trustees' Report

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

The annual report was approved by the Trustees of the Charity on 26 May 2020 and signed on its behalf by:

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

ME Research UK

Statement of Trustees' Responsibilities

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

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

- select suitable accounting policies and apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company 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 2019, which comprise the Statement of Financial Activities, Balance Sheet, 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 2019 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 Companies Act 2006, 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.

Material uncertainty relating to going concern

In forming our opinion on the financial statements, which is not modified, we have considered the current outbreak of Covid-19 and its impact on the economy as a material uncertainty. However, given the level of funds held by the charity we do not consider there to be any impact to going concern in the next 12 months. The trustees and management also have contingency plans in place in relation to working from home, we consider the impact to daily operations of the charity to be low.

Although the overall risk to the charity is considered to be low, given the nature of the developments in the Covid-19 outbreak, we feel it is appropriate to disclose this a material uncertainty.

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.

Opinion on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' Report has been prepared in accordance with applicable legal requirements.

The prior period's financial statements were not audited and therefore the corresponding figures in these financial statements are unaudited.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the company 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 18], 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.

The trustees have elected for the financial statements to be audited in accordance with the Charities and Trustee Investment (Scotland) Act 2005 rather than also with the Companies Act 2006. Accordingly we have been appointed as auditor under section 44 (1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and report in accordance with that Act.

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:

ME Research UK

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

- 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.
- 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 charitable company'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 charitable company and its trustees as a body, for our audit work, for this report, or for the opinions we have formed.

.....
Morris & Young, Statutory Auditor

Chartered Accountants
6 Atholl Crescent
PERTH
PH1 5JN

Morris & Young, Chartered Accountants is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

27 May 2020

ME Research UK

Statement of Financial Activities for the Year Ended 31 October 2019 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2019 £	Total 2018 £
Income and Endowments from:					
Donations and legacies	2	223,815	967,213	1,191,028	261,638
Other trading activities	3	7,319	-	7,319	7,015
Investment income	4	4,002	2,394	6,396	3,745
Total Income		<u>235,136</u>	<u>969,607</u>	<u>1,204,743</u>	<u>272,398</u>
Expenditure on:					
Raising funds	5	(44,113)	(64)	(44,177)	(38,661)
Charitable activities	6	(103,687)	(177,151)	(280,838)	(66,604)
Total Expenditure		<u>(147,800)</u>	<u>(177,215)</u>	<u>(325,015)</u>	<u>(105,265)</u>
Gain on investment assets		1,249	-	1,249	(1,538)
Net income		<u>88,585</u>	<u>792,392</u>	<u>880,977</u>	<u>165,595</u>
Net movement in funds		88,585	792,392	880,977	165,595
Reconciliation of funds					
Total funds brought forward		<u>364,385</u>	<u>125,743</u>	<u>490,128</u>	<u>324,533</u>
Total funds carried forward	19	<u>452,970</u>	<u>918,135</u>	<u>1,371,105</u>	<u>490,128</u>

All of the charity's activities derive from continuing operations during the above two periods.
The funds breakdown for 2018 is shown in note 19.

ME Research UK

**(Registration number: SC036942)
Balance Sheet as at 31 October 2019**

	Note	2019 £	2018 £
Fixed assets			
Tangible assets	12	279	557
Investments	13	<u>37,906</u>	<u>36,657</u>
		<u>38,185</u>	<u>37,214</u>
Current assets			
Stocks	14	1,408	1,193
Debtors	15	21,309	29,698
Cash at bank and in hand		<u>1,566,863</u>	<u>614,109</u>
		1,589,580	645,000
Creditors: Amounts falling due within one year	16	<u>(132,879)</u>	<u>(126,698)</u>
Net current assets		<u>1,456,701</u>	<u>518,302</u>
Total assets less current liabilities		1,494,886	555,516
Creditors: Amounts falling due after more than one year	17	<u>(123,781)</u>	<u>(65,388)</u>
Net assets		<u>1,371,105</u>	<u>490,128</u>
Funds of the charity:			
Restricted funds		918,135	125,743
Unrestricted income funds			
Unrestricted funds		<u>452,970</u>	<u>364,385</u>
Total funds	19	<u>1,371,105</u>	<u>490,128</u>

The financial statements on pages 22 to 35 were approved by the Trustees, and authorised for issue on 26 May 2020 and signed on their behalf by:

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

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

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

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 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.

Exemption from preparing a cash flow statement

The charity opted to adopt Bulletin 1 published on 2 February 2016 and have therefore not included a cash flow statement in these financial statements.

Going concern

The Trustees have considered the impact of the current outbreak of Covid-19 on the charity. Given the nature of the charities activities and level of funds available the Trustees consider the preparation of the accounts on a going concern basis appropriate.

Income and endowments

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

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

Donations and legacies

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

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

Investment income

Investment income is recognised on a receivable basis.

Other income

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

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

Governance costs

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

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% reducing balance

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 2019

2 Income from donations and legacies

	Unrestricted funds		Total 2019 £	Total 2018 £
	General £	Restricted funds £		
Donations and legacies;				
Donations from companies, trusts and similar proceeds	749	-	749	672
Donations from individuals	172,115	206,108	378,223	191,751
Legacies	33,164	756,115	789,279	45,639
Gift Aid reclaimed	17,787	4,990	22,777	23,576
	<u>223,815</u>	<u>967,213</u>	<u>1,191,028</u>	<u>261,638</u>

Individual donations of £59,799, legacies of £1,000 and gift aid of £7,488 received during 2018 was Restricted, totalling £68,287. Other income from donations and legacies during 2018 totalling £193,351 was Unrestricted.

3 Income from other trading activities

	Unrestricted funds		Total 2019 £	Total 2018 £
	General £	Restricted funds £		
Trading income;				
Other trading income		7,319	7,319	7,015
		<u>7,319</u>	<u>7,319</u>	<u>7,015</u>

Other trading income of £7,015 during 2018 was Unrestricted.

4 Investment income

	Unrestricted funds		Total 2019 £	Total 2018 £
	General £	Restricted funds £		
Income from dividends;				
Dividends receivable from other listed investments	1,329	-	1,329	1,265
Interest receivable and similar income;				
Interest receivable on bank deposits	2,673	2,394	5,067	2,480
	<u>4,002</u>	<u>2,394</u>	<u>6,396</u>	<u>3,745</u>

Interest receivable on bank deposits of £1,458 during 2018 was Restricted. Other investment income totalling £2,287 was Unrestricted.

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

5 Expenditure on raising funds

	Unrestricted funds £	Restricted funds £	Total 2019 £	Total 2018 £
Staff costs	17,926	-	17,926	13,483
Communication costs	2,971	-	2,971	3,243
Office and accommodation costs	2,942	-	2,942	2,117
Fundraising costs and fees	3,324	-	3,324	4,348
Advertising	13,901	-	13,901	10,819
Costs of goods sold	2,383	-	2,383	2,321
Other	666	64	730	2,330
	<u>44,113</u>	<u>64</u>	<u>44,177</u>	<u>38,661</u>

'Other' costs of £152 during 2018 were Restricted. Other expenditure on raising funds during 2018 totalling £38,509 was Unrestricted.

6 Expenditure on charitable activities

	Unrestricted funds £	Restricted funds £	Total 2019 £	Total 2018 £
Research grant funding	1,521	165,885	167,406	10,495
Staff costs	81,188	-	81,188	36,286
Accommodation	5,826	-	5,826	5,801
Breakthrough costs	6,065	-	6,065	3,819
Trustee travel and accommodation costs	3,404	-	3,404	3,866
Employee travel and accommodation costs	1,783	-	1,783	962
Governance costs	3,900	-	3,900	4,800
Other	-	11,266	11,266	575
	<u>103,687</u>	<u>177,151</u>	<u>280,838</u>	<u>66,604</u>

Research grant funding of £10,495 during 2018 was Restricted. Other expenditure on charitable activities during 2018 totalling £56,109 was Unrestricted.

Other costs include £11,266 (2018 - £nil) 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 held at 31 October 2019 were translated into £ Sterling at the balance sheet date.

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

Research grant funding

	Total 2019 £	Total 2018 £
Grant funding	201,785	10,495
Cancelled research project	(35,900)	-
	165,855	10,495

Previously approved grant funding of £35,900 was cancelled following notification from the prospective researcher that they had been unable to recruit the required specialist staff.

7 Analysis of governance and support costs

Governance costs

	Unrestricted funds £	Total 2019 £	Total 2018 £
Audit fee	3,300	3,300	-
Independent examiner's fee	-	-	900
Legal fees	600	600	3,900
	3,900	3,900	4,800

Governance costs of £4,800 during 2018 were Unrestricted.

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

8 Grant-making

Grants payable at 1 November 2018	188,931
Grants paid	(104,206)
New grants committed/withdrawn	165,885
Grants payable at 31 October 2019	250,610

Grants paid and payable

		Grants paid	Grants committed/ withdrawn	Payable	
Institution	Title of project	2019	2019	2019	2018
The Australian National University	Two dimensional sequencing and machine learning to ME cohort for enhanced diagnosis	12,431	-	-	12,431
Charité University, Berlin	The role of autoantibodies in ME/CFS	35,230	-	-	35,230
University of Dundee	Insights into Pathophysiology of CFS/ME	28,039	-	20,319	48,358
University of Newcastle	Investigating abnormalities in AMPK activation	28,506	-	28,506	57,012
University Hospital of North Durham	Exploring the association between CFS and IBS through immune and microbiome analysis	-	(35,900)	-	35,900
University of Alabama at Birmingham	Tracking peripheral immune cell infiltration of the brain in ME	-	113,901	113,901	-
University of Vermont College of Medicine	Exploring an anti-citrullinated antibody signature in ME/CFS	-	14,868	14,868	-
Oxford Brookes University	Investigating sensory processing and cognitive function in people with ME: a pilot study	-	29,641	29,641	-
University Hospital of North Durham	Exploring the association between CFS and IBS through immune and microbiome analysis	-	43,375	43,375	-
		104,206	165,885	250,610	188,931

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 2019

9 Trustees remuneration and expenses

Five Trustees were reimbursed for travelling expenses totalling £3,296.86 during the year (2018 - £3,727.71). 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:

	2019 £	2018 £
Staff costs during the year were:		
Wages and salaries	90,098	48,414
Social security costs	9,016	1,355
	99,114	49,769
	2019	2018
	No	No
Charitable activities	1.1	1.2
Fundraising	0.4	-
Governance	1.1	0.5
	2.6	1.7
	2.6	1.7

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 £58,256 (2018 - £6,168).

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

11 Taxation

No corporation tax was charged during the year (2018: £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 2018	5,917	5,917
Additions	-	-
Disposals	-	-
At 31 October 2019	<u>5,917</u>	<u>5,917</u>
Depreciation		
At 1 November 2018	5,360	5,360
Charge for the year	278	278
Eliminated on disposals	-	-
At 31 October 2019	<u>5,638</u>	<u>5,638</u>
Net book value		
At 31 October 2019	<u>279</u>	<u>279</u>
At 31 October 2018	<u>557</u>	<u>557</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

13 Fixed asset investments

Other investments

	Listed investments £	Total £
Cost or Valuation		
Cost brought forward	36,657	36,657
Revaluation	1,249	1,249
At 31 October 2019	37,906	37,906
Net book value		
At 31 October 2019	37,906	37,906
At 31 October 2018	36,657	36,657

The market value of the listed investments at 31 October 2019 was £37,906 (2018 - £36,657).

All investment assets were held in the UK.

14 Stock

	2019 £	2018 £
Stock	1,408	1,193

15 Debtors

	2019 £	2018 £
Other debtors	21,309	29,698

16 Creditors: amounts falling due within one year

	2019 £	2018 £
Other creditors	126,830	123,543
Accruals	6,049	3,155
	132,879	126,698

17 Creditors: amounts falling due after one year

	2019 £	2018 £
Other creditors	123,781	65,388

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

18 Obligations under leases and hire purchase contracts

	2019 £	2018 £
Land and buildings		
Within one year	2,222	2,179

19 Funds

	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	125,743	969,607	(177,215)	-	918,135
Total funds	490,128	1,204,743	(325,015)	1,249	1,371,105

	Balance at 1 November 2017 £	Incoming resources £	Resources expended £	Transfers £	Other recognised gains/(losses) £	Balance at 31 October 2018 £
Unrestricted funds						
<i>General</i>						
Unrestricted funds	258,408	202,653	(94,618)	(520)	(1,538)	364,385
Restricted funds						
Restricted funds	66,125	69,745	(10,647)	520	-	125,743
Total funds	324,533	272,398	(105,265)	-	(1,538)	490,128

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.

Transfers are made from Unrestricted Funds to ensure that sufficient funds are held in Restricted Funds to cover the charity's grant-making obligations, and to effect minor adjustments.

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2019

20 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds 2019	Unrestricted funds	Restricted funds	Total funds 2018
	£	£	£	£	£	£
Tangible fixed assets	279	-	279	557	-	557
Fixed asset investments	37,906	-	37,906	36,657	-	36,657
Current assets	420,834	1,168,746	1,589,580	330,326	314,674	645,000
Current liabilities	(6,049)	(126,830)	(132,879)	(3,155)	(123,543)	(126,698)
Creditors over 1 year	-	(123,781)	(123,781)	-	(65,388)	(65,388)
Total net assets	<u>452,970</u>	<u>918,135</u>	<u>1,371,105</u>	<u>364,385</u>	<u>125,743</u>	<u>490,128</u>

21 Analysis of net funds

	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>

22 Related party transactions

Controlling entity

The charity is controlled by the Trustees of the charity.

Related party transactions

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

Insights into Pathophysiology of CFS/ME

The above Project was paid funding of £28,039 during the year (2018 - paid funding of £3,854 and awarded additional funding of £10,495). £20,319 remains payable at 31 October 2019 (2018 - £48,358). 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.