



**Annual Report & Accounts
2016–2017**

ME Research UK

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ME Research UK

Reference and Administrative Details

Charity name	ME Research UK
Charity registration number	SC036942
Trustees	Dr Vance A Spence, Chairman Mrs Sue Waddle, Vice Chair Mrs Jan Mckendrick, Secretary Edward Dunkerley Prof Faisal Khan Dr Stephen A Logan (appointed 18 October 2017)
Founding Patron	Roger Jefcoate CBE DL
Patron	The Countess of Mar
Honorary President	Robert D McRae
Registered Office	The Gateway North Methven Street Perth PH1 5PP
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Independent Examiner	Alexander J Fyfe M.A.A.T., C.A., DChA Morris and Young Chartered Accountants 6 Atholl Crescent Perth PH1 5JN

ME Research UK

Trustees' Report

The Trustees present their report along with the financial statements of the charity for the period 1st November 2016 to 31st October 2017 – 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 4th August 2016; 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).

History

ME Research UK was recognised by the Office of the Scottish Charity Regulator (OSCR) as a single tier Scottish Charitable Incorporated Organisation (SCIO) on 8th November 2011 and allocated Scottish Charity No. SC036942. The SCIO assumed the assets, liabilities and activities of a former charity of the same name.

The precursor charity (ME Research Group for Education and Support (MERGE), working name “ME Research UK”) was established in the year 2000 by Robert D McRae, Dr Vance A Spence and Founding Patron, Roger Jefcoate CBE DL. From 2000 to 2005, it was registered with the Charity Commission for England and Wales but on 24th November 2005 the charity came under the jurisdiction of OSCR. By 2011, the Trustees considered that the objectives of the charity were better served by availing themselves of the opportunities offered by SCIO status. The former entity was deregistered as a charity by OSCR on 7th November 2011.

Objectives and activities

In terms of the Constitution, the charity's principal aim is to commission and fund high-quality scientific (biomedical) investigation into the causes, consequences and treatment of ME/CFS.

ME Research UK furthers its charitable purposes (either alone or in tandem with other bodies) through its grant-making policy which aims to:

- Stimulate high quality biomedical research into ME/CFS globally with the objective of enriching scientific understanding of the disease, leading to increased awareness of the illness and, ultimately, therapeutic help for patients. The Trustees believe that only through research can the causes of the illness be identified and, eventually, a treatment found.
- Encourage researchers with fresh, novel ideas to become active in ME/CFS research and provide them with the resources to undertake scientific investigations. 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 research projects which would otherwise not be funded.
- Support research groups (especially those new to the field) to the stage where they can apply, on the basis of their ME Research UK funded work, to major funding agencies for support.

The other objectives of the charity are to provide education about the illness and the need for research (by, for example, producing high-quality professional reviews and reports, and presenting research at meetings and conferences), and to support people with ME/CFS by providing information on accessing the services they require. In general, the charity considers that its mission is to "Energise ME Research" globally.

Governance and Management

At regular 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 (newly created) Director of Research & Communications.

ME Research UK

Trustees' Report

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.

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 Trustee(s) who may be sought by open advertisement.

The Trustees were delighted to appoint, on 18th October 2017, Stephen A Logan as a Trustee following an open application process featuring both on-line and print advertising for applicants. It is hoped to further augment the Board next year.

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

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 Scientific Advisory Board, 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 Scientific Advisory Board 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.

ME Research UK

Trustees' Report

Grant making Objectives

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.

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 Scientific Advisory Board 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 recovered. Research grant instalments are normally paid only upon receipt of regular progress reports.

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

ME Research UK

Trustees' Report

Review of Achievements and Performance

A - Research

Research grants

The most significant aspect of our charity and the core to our charitable purposes and aims is the provision of funding for research. Three new projects were actioned in 2016/2017, with six projects continuing from previous years.

Our 2016 'Call for Funding Applications'

Of the three projects funded, one is based in Berlin, Germany (The role of autoantibodies in ME/CFS), and one in Newcastle, UK (Investigating abnormalities in AMPK activation) and one within the University Hospital of North Durham (Exploring the Association between CFS and IBS). Further details are given below.

Study 1: The role of autoantibodies in ME/CFS

In 2016, Dr Madlen Löbel and Prof. Carmen Scheibenbogen at the Institute of Medical Immunology in Berlin found that nearly a third of ME/CFS patients they studied had increased levels of autoantibodies against adrenergic receptors. Furthermore, these levels decreased in individuals who responded to treatment with rituximab.

This unexpected finding suggests that, in a subgroup of patients, some of the symptoms of ME/CFS may be caused by these autoantibodies, although their exact role in the illness is not yet clear. ME Research UK awarded funding to Dr Löbel and Prof. Scheibenbogen to continue their investigations by looking at the function of β 2 adrenergic receptor autoantibodies in ME/CFS.

They will identify patients with these autoantibodies and those without, and compare a wide range of clinical and immunological measures between the two groups. These measures will include clinical symptoms such as fatigue, physical function and signs of autonomic dysfunction, as well as blood vessel function, immune marker expression, and the proliferation of T and B cells.

In this way, the researchers hope to discover which of these symptoms and immune abnormalities might be affected by the presence of these potentially harmful autoantibodies.

Study 2: Investigating abnormalities in AMPK activation

Abnormal muscle fatigue is one of the most common symptoms reported by people with ME/CFS, and can occur even after periods of only mild exercise. Since 2006, ME Research UK has provided pilot funding for a number of projects at Newcastle University exploring the mechanisms underlying this symptom, and one of their findings was of a higher than normal build-up in acidity during exercise, and a slower recovery back to resting levels afterwards. This suggests abnormalities in the way muscle cells handle acid in ME/CFS. Following this finding, published April 2015, Prof. David Jones and Prof. Julia Newton went on to look more closely at the function of muscle cells.

To achieve this, they took muscle cell biopsies from ME/CFS patients, and cultured them to provide sufficient numbers of cells to examine in standardised laboratory conditions without the influence of other complicating factors.

A series of electrical pulses was applied to these cultured muscle cells to simulate the muscle contraction that occurs during exercise, and the researchers found two defects in their function.

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Trustees' Report

Activation of AMP-activated protein kinase (AMPK) and also glucose uptake were both impaired; AMPK has an important role in regulating energy in the cell and is normally activated during muscle contraction, while glucose is an important energy source.

Although AMPK was not activated by simulated muscle contraction in these cells from ME/CFS patients, later experiments showed that it could be activated by treatment with metformin, a drug known to have this effect in healthy cells. This raises the possibility of whether a treatment such as this could improve muscle function in patients.

Following on from these results, ME Research UK has awarded further funding for Dr Audrey Brown and Prof. Newton to continue investigating these abnormalities in AMPK activation.

Their new project will use 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.

Study 3 - Exploring the Association between CFS and IBS through Immune and Microbiome Analysis: a feasibility study

Prof. Yan Yiannakou and his team in Newcastle have been awarded a research grant from ME Research UK to explore the association between ME/CFS and inflammatory bowel disease (IBS) by looking at immune and microbiome changes in the gut. IBS is a common condition which causes stomach cramps, bloating, diarrhoea and constipation. ME/CFS is 35 times more common among patients with IBS than it is in the general population, and similarities between the two conditions suggest that they may have a shared pathophysiology. Prof. Yiannakou aims to collect blood and stool samples, as well as gut biopsies, from patients with ME/CFS, those with IBS, and those with both ME/CFS and IBS, to compare measures of immune activation and gut microbiome between the three groups. The microbiome comprises the genes of the various microbes that reside in our gut. If ME/CFS and IBS are indeed part of a spectrum of illness, then we would expect to see similar abnormalities in each group, although perhaps less pronounced in those with ME/CFS alone. Prof. Yiannakou's hope is that the results of this analysis will lead to a larger study looking at the association in more detail.

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New Projects funded in 2016/17	Total cost £
The role of autoantibodies in ME/CFS. Dr Madlen Löbel & Prof. Carmen Scheibenbogen, Institute of Medical Immunology. <i>Charité University Medicine Berlin, Berlin, Germany</i>	70,460
Investigating abnormalities in AMPK activation. Dr Audrey Brown, Institute of Cellular Medicine. <i>Newcastle University, Newcastle, UK</i>	85,518
Exploring the Association Between CFS and IBS Through Immune and Microbiome Analysis: a feasibility study, Prof Yiannakou. <i>University Hospital of North Durham, Durham, UK</i>	35,900
<hr/>	
Ongoing projects, initiated in previous financial years, payable (subject to progress) in 2016/17	Total cost £
Two-year program grant: biomedical basis of ME/CFS. Prof Julia Newton, School of Clinical Medical Sciences. <i>University of Newcastle, Newcastle</i>	100,000
A study examining Nrf2 antioxidant gene expression and its role in combatting oxidative stress. Prof F Khan, The Institute of Cardiovascular Research. <i>University of Dundee</i>	61,953
Epigenetics of the brain derived neurotrophic factor gene and its relevance for pain in ME/CFS: an explorative study. Prof Jo Nijs, Faculty of Physical Education and Physiotherapy. <i>Vrije Universiteit Brussel, Belgium</i>	44,859
Comparisons of ME & MS. Prof Jo Nijs, Faculty of Physical Education and Physiotherapy. <i>Vrije Universiteit Brussel, Belgium</i>	41,588
Two dimensional (2D) sequencing and machine learning to maximise genetic marker detection in a clinically well-defined ME cohort for enhanced diagnosis. Prof Brett Lidbury, The John Curtin School of Medical Research. <i>The Australian National University, Acton, Australia</i>	49,724

ME Research UK

Trustees' Report

Impact and 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 45 specific grants totaling c.£1.6 million, to research institutions in the UK, Australia, Belgium, Canada, Germany and Sweden. The results have been published in 71 research papers in peer-reviewed scientific journals world-wide and are available to researchers globally.

In addition, the following outcomes have been achieved during the year with the diverse topics explored being indicative of the range of research being carried out with funding supplied by the charity.

a) Reviews of severe and very severe ME/CFS

As part of an ongoing programme of research at Newcastle University concentrating on severely affected ME/CFS patients, Victoria Strassheim and colleagues undertook a review of studies conducted in this subgroup, published in *Fatigue: Biomedicine, Health & Behaviour*. We still understand very little about the origin and outcomes of severe ME/CFS, but the prospects for recovery tend to be worse, patients are predisposed to develop secondary medical conditions, and the cumulative impact of severe illness over many years can be profound. This review identified 21 papers published over a 24-year period addressing the severely and very severely affected categories of ME/CFS patients, highlighting how little research has been focused on these individuals. Five different sets of diagnostic criteria were used across these studies, making it difficult to compare results between them, and difficult to know if the same illness is being sampled in each. The main cause of disability was not clear, and several measures were used to assess disability. The progress of the disease was poorly characterised, possibly because of the range of symptoms and dysfunctions reported.

The researchers have also published a review in *Physical Therapy Reviews* looking at the potential adverse effects of microgravity on the physiology of patients with severe ME/CFS, their clinical significance, and the implications on patient management. Microgravity describes an environment with very little gravitational force, such as that experienced by astronauts in space. Human physiology has evolved to adapt to the effects of gravity, so reducing exposure to gravity can result in deconditioning of these systems. It is suggested that patients with severe ME/CFS who spend prolonged periods in a supine position experience an environment similar to microgravity, and this may be the mechanism through which orthostatic intolerance develops in the illness. Other physiological changes in ME/CFS affecting the cardiovascular and autonomic nervous systems may exacerbate these effects.

b) Role of glial activation in the development of central sensitisation

Prof. Jo Nijs and colleagues at Vrije Universiteit Brussel in Belgium are currently using laser-evoked potentials to investigate the presence of hypersensitivity of the central nervous system (or central sensitisation) in patients with ME/CFS. Central sensitisation appears to provide a partial explanation of the chronic pain experienced by these individuals, but the mechanisms underlying it are not well understood. As part of their research, the team conducted a review of mostly preclinical and animal studies looking at the role of abnormal glial activation in central sensitisation. Glial cells surround and insulate neurons, and are known as the supporting cells of the nervous system. Glial activation causes a low-grade neuroinflammatory state which increases the sensitivity of the central nervous system. This abnormal glial activity may be triggered by severe exposure to stress or sleep disturbances, each of which are known to initiate the development of chronic pain. These findings suggest potential treatment options, such as sleep management, stress management, exercise therapy and drugs to reduce glial activity. This work was published in the journal, *Expert Opinion on Therapeutic Targets*.

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Trustees' Report

c) UK ME/CFS Biobank

The UK ME/CFS Biobank has been developed as a research resource for scientists at the London School of Hygiene & Tropical Medicine and for the international community of researchers interested in conducting research using tissue from ME/CFS patients. It was established with funding from three charities, including ME Research UK. Dr Eliana Lacerda and colleagues at the Biobank have published an article in the Open Journal of Bioresources which provides updated information on recruitment. At the time of publication of recruitment data (February 2017), the Biobank had recruited 479 participants, including 284 clinically-confirmed ME/CFS cases, 60 neurologist-diagnosed multiple sclerosis cases, and 135 healthy individuals. A total of 29,863 aliquot samples have been stored, including serum, plasma, peripheral blood mononuclear cells, red blood cells/granulocyte pellets, whole blood and RNA samples.

B - Publications, Education and Awareness Raising

During 2016/17, the charity continued its role as providers of high-quality information and education for healthcare professionals and the public. We provided invaluable support and information to the general public, in particular to those affected directly or indirectly by ME/CFS, to health care professionals and to research scientists. 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 newly funded research applications 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, with a readership of almost 5000 in hard copy and more on-line digests research news from around the world and 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 (MERResearchUK) 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 five years ago, our Facebook page has amassed over 6000 'likes' – an increase of 25% from 2015-16 – 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 has hoped that the newly active twitter account will further drive the successful dissemination of our research news.

ME Research UK has been able to activate its twitter account (MERResearchUK) as a further avenue to engage more fully with potential donors and to create a community of supporters.

After much consideration, the Trustees decided to withdraw from the UK CFS/ME Collaborative in order to permit the charity to focus its resources on its own projects and evolution.

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 Prof. Julia Newton, Dr Wan Ng and colleagues at Newcastle University who, in 2012, were awarded almost £1 million from the Medical Research Council. At the time, Prof. Newton acknowledged ME Research UK for providing “the pilot/seedcorn 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.

Donated facilities and services

It is estimated that approximately 1191 voluntary hours were donated by members i.e. the Trustees of ME Research UK, and 278 voluntary hours were donated by volunteers.

Google AdWords enables the charity to advertise free via Google searches. The value of this donation in kind is approximately \$31,158 (£24,550) and has been recognised in the accounts.

Key management personnel remuneration

No key management personnel of the charity receive any remuneration. Strategic decisions and direction come from the Trustees, who receive no remuneration. Staff of the charity carry out the decisions of the Trustees and have no input, with exception of provision of background reports and recommendations, in strategic decision making.

Financial review

The total funds held at the year-end were £324,533 (2016: £354,166), including £66,125 of restricted funds (2016: £37,515). These funds are further explained at note 21.

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 16.

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.

Risk management

The Board of Charity Trustees has considered the major risks to which the charity is exposed and has reviewed those risks and established procedures to manage them. At their meeting on 12th July 2017 the Trustees adopted an updated Risk Register and the items recorded therein will remain under scrutiny.

ME Research UK

Trustees' Report

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 establishment and nurturing of the Ambassadors scheme will continue. 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 Advisory Board 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.

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.

ME Research UK

Trustees' Report

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 minimize financial risk. At their meeting on 12th July 2017 the Trustees adopted a formal 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.

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

The annual report was approved by the Trustees of the Charity on 25 April 2018 and signed on its behalf by:

.....
Dr Vance Spence
Chairman/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 & 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 Examiner's Report to the trustees of ME Research UK

I report on the accounts of the charity for the year ended 31 October 2017 which are set out on pages 15 to 28.

Respective responsibilities of Trustees and Examiner

The Trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended). The Trustees consider that the audit requirement of Regulation 10(1) (a) to (c) of the 2006 Accounts Regulations does not apply.

It is my responsibility to examine the accounts as required under section 44(1) (c) of the Act and to state whether particular matters have come to my attention.

Basis of Independent Examiner's Report

My examination was carried out in accordance with Regulation 11 of the 2006 Accounts Regulations. An examination includes a review of the accounting records kept by the Charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as Trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an opinion on the view given by the accounts.

Independent Examiner's statement

In the course of my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that in any material respect the requirements:
 - to keep accounting records in accordance with Section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations, and
 - to prepare accounts which accord with the accounting records and comply with the Regulation 8 of the 2006 Accounts Regulationshave not been met; or
- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

.....
Alexander J Fyfe, M.A.A.T., C.A., DChA

Morris & Young
Chartered Accountants
6 Atholl Crescent
PERTH
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Date:.....

ME Research UK

Statement of Financial Activities for the Year Ended 31 October 2017 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2017 £	Total 2016 £
Income and Endowments from:					
Donations and legacies	2	162,331	48,514	210,845	225,753
Other trading activities	3	7,618	-	7,618	7,843
Investment income	4	<u>2,023</u>	<u>829</u>	<u>2,852</u>	<u>4,356</u>
Total Income		<u>171,972</u>	<u>49,343</u>	<u>221,315</u>	<u>237,952</u>
Expenditure on:					
Raising funds	5	(39,914)	(55)	(39,969)	(37,474)
Charitable activities	6	(37,500)	(137,778)	(175,278)	(124,478)
Other expenditure	7	<u>(37,706)</u>	<u>-</u>	<u>(37,706)</u>	<u>(36,169)</u>
Total Expenditure		(115,120)	(137,833)	(252,953)	(198,121)
Gain on investment assets		<u>2,005</u>	<u>-</u>	<u>2,005</u>	<u>2,172</u>
Net income/(expenditure)		58,857	(88,490)	(29,633)	42,003
Transfers between funds		<u>(117,100)</u>	<u>117,100</u>	<u>-</u>	<u>-</u>
Net movement in funds		(58,243)	28,610	(29,633)	42,003
Reconciliation of funds					
Total funds brought forward		<u>316,651</u>	<u>37,515</u>	<u>354,166</u>	<u>312,163</u>
Total funds carried forward	21	<u><u>258,408</u></u>	<u><u>66,125</u></u>	<u><u>324,533</u></u>	<u><u>354,166</u></u>

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

The funds breakdown for 2016 is shown in note 21.

ME Research UK

**(Registration number: SC036942)
Balance Sheet as at 31 October 2017**

	Note	2017 £	2016 £
Fixed assets			
Tangible assets	14	167	335
Investments	15	<u>38,196,361</u>	<u>36,526</u>
		<u>38,363</u>	<u>36,526</u>
Current assets			
Stocks	16	1,305	1,388
Debtors	17	12,664	7,718
Cash at bank and in hand		<u>648,551</u>	<u>603,303</u>
		662,520	612,409
Creditors: Amounts falling due within one year	18	<u>(254,236)</u>	<u>(234,570)</u>
Net current assets		<u>408,284</u>	<u>377,839</u>
Total assets less current liabilities		446,647	414,365
Creditors: Amounts falling due after more than one year	19	<u>(122,114)</u>	<u>(60,199)</u>
Net assets		<u>324,533</u>	<u>354,166</u>
Funds of the charity:			
Restricted funds		66,125	37,515
Unrestricted income funds			
Unrestricted funds		<u>258,408</u>	<u>316,651</u>
Total funds	21	<u>324,533</u>	<u>354,166</u>

The financial statements on pages 15 to 29 were approved by the Trustees, and authorised for issue on 25 April 2018 and signed on their behalf by:

.....
Dr Vance A Spence
Chairman/Trustee

.....
Mrs Sue Waddle
Vice-Chair

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2017

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.

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 2017

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.

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

3 years straight line

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2017

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.

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.

2 Income from donations and legacies

	Unrestricted funds	Restricted funds	Total 2017	Total 2016
	General £	£	£	£
Donations and legacies;				
Donations from companies, trusts and similar proceeds	911	-	911	2,801
Donations from individuals	145,505	41,917	187,422	203,577
Legacies	-	500	500	250
Gift Aid reclaimed	15,915	6,097	22,012	19,125
	<u>162,331</u>	<u>48,514</u>	<u>210,845</u>	<u>225,753</u>

3 Income from other trading activities

	Unrestricted funds	Total 2017	Total 2016
	General £	£	£
Trading income;			
Other trading income	7,618	7,618	7,843
	<u>7,618</u>	<u>7,618</u>	<u>7,843</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2017

4 Investment income

	Unrestricted funds	Restricted funds	Total 2017	Total 2016
	General £	£	£	£
Income from dividends;				
Dividends receivable from other listed investments	1,197	-	1,197	1,137
Interest receivable and similar income;				
Interest receivable on bank deposits	826	829	1,655	3,219
	<u>2,023</u>	<u>829</u>	<u>2,852</u>	<u>4,356</u>

5 Expenditure on raising funds

a) Costs of generating donations and legacies

		Unrestricted funds	Restricted funds	Total 2017	Total 2016
	Note	General £	£	£	£
Donations		<u>37,356</u>	<u>55</u>	<u>37,411</u>	<u>35,028</u>

b) Costs of trading activities

		Unrestricted funds	Total 2017	Total 2016
	Note	General £	£	£
Costs of goods sold		<u>2,558</u>	<u>2,558</u>	<u>2,446</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2017

6 Expenditure on charitable activities

	Unrestricted funds		Restricted funds	Total 2017	Total 2016
Note	General £		£	£	£
Grant funding of activities	-		137,778	137,778	71,133
Staff costs	36,600		-	36,600	52,445
Governance costs	900	8	-	900	900
	<u>37,500</u>		<u>137,778</u>	<u>175,278</u>	<u>124,478</u>

Grant funding of activity

	2017	2016
	£	£
Grant funding	191,878	101,837
Returned Grant funding	(54,100)	(30,704)
	<u>137,778</u>	<u>71,133</u>

Grant funding of £54,100 was withdrawn (2016: £30,704) due to the decision not to proceed with the specific project.

7 Other expenditure

	Unrestricted funds		Total 2017	Total 2016
Note	General £		£	£
Other resources expended	37,706		37,706	36,169
	<u>37,706</u>		<u>37,706</u>	<u>36,169</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2017

8 Analysis of governance and support costs

Governance costs

	Unrestricted funds	Total 2017	Total 2016
	General £	£	£
Independent examiner's fee	900	900	900
	<u>900</u>	<u>900</u>	<u>900</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2017

9 Grant-making

Grants payable at 1 November 2016	293,215
Grants paid	(56,733)
New grants committed/withdrawn	137,778
Grants payable at 31 October 2017	374,260

Grants paid and payable

		Grants paid	Grants committed/ withdrawn	Payable	
Institution	Title of project	2017	2017	2017	2016
University of Newcastle	2 Year Program Grant: Biomedical Basis of ME/CFS	33,229	-	16,925	50,154
University of Dundee	Insights into Pathophysiology of CFS/ME	11,073	-	41,717	52,790
The Australian National University	Two dimensional sequencing and machine learning to ME cohort for enhanced diagnosis	12,431	-	37,293	49,724
University of British Columbia	ME/CFS patients who will benefit from B cell depletion with rituximab	-	(54,100)	-	54,100
Universiteit Brussel	Comparison of ME & MS definitions	-	-	41,588	41,588
Universiteit Brussel	Epigenetics of the Brain Derived Neurotrophic Factor Gene and its relevance for Pain in ME/CFS	-	-	44,859	44,859
University Medicine Berlin	The role of autoantibodies in ME/CFS	-	70,460	70,460	-
University of Newcastle	Investigating abnormalities in AMPK activation	-	85,518	85,518	-
University Hospital of North Durham	Exploring the association between CFS and IBS through immune and microbiome analysis	-	35,900	35,900	-
		56,733	137,778	374,260	293,215

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 2017

10 Net incoming/outgoing resources

Net incoming resources for the year include:

	2017	2016
	£	£
Independent examiner's remuneration	900	900
Depreciation	168	167
	<u>1,068</u>	<u>1,067</u>

11 Trustees remuneration and expenses

Three Trustees were reimbursed for travelling expenses totalling £1,262.21 during the year (2016 - £1,431.06). No Trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

12 Staff costs

The aggregate payroll costs were as follows:

	2017	2016
	£	£
Staff costs during the year were:		
Wages and salaries	60,817	73,169
Social security costs	<u>3,330</u>	<u>4,018</u>
	<u>64,147</u>	<u>77,187</u>

The monthly average number of persons (including senior management team) employed by the charity during the year expressed as full time equivalents was as follows:

	2017	2016
	No	No
Charitable activities	1	1
Fundraising	1	2
Governance	<u>1</u>	<u>1</u>
	<u>3</u>	<u>4</u>

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

The total employee benefits of the key management personnel of the Charity were £Nil (2016 - £Nil).

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2017

13 Taxation

ME Research UK is a registered charity and is, therefore, exempt from taxation.

14 Tangible fixed assets

	Furniture and equipment	Total
	£	£
Cost		
At 1 November 2016	5,695	5,695
At 31 October 2017	<u>5,695</u>	<u>5,695</u>
Depreciation		
At 1 November 2016	5,360	5,360
Charge for the year	168	168
At 31 October 2017	<u>5,528</u>	<u>5,528</u>
Net book value		
At 31 October 2017	<u>167</u>	<u>167</u>
At 31 October 2016	<u>335</u>	<u>335</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2017

15 Fixed asset investments

Other investments

	Listed investments £	Total £
Cost or Valuation		
Cost brought forward	36,191	36,191
Revaluation	<u>2,005</u>	<u>2,005</u>
At 31 October 2017	<u>38,196</u>	<u>38,196</u>
Net book value		
At 31 October 2017	<u>38,196</u>	<u>38,196</u>
At 31 October 2016	<u>36,191</u>	<u>36,191</u>

The market value of the listed investments at 31 October 2017 was £38,196 (2016 - £36,191).

All investment assets were held in the UK.

16 Stock

	2017 £	2016 £
Stock	<u>1,305</u>	<u>1,388</u>

17 Debtors

	2017 £	2016 £
Prepayments	<u>12,664</u>	<u>7,718</u>

18 Creditors: amounts falling due within one year

	2017 £	2016 £
Other creditors	252,146	233,016
Accruals	<u>2,090</u>	<u>1,554</u>
	<u>254,236</u>	<u>234,570</u>

19 Creditors: amounts falling due after one year

	2017 £	2016 £
Other creditors	<u>122,114</u>	<u>60,199</u>

ME Research UK

Notes to the Financial Statements for the Year Ended 31 October 2017

20 Obligations under leases and hire purchase contracts

	2017	2016
	£	£
Land and buildings		
Within one year	2,179	2,179
	<u>2,179</u>	<u>2,179</u>

21 Funds

	Balance at 1 November 2016 £	Incoming resources £	Resources expended £	Transfers £	Other recognised gains/(losses) £	Balance at 31 October 2017 £
Unrestricted funds						
<i>General</i>						
Unrestricted funds	316,651	171,972	(115,120)	(117,100)	2,005	258,408
Restricted funds						
Restricted funds	<u>37,515</u>	<u>49,343</u>	<u>(137,833)</u>	<u>117,100</u>	<u>-</u>	<u>66,125</u>
Total funds	<u>354,166</u>	<u>221,315</u>	<u>(252,953)</u>	<u>-</u>	<u>2,005</u>	<u>324,533</u>

	Balance at 1 November 2015 £	Incoming resources £	Resources expended £	Transfers £	Other recognised gains/(losses) £	Balance at 31 October 2016 £
Unrestricted funds						
<i>General</i>						
Unrestricted funds	298,307	153,282	(126,934)	(10,176)	2,172	316,651
Restricted funds						
Restricted funds	<u>13,856</u>	<u>84,670</u>	<u>(71,187)</u>	<u>10,176</u>	<u>-</u>	<u>37,515</u>
Total funds	<u>312,163</u>	<u>237,952</u>	<u>(198,121)</u>	<u>-</u>	<u>2,172</u>	<u>354,166</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.

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 2017

22 Analysis of net assets between funds

	Unrestricted funds	Restricted funds	Total funds
	General £	£	£
Tangible fixed assets	167	-	167
Fixed asset investments	38,196	-	38,196
Current assets	222,135	440,385	662,520
Current liabilities	(2,090)	(252,146)	(254,236)
Creditors over 1 year	-	(122,114)	(122,114)
Total net assets	<u>258,408</u>	<u>66,125</u>	<u>324,533</u>

23 Analysis of net funds

	At 1 November 2016 £	Cash flow £	At 31 October 2017 £
Cash at bank and in hand	603,303	45,248	648,551
Net debt	<u>603,303</u>	<u>45,248</u>	<u>648,551</u>

24 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:

Dr Faisal Khan

Insights into Pathophysiology of CFS/ME

The above Project was paid funding of £11,073 during the year (2016 - £9,163). £41,717 remains payable within one year at 31 October 2017 (2016 - £52,790). This is recognised in grants payable at the year-end. Dr Khan joined the Board after the decision was made to award this Project a grant.