



**Annual Report & Accounts  
2014–2015**

# ME Research UK

## Contents

Reference and Administrative Details	1
Trustees' Report	2 to 13
Trustees' responsibilities in relation to the financial statements	14
Independent examiner's report	15
Statement of financial activities	16 to 17
Balance Sheet	18
Notes to the financial statements	19 to 29

## ME Research UK

### Reference and Administrative Details

<b>Charity name</b>	ME Research UK
<b>Charity registration number</b>	SC036942
<b>Trustees</b>	Dr Vance A Spence, Chairman Robert D McRae, Secretary Mrs Sue Waddle, Vice Chair Edward Dunkerley Mrs Jan McKendrick Dr Faisal Khan
<b>Founding Patron</b>	Roger Jefcoate CBE DL
<b>Patron</b>	The Countess of Mar
<b>Registered Office</b>	The Gateway North Methven Street Perth PH1 5PP
<b>Telephone</b>	01738 451234
<b>Email</b>	meruk@pkavs.org.uk
<b>Web</b>	<a href="http://www.mereseearch.org.uk">www.mereseearch.org.uk</a>
<b>Facebook</b>	MEReseearchUK
<b>Independent Examiner</b>	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 2014 to 31st October 2015 – 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 27th October 2011; 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 recognized as a single tier Scottish Charitable Incorporated Organisation (SCIO) on 8th November 2011 and was 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, working name "ME Research UK") was established in the year 2000 by Robert McRae, Dr Vance 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. Under the new Constitution of ME Research UK the Founding Trustees were Dr Vance A Spence, Robert D McRae and Mrs Betty McRae. The charity ME Research UK, having been deemed to have transferred all assets, including all bank deposits and investments, to the successor body, was deregistered 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 the 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 cure be found.
- Encourage researchers with fresh, novel ideas to be recruited and provided with the resources to undertake research in the field of ME/CFS. 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 that 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 previously published 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.

# **ME Research UK**

## **Trustees' Report**

### **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 Management Group is delegated to the Research and Operations Director.

The Management Group meets every 2 months, or more frequently if felt expedient, and is delegated with all necessary powers to carry out the will, directions and policies of the Board of Charity Trustees. It therefore actions policy decisions, considers new grant applications and recommends qualifying grant applications for funding. The Group also considers monitoring information concerning the performance of grants to date, makes recommendations to the Board of Charity Trustees concerning the extension, cessation or suspension of existing grant approvals and conducts a full review of the charity's finances, including its current obligations. ME Research UK has a policy and procedures structure formulated in accordance with charity best practice.

The structure outlined ensures subsidiarity and effective scrutiny and control.

### **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. Policy 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 costings which are justifiable.

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. All applications are subject to Peer Review (including review by external experts) and assessment by members of our own Scientific Advisory Board utilizing a Standardized scoring system to facilitate consistent decision-making.

In the current year, a number of grant applications were unsuccessful either in 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 methodology – ME Research UK strives to ensure proper and rigorous safeguards for the stewardship of funds under its control.

## **ME Research UK**

### **Trustees' Report**

ME Research UK's Standard Grant Conditions lay down that all payments of research funding are dependant 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 utilized 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 will be conducted in accordance with the principles outlined in the Declaration of Helsinki, and approved by local research ethics committees.

#### **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 now 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.

The beneficiaries of our grant making programme are ultimately those affected 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 replicated 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 (including the UK CFS/ME Research Collaborative 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 three 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 standardized 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 will be protected and recovered. Research grant instalments are normally paid only upon receipt of regular progress reports.

## **ME Research UK**

### **Trustees' Report**

By the 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](http://www.mereseearch.org.uk)

#### **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 2014/15, with 6 projects continuing from previous years.

As a direct response to our world-wide 'Call for Funding Applications', three projects were deemed by our Scientific Advisory Board to fulfil the necessary criteria and thus be recommended to the Trustees for funding. The number and geographic spread of applications received is indicative of the global nature of the illness – one is based in Canada (gene expression during exercise), one in Australia (brain imaging in young people with ME/CFS), and one in Belgium (epigenetic activation of the gene controlling pain), and further details are given below.

###### Study 1: Gene expression during post-exertion symptom flare

A hallmark of ME/CFS is that symptoms are made worse by exercise, sometimes 24-48 hours afterwards, even if the exercise is quite mild by normal standards. Dr David Patrick and colleagues at the University of British Columbia in Canada are examining post-exercise symptoms of patients using newly available gene sequencing technologies that allow a much deeper probe of host gene expression than has previously been possible. The National Institutes of Health in the US has funded most of the work involving RNA sequencing of samples, and ME Research UK's funding will allow additional measurements of mRNA expression up to 7 days after exercise. The research group hopes to identify specific gene expression patterns or responses in ME/CFS patients that might explain prolonged post-exercise symptoms.

###### Study 2: Neurological biomarkers in youngsters

There is now very good evidence of difficulties with memory, concentration/attention, and information processing in adults with ME/CFS. These include problems with visual & verbal memory, short-term and long-term recall, and mental clouding ("brain fog") – all have significant effects on daily functioning at home or work, as most patients know. Much less is known about these neurocognitive difficulties in youngsters, particularly the role of mental exertion in worsening these symptoms. In fact, advanced structural and functional neuroimaging techniques have only rarely been applied to understanding the impact of ME/CFS on the function of the developing brain of young people. ME Research UK's funding to Dr Sarah Knight and colleagues of the Murdoch Children's Research Institute in Melbourne will allow the team to examine how the brain and its underlying functioning responds to mental exertion in adolescents with ME/CFS, using a variety of neuroimaging techniques.

## ME Research UK

### Trustees' Report

#### Study 3: BDNF gene & pain

Chronic pain is debilitating and very common, and is a particular problem in people with ME/CFS, 80–90% of whom report severe pain and/or muscle or joint pain. Overall, there is now evidence that brain-orchestrated inhibition of pain at rest and during exercise is impaired in people with ME/CFS, in line with the occurrence of hypersensitivity of the central nervous system ('central sensitization'). The logical next step is to unravel the mechanisms of the pain associated with central sensitization by examining factors known to increase it. One such factor is brain-derived neurotrophic factor (BDNF), a protein which is produced by a variety of cells, including sensory and motor neurons, and immune cells. The new exploratory study funded by ME Research UK will allow a cross-disciplinary team of researchers in Belgium to explore the presence of epigenetic changes in the *BDNF* gene and whether they are more prevalent in ME/CFS patients than in the general population. Given the current understanding of BDNF's role in central sensitization, their hypothesis is that epigenetic activation of the *BDNF* gene is related to the pain experienced by people with the illness.

All grant-making disclosed in Note 9 to the accounts relates to research which advances the objectives of the charity.

<u>New Projects in 2014/15</u>	<u>Total Cost £</u>
Epigenetics of the Brain Derived Neurotrophic Factor Gene and its Relevance for Pain in ME/CFS: an Explorative Study. <i>Prof Jo Nijs, Faculty of Physical Education and Physiotherapy, Vrije Universiteit Brussel, Belgium</i>	44,859
Characterising neurological biomarkers of paediatric ME/CFS. <i>Dr Sarah Knight, Murdoch Childrens Research Institute, University of Melbourne, Australia</i>	46,231
Exploring host gene expression during post-exertional symptom flare in ME/CFS: An experimental approach. <i>Dr David Patrick, School of Population and Public Health, University of British Columbia, Canada</i>	36,450



## ME Research UK

### Trustees' Report

Ongoing projects, initiated in previous financial years, potentially billing for payment in 2014/15	Total Cost £
Reading between the lines of visual discomfort in CFS/ME. <i>Dr Claire Hutchinson, Vision and Language Group, School of Psychology, College of Medicine, Biological Sciences and Psychology, University of Leicester</i>	15,922
A Study Examining Nrf2 Antioxidant Gene Expression and its Role in Combatting Oxidative Stress. <i>Dr F Khan, The Institute of Cardiovascular Research, University of Dundee</i>	61,953
Transfer of the ME Disease Register to Buckinghamshire New University, and the Implementation of a Research Program. <i>Dr Derek Pheby, Buckinghamshire New University</i>	5,006
Comparison of ME & MS definitions <i>Prof J Nijs, Faculty of Physical Education and Physiotherapy, Vrije Universiteit Brussel, Belgium</i>	41,588
2-Year Program Grant: Biomedical Basis of ME/CFS. <i>Prof Julia Newton, School of Clinical Medical Sciences, University of Newcastle, Newcastle</i>	100,000
Assessment of visual function in CFS/ME <i>Dr Claire Hutchison, Vision and Language Group, School of Psychology, College of Medicine, Biological Sciences and Psychology, University of Leicester</i>	4,156
Biobank Project Phase 2 <i>Dr Luis Nacul, London School of Hygiene and Tropical Medicine</i>	3,614
Common pathways leading to fatigue <i>Dr Clive Carter, Leeds NHS Teaching Hospital NHS Trust</i>	22,500

#### *Impact and Publications*

A widely accepted means by which the work of the charity can be assessed is to gauge the number of times that an ME Research UK funded paper has been referred to by other scientists. Since 2000, ME Research UK has awarded 41 specific grants totaling £1.3 million, to research institutions in the UK, Australia, Belgium, Canada and Sweden. The results have been published in 69 research papers in peer-reviewed scientific journals world-wide. At July 2015, these studies had been cited 1134 times and this tally can but increase over time.

As regards publications, some of our previously funded work has been published, "in press" or submitted for publication. A list of publications from ongoing and previous projects can be found on our website at <http://www.meresearch.org.uk/our-research/>.

## **ME Research UK**

### **Trustees' Report**

ME Research UK is also able to report that thanks to its funding, eight papers have been published in peer-reviewed scientific journals emanating from grants paid. 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) Problems with eyes and vision occur in around three-quarters of people with ME/CFS, yet these symptoms are rarely recognized. Since 2012, ME Research UK (in conjunction with the Irish ME Trust) has been funding Dr Claire Hutchinson and colleagues at the University of Leicester to identify and quantify vision-related problems in the disease. The work has resulted in three robust scientific papers reporting that ME/CFS patients perform worse than matched controls across three specific aspects of vision; that eye movement dysfunction is a prominent feature; and that vision-related symptoms (sensitivity to bright lights; problems focusing vision and/or attention; and eye pain) are a significant clinical feature. In 2014, we gave additional funding to the team to investigate visual discomfort during reading, a common activity which is important for optimal quality of life but which many people with ME/CFS find difficult. During, the first short report from this project was published in the journal 'Perception'. The research team found that "pattern-related visual stress" (a form of visual hypersensitivity to patterns, such as a page of words) was present in ME/CFS patients who experience visual distortions that healthy people do not.

b) Patients diagnosed with ME/CFS frequently highlight the importance of peripheral fatigue – such as impairment of muscle power – in their experience of illness. Research in other diseases has highlighted important biological mechanisms that appear to underlie muscle fatigue, and since 2006 ME Research UK has provided the pilot funding for many distinct projects at the University of Newcastle to explore the role of these mechanisms in ME/CFS. Part of this funding was to investigate a 'model' of exercise in isolated muscle cells, and a scientific paper on these findings was published in July 2015. The researchers found abnormalities of AMPK activation and glucose uptake in the cultured skeletal muscle cells, a fascinating result which points to an exercise-related, primary abnormality in the muscle of ME/CFS patients which, because it was observed in cultured isolated muscle cells, may well have a genetic or epigenetic basis.

c) Sleep disturbances are common in ME/CFS and one of the key symptom complaints, yet very little scientific study has been conducted. In 2014–15, two scientific papers were published on sleep from ME Research UK part-funded studies. The first, in the British Journal of Health Psychology, and was a qualitative investigation, and the researchers from Northumbria University reported on the experience of sleep. Three overarching themes were observed: sleep pattern variability over illness course; sleep effects on daytime functioning; and patients' attempts to cope and manage sleep. Interestingly, every participant regarded their sleep as in some way 'broken' and in need of management or repair. The second study, published in PLoS One, was also from Northumbria University and it examined daytime napping and cognitive function. The main finding was that napping, particularly in the afternoon (a relatively common phenomenon among patients) was associated with poorer cognitive functioning and more daytime sleepiness.

## ME Research UK

### Trustees' Report

d) There are many definitions of ME and CFS, but each is different, and the terms ME, CFS and their various combinations mean different things to different people today. Many different views and opinions exist about which definition might be 'best', but hard data is thin on the ground. ME Research UK funded Prof Julia Newton to explore the use of a standard questionnaire, the DePaul Symptom Questionnaire (DSQ) devised by Prof Leonard Jason of DePaul University, Chicago, to assess core symptoms of ME/CFS. In 2014–15, these groups published a scientific paper in the Journal of Prevention & Intervention in the Community using the DSQ to examine definitional issues. Their results indicate that definitional criteria for ME alone identify a group of patients with more functional disabilities and more severe post-exertional malaise than definitional criteria for CFS, an important finding that indicates that careful selection of criteria and of patient groups is essential.

e) The Vascular and Inflammatory Diseases Research Unit in Dundee has received a range of grants from ME Research UK in the past 12 years, and has reported a number of abnormalities, including increased levels of free radicals in the blood, biochemical anomalies in children mirroring those found in adults, and, latterly, an association between vitamin D and cardiovascular risk in ME/CFS patients. In 2014–15, the group published its latest report in the journal Nutrition, Metabolism & Cardiovascular Diseases, describing the results of an ME Research UK-funded clinical trial on vitamin D supplementation in people with ME/CFS. The conclusion was that high-dose oral vitamin D did not improve markers of vascular health or fatigue in patients, and the authors speculate that either low vitamin D levels be a result of ME/CFS *per se* (in which case, supplying more would not necessarily reverse the vascular dysfunction) or that even larger or more frequent dosing be needed specifically in ME/CFS patients.

f) 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, and in 2014–15 the CURE-ME research team at the London School announced that the establishment had been completed. The funding had enabled the Biobank to obtain a £1 million research grant from the US National Institutes of Health, which will fund the project through to mid-2016. At July 2015, it had recruited 390 participants (245 ME/CFS cases, 101 healthy controls, and 44 patients with MS), 22,500 aliquot samples were stored, and the resource aimed to open samples to research groups on a cost-recovery basis in the very near future.

#### B - Publications and Education

During 2014/15, the charity continued its role as providers of high-quality information and education for healthcare professionals and the public. Despite limited staffing, we provided invaluable support and information to the general public, health care professionals and 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.

## **ME Research UK**

### **Trustees' Report**

During the reporting year our 'Breakthrough' magazine was completely redesigned. This unique publication 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 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 or nurses 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 four years ago, our Facebook page has amassed over 3600 'likes' – an increase of two-thirds from 2013–14 – 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.

Through our membership of the UK CFS/ME Research Collaborative (CMRC) we continue to raise the profile of biomedical research on a wider stage. The aim of the CMRC - the first of its kind in the world - is to promote the highest quality of basic and applied evidenced-based and peer reviewed research into ME/CFS by bringing together national agencies, ME/CFS charities, and working researchers from across the UK who wish to work towards that common goal. Membership of the CMRC increases the opportunities we have to engage directly with researchers working with other charities, and with larger national funding bodies, such as the Medical Research Council, which have associate membership status. In 2014/15, we attended four meetings of the CMRC, and had three representatives at the second CMRC scientific conference held in Newcastle in October. We had offered funding to researchers for going to this conference, and it was attended by many of the researchers we have funded, including Prof Jo Nijs (Vrije Universiteit Brussel, Belgium); Dr Faisal Khaan (University of Dundee); Dr Clive Carter (Leeds NHS Trust); Dr Erinna Bowman (London School of Hygiene & Tropical Medicine); and Victoria Strassheim & Prof Julia Newton (Newcastle University). Through our continuing membership, we hope to dramatically alter the research landscape to the benefit of ME/CFS patients everywhere.

#### **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**

### **Trustees' Report**

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

#### **Donated facilities and services**

It is estimated that approximately 872 voluntary hours were donated by members and 60 voluntary hours were donated by volunteers.

Google ad words enables the charity to advertise free via Google searches. The value of this donation in kind is approximately \$8,967.20 (£5,812.54) and has been recognised in the accounts.

#### **Financial review**

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 7 to the accounts, and the charities assets and liabilities are detailed in the Balance Sheet presented in page 18.

The charity's work is entirely reliant on voluntary income.

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 16th July 2014 the Trustees adopted an updated Risk Register and the items recorded therein 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 establishment and nurturing of the Ambassadors scheme will continue.

## **ME Research UK**

### **Trustees' Report**

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. In addition, ME Research UK is an active participant in the UK CFS/ME Research Collaborative, the aims and objectives of which largely mirror those of the charity. By supporting initial research, matching funding is often released within researchers' own institutions thus leveraging additional benefit for the sums invested. As can be observed from the scientific papers funded, ME Research UK also collaborates with other charities and funding bodies to facilitate research which would otherwise be impossible for individual bodies alone to bear financially.

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. It was for this reason that ME Research UK became a founding member of the CFS/ME UK Research Collaborative. In addition, a pro-active 'call for applications' has been made to potential recipients working in the field.

## **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 minimize financial risk. Within Unrestricted Funds, three months' operating expenses (£30,000) are identified as a financial reserve. Surplus funds beyond this level are available for immediate utilization 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.

Approved by the Board on 13 April 2016 and signed on its behalf by:

.....  
Dr Vance A Spence  
Chairman of the Board of Trustees/Trustee

## **ME Research UK**

### **Trustees' Responsibilities in relation to the Financial Statements**

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

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 charitable company and of the incoming resources and application of resources, including income and expenditure, of the charitable company for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then 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 proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Charities & Trustee Investment (Scotland) Act 2005, regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the provisions of the Trust Deed. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.



**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 2015, which are set out on pages 16 to 29.

**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 audit 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  
PH1 5JN

Date:.....

## ME Research UK

### Statement of Financial Activities (including Income and Expenditure Account and Statement of Total Recognised Gains and Losses) for the Year Ended 31 October 2015

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
<b>Incoming resources</b>					
Incoming resources from generated funds					
Voluntary income	2	187,665	61,133	248,798	251,554
Activities for generating funds	3	6,364	-	6,364	7,181
Investment income	4	<u>2,330</u>	<u>1,625</u>	<u>3,955</u>	<u>4,406</u>
Total incoming resources	-	<u>196,359</u>	<u>62,758</u>	<u>259,117</u>	<u>263,141</u>
<b>Resources expended</b>					
Costs of generating funds					
Costs of generating voluntary income	5	22,897	-	22,897	23,353
Fundraising trading: cost of goods sold and other costs	6	2,169	-	2,169	2,826
Charitable activities	8,7	80,739	127,564	208,303	149,077
Governance costs	10	<u>900</u>	-	<u>900</u>	<u>942</u>
Total resources expended	-	<u>106,705</u>	<u>127,564</u>	<u>234,269</u>	<u>176,198</u>
Net income before transfers		89,654	(64,806)	24,848	86,943
<b>Transfers</b>					
Gross transfers between funds	-	<u>(28,596)</u>	<u>28,596</u>	-	-
Net income before other recognised gains and losses		61,058	(36,210)	24,848	86,943
<b>Other recognised gains/losses</b>					
Gains/(losses) on investments	-	<u>536</u>	-	<u>536</u>	<u>490</u>
Net movements in funds		61,594	(36,210)	25,384	87,433

The notes on pages 19 to 29 form an integral part of these financial statements.

## ME Research UK

### Statement of Financial Activities (including Income and Expenditure Account and Statement of Total Recognised Gains and Losses) for the Year Ended 31 October 2015

..... continued

#### Reconciliation of funds

Total funds brought forward	<u>236,713</u>	<u>50,066</u>	<u>286,779</u>	<u>199,346</u>
Total funds carried forward	<u>298,307</u>	<u>13,856</u>	<u>312,163</u>	<u>286,779</u>

All incoming resources and resources expended derive from continuing operations.

## ME Research UK

### Balance Sheet as at 31 October 2015

		2015		2014	
Note	£	£	£	£	£
<b>Fixed assets</b>					
Investments	16		34,019		33,483
<b>Current assets</b>					
Stocks and work in progress		1,496		1,869	
Debtors	17	44,692		9,669	
Cash at bank and in hand	-	<u>553,844</u>	-	<u>497,942</u>	
		600,032		509,480	
<b>Creditors: Amounts falling due within one year</b>					
	18	-	<u>(186,830)</u>	-	<u>(139,695)</u>
<b>Net current assets</b>					
		-	<u>413,202</u>	-	<u>369,785</u>
<b>Total assets less current liabilities</b>					
			447,221		403,268
<b>Creditors: Amounts falling due after more than one year</b>					
	19	-	<u>(135,058)</u>	-	<u>(116,489)</u>
<b>Net assets</b>					
			<u>312,163</u>		<u>286,779</u>
<b>The funds of the charity:</b>					
<b>Restricted funds</b>					
			13,856		50,066
<b>Unrestricted funds</b>					
Unrestricted income funds		-	<u>298,307</u>	-	<u>236,713</u>
<b>Total charity funds</b>					
			<u>312,163</u>		<u>286,779</u>

Approved by the Board on 13 April 2016 and signed on its behalf by:

.....  
 Dr Vance A Spence  
 Chairman of the Board of Trustees/Trustee

.....  
 Robert D McRae  
 Secretary/Trustee

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

#### 1 Accounting policies

##### **Basis of preparation**

The financial statements have been prepared under the historical cost convention and in accordance with the Statement of Recommended Practice 'Accounting and Reporting by Charities (SORP 2005)', issued in March 2005, the Financial Reporting Standard for Smaller Entities (effective April 2008) and the Companies Act 2006.

##### **Fund accounting policy**

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

Restricted 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.

##### **Incoming resources**

Voluntary income including donations, legacies and grants that provide core funding or are of a general nature is recognised where there is entitlement, certainty of receipt and the amount can be measured with sufficient reliability.

The value of any voluntary help received is not included in the Accounts but is described in the Trustees' report.

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

Where incoming resources have related expenditure, the income and expenditure are reported gross in the statement of financial activities.

Investment income is recognised on a receivable basis.

##### **Resources expended**

Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to the expenditure. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category.

Costs of generating funds comprise the costs associated with attracting voluntary income and the costs of trading for fundraising purposes. No allocation of support costs are made hereto.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries.

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.

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

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... continued

#### **Governance costs**

Governance costs include costs of the preparation and examination of the statutory accounts, the costs of trustee meetings and the cost of any legal advice to trustees on governance or constitutional matters.

#### **Fixed assets**

Individual fixed assets costing £500 or more are initially recorded at cost.

#### **Depreciation**

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:

Fixtures and fittings	Depreciated over 3 years
-----------------------	--------------------------

#### **Investments**

Fixed asset 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 the 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 net realisable value, after due regard for obsolete and slow moving stocks. Net realisable value is based on selling price less anticipated costs to completion and selling costs. Items donated for resale or distribution are not included in the financial statements until they are sold or distributed.

#### **Operating leases**

Rentals payable under operating leases are charged in the statement of financial activities on a straight line basis over the lease term.

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... continued

#### 2 Voluntary income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
<b>Donations and legacies</b>				
Legacies and bequests	37,556	-	37,556	43,211
Appeals and donations	130,071	58,302	188,373	184,251
Gift Aid reclaimed	19,374	2,831	22,205	23,408
Trusts and foundations	664	-	664	684
	187,665	61,133	248,798	251,554

#### 3 Activities for generating funds

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
<b>Fundraising trading</b>				
Christmas Cards	6,364	-	6,364	7,181

#### 4 Investment income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
Income tax reclaimed	31	-	31	-
Interest on cash deposits	1,329	1,625	2,954	3,207
Charifund dividends	970	-	970	1,199
	2,330	1,625	3,955	4,406

#### 5 Costs of generating voluntary income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
<b>Donations and legacies</b>				
Wages and salaries	12,491	-	12,491	12,119
Staff NIC (Employers)	762	-	762	739
Accommodation	1,724	-	1,724	1,901

	<b>ME Research UK</b>			
Other Direct costs	-	<u>7,920</u>	-	<u>8,594</u>
		<u>22,897</u>		<u>23,353</u>
<b>Notes to the Financial Statements for the Year Ended 31 October 2015</b>				

..... continued



## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... continued

#### 6 Fundraising trading: cost of goods sold and other costs

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
<b>Fundraising trading</b>				
Christmas cards	2,169	-	2,169	2,826

#### 7 Analysis of charitable activities

	Charitable activities £		Total £
Grant funding of activities	127,540		127,540
Employment costs	53,854		53,854
Accommodation	7,003		7,003
Breakthrough costs	3,570		3,570
Other direct costs		16,336	-
	16,336		208,303
			208,303

#### 8 Details of charitable activities

	Activities undertaken directly £	Grant funding of activities £	2015 £	2014 £
Charitable activities	80,763	127,540	208,303	149,077

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... continued

#### 9 Grant-making

	<b>£</b>
Grants payable at 1 November 2014	254,739
Grants paid	63,439
New grants committed	<u>127,540</u>
Grants payable at 31 October 2015	<u><u>318,840</u></u>

#### Grants paid and payable

Institution	Title of Project	Grants paid		Grants committed		Payable	
		2015	2015	2015	2015	2015	2014
Faculty of Physical Education and Physiotherapy, Vrije Universiteit Brussel, Belgium	Comparison of ME & MS definitions	-	-	-	-	41,588	41,588
Vision and Language Group, School of Psychology, College of Medicine, Biological Sciences and Psychology, University of Leicester	Assessment of visual function in CFS/ME	-	-	-	-	4,156	4,156
London School of Hygiene and Tropical Medicine	Biobank Project Phase 2	3,614	-	-	-	-	3,614
Buckinghamshire New University	Transfer of ME Disease Register to Buckinghamshire New University & the implementation of a Research Programme	-	-	-	-	5,006	5,006
Leeds NHS Teaching Hospital NHS Trust	Common pathways leading to fatigue	16,000	-	-	-	6,500	22,500

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... *continued*

School of Medical Sciences, University of Newcastle	2 Year Program Grant: Biomedical Basis of ME/CFS	17,263	-	82,737	100,000
The Institute of Cardiovascular Research, University of Dundee	Insights into Pathophysiology of CFS/ME	-	-	61,953	61,953
Vision and Language Group, School of Psychology, College of Medicine, Biological Sciences and Psychology, University of Leicester	Reading between the lines Visual Discomfort	8,000	-	7,922	15,922
Faculty of Physical Education and Physiotherapy, Vrije Universiteit Brussel, Belgium	Epigenetics of the Brain Derived Neurotrophic Factor Gene and its relevance for Pain in ME/CFS	-	44,859	44,859	-
Murdoch Childrens Research Institute, University of Melbourne, Australia	Characterising neurological biomarkers of paediatric ME/CFS	-	46,231	46,231	-
School of Population and Public Health, University of British Columbia, Canada	Exploring host gene expression during post-exertional symptom flare in ME/CFS	18,562	36,450	17,888	-
		<u>63,439</u>	<u>127,540</u>	<u>318,840</u>	<u>254,739</u>

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

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... continued

#### 10 Governance costs

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
Independent examiner's fee	900	-	900	900
Auditors' remuneration	-	-	-	<u>42</u>
	<u>900</u>	-	<u>900</u>	<u>942</u>

#### 11 Trustees' remuneration and expenses

Two trustees were reimbursed for travelling expenses totalling £1,725.41 during the year (2014 - £983.81). No trustees received any remuneration during the year.

#### 12 Net income

Net income is stated after charging:

	2015		2014	
	£	£	£	£
Auditors' remuneration		-		42
Independent examiner's fee		900		900
		<u>900</u>		<u>942</u>

#### 13 Employees' remuneration

The average number of persons employed by the charity during the year, analysed by category, was as follows:

	2015 No.	2014 No.
Charitable activities	1	1
Fundraising trading	1	1
Governance	<u>1</u>	<u>1</u>
	<u>3</u>	<u>3</u>

The aggregate payroll costs of these persons were as follows:

	2015 £	2014 £
Wages and salaries	63,687	61,854
Social security	<u>3,420</u>	<u>3,321</u>
	<u>67,107</u>	<u>65,175</u>

No employee is paid more than £60,000 per annum.

## ME Research UK

### 14 Taxation

ME Research UK is a registered charity and is therefore exempt from taxation  
**Notes to the Financial Statements for the Year Ended 31 October 2015**

..... *continued*

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... continued

#### 15 Tangible fixed assets

	<b>Fixtures, fittings and equipment £</b>
<b>Cost</b>	
As at 1 November 2014 and 31 October 2015	<u>5,825</u>
<b>Depreciation</b>	
As at 1 November 2014 and 31 October 2015	<u>5,825</u>
<b>Net book value</b>	
As at 31 October 2015	<u>          -</u>
As at 31 October 2014	<u>          -</u>

#### 16 Investments held as fixed assets

	<b>Listed investments £</b>
<b>Market value</b>	
As at 1 November 2014	33,483
Revaluation	<u>536</u>
As at 31 October 2015	<u>34,019</u>
<b>Net book value</b>	
As at 31 October 2015	<u>34,019</u>
As at 31 October 2014	<u>33,483</u>

All investment assets were held in the UK.

#### 17 Debtors

	<b>2015 £</b>	<b>2014 £</b>
Prepayments and accrued income	<u>44,692</u>	<u>9,669</u>

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... continued

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

	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
Other creditors	183,782	138,250
Accruals and deferred income	<u>3,048</u>	<u>1,445</u>
	<u>186,830</u>	<u>139,695</u>

#### 19 Creditors: Amounts falling due after more than one year

	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
Other creditors	<u>135,058</u>	<u>116,489</u>

#### 20 Operating lease commitments

As at 31 October 2015 the charity had annual commitments under non-cancellable operating leases as follows:

Operating leases which expire:

	<b>Land and Buildings</b>	
	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
Within one year	<u>4,930</u>	<u>4,510</u>

## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... continued

#### 21 Related parties

##### 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 granted funding of £61,953 during the previous year, with £61,953 still remaining payable within one year at 31 October 2015. 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.

#### 22 Analysis of funds

	At 1 November 2014	Incoming resources	Resources expended	Other recognised gains/losses	Transfer between funds	At 31 October 2015
<b>General Funds</b>						
Unrestricted income fund	236,713	196,359	(106,705)	536	(28,596)	298,307
<b>Restricted Funds</b>						
Research Projects	<u>50,066</u>	<u>62,758</u>	<u>(127,564)</u>	-	<u>28,596</u>	<u>13,856</u>
	<u>286,779</u>	<u>259,117</u>	<u>(234,269)</u>	<u>536</u>	<u>-</u>	<u>312,163</u>

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.

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



## ME Research UK

### Notes to the Financial Statements for the Year Ended 31 October 2015

..... continued

#### 23 Net assets by fund

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2015 £</b>	<b>Total Funds 2014 £</b>
Tangible assets	-	-	-	-
Investments	34,019	-	34,019	33,483
Current assets	267,336	332,696	600,032	509,480
Creditors: Amounts falling due within one year	(3,048)	(183,782)	(186,830)	(139,695)
Creditors: Amounts falling due after more than one year	-	(135,058)	(135,058)	(116,489)
Net assets	<u>298,307</u>	<u>13,856</u>	<u>312,163</u>	<u>286,779</u>