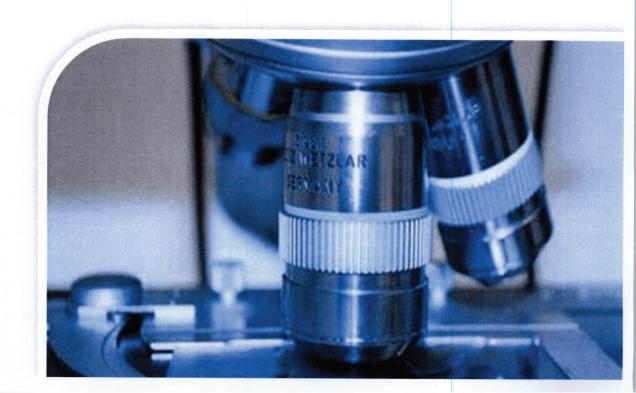




SCIO - Scottish Charity No SC036942

Annual Report & Accounts 2017 – 2018



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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 to 25 April 2018)

Edward Dunkerley Prof Faisel Khan

Dr Stephen A Logan (resigned 14 September 2018)

Jonathan P J Davies (appointed 19 January 2018 and

appointed Secretary from 25 April 2018)

Mrs Lesley J Carr (appointed 22 May 2018)

Founding Patron Roger Jefcoate CBE DL

Patron The Countess of Mar

Honorary President Robert D McRae

Chief Executive Officer Simon Phillips

Registered Office The Gateway

North Methven Street

Perth

PH1 5PP

Telephone 01738 451234

Email meruk@pkavs.org.uk

Web www.meresearch.org.uk

Facebook MEResearchUK

Twitter MEResearchUK

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

Morris and Young
Chartered Accountants
6 Atholl Crescent

Perth PH1 5JN

Trustees' Report

Chairman's Introduction



It gives me great pleasure to present ME Research UK's latest annual report and highlight what has been an exciting year for the charity.

We are indebted to all our supporters – both new and old – for the faith they have placed in us and in the work we do. We simply could not fund biomedical research or, indeed, to provide Breakthrough magazines to all, without the commitment of our fundraisers and friends.

Since the year 2000, when Roger Jefcoate DL CBE, our now President, Bob McRae, and I, laid the foundations of the charity, I dared not hope that 18 years' later we would have

committed almost £1.6 million to 48 distinct studies world-wide. Much has changed in the scientific community since then but what has remained is the cold, hard necessity that much more biomedical research into the causes and consequences of ME/CFS still requires to be done. ME Research UK remains committed to the single goal of funding such high quality research. We can all be proud of what our projects have achieved but, even more than ever, we must drive forward with research.

In a significant milestone, we have approved funding for the first time in the United States of America. Subject to acceptance, the USA joins Scotland, England, Germany, Sweden and Australia as countries where ME Research UK's projects are currently being undertaken. Due to your support, we have funded projects in 8 countries – Australia, Belgium, Canada, England, Germany, Sweden, Scotland and the USA. The areas of study range from the circulatory system to the brain and from the gut to muscles with other applications for funding currently being evaluated by our Scientific Advisory Committee. We hope to be able to make further announcements soon.

To meet the challenges facing the charity and to build on the sound foundations laid by the team at ME Research UK, the Board appointed ME Research UK's first Chief Executive Officer – Simon Phillips in September 2018. In addition, we welcomed two new Trustees – Jonathan Davies and Lesley Carr – to the Board and we are already reaping the benefits of their experience and input. I would also like to thank Dr Steve Logan, who left the Board in September for his time and commitment to the charity.

Be assured that everyone at the charity is committed to ensuring that we get the greatest impact from donations, whether through focusing considerable investment in research or in the provision of high-quality information on the illness.

Once more, thanks to all our friends for your invaluable support and the Board looks forward to the opportunities which next year brings.

Dr Vance Spence

Chair of Board of Charity Trustees

Trustees' Report

CEO's Report



I am delighted to join Vance and his fellow Trustees in presenting our latest annual report to you. As the new Chief Executive Officer of ME Research UK, I very much look forward to helping the organisation deliver its mission to fund research into the causes and consequences of ME/CFS. As well as continuing to build on the work that has taken place in the past, I hope to find ways to increase funding for future research.

There is a huge amount of scientific knowledge within this organisation and I hope that my own background in the charity sector since 2006 and prior to that, in the private sector for many years, will complement those existing skills and enable us to develop and deliver ambitious goals over the next few years.

My first weeks in the role have been overwhelmingly positive. I have found the dedication and commitment of researchers, staff, volunteers and others hugely motivating and I look forward to working with all of them in the future. I am

also excited to see some new research projects due to start in the coming few months and also that we are supporting research in new parts of the globe.

ME is clearly a complex, challenging and debilitating condition. We fund vital biomedical research throughout the world and this must remain at the heart of our work. The Board of Trustees, the staff and I are committed to ensuring that focused biomedical research continues in order to find ways to understand, diagnose and, eventually, treat this condition. This can only happen with your support.

Finally, I would like to thank all of the Trustees, staff and friends who continue to support our organisation. I look forward to working with you all over the coming months and years.

Simon Phillips

Chief Executive Officer

Trustees' Report

The Trustees present their report along with the financial statements of the charity for the period 1st November 2017 to 31st October 2018 – 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).

The Illness

Myalgic encephalomyelitis (ME) is characterised by a range of neurological symptoms and signs, muscle pain with intense physical or mental exhaustion, relapses, and specific cognitive disabilities. The World Health Organisation's 'International Classification of Disease' lists ME as a disorder of the nervous system, under 'Post-Viral Fatigue Syndrome'.

During the 1990s, the term Chronic Fatigue Syndrome (CFS) came into use. As there was (and presently remains) no specific diagnostic test for ME, and as post-exercise 'fatigue' was one of its prominent symptoms, people with ME began to be diagnosed with CFS. In recent years, however, there has been a growing recognition that the diagnosis 'CFS'—based on a list of vague non-specific symptoms shared with other illnesses—is so broad that it can encompass a range of diverse patient groups. For this reason, there have been a number of attempts to devise a more sensitive way of diagnosing patients.

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

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

Yet, it is widely acknowledged that ME/CFS has faced significant under-investment in biomedical research over many years, both in the UK and overseas. Within the UK specifically, for example, ME/CFS receives comparatively little funding compared to other neurological disorders. MS affects about 100,000 people compared to the 240,000 estimated to have ME/CFS but has received 20 times the funding. ME Research UK exists solely to fund research, to date, we've invested approximately £1.6 million in biomedical research world-wide on 48 distinct projects and have funded more specific research projects on ME/CFS than any other single organisation in the world outside North America. Much more research needs to be done. As the NICE Clinical Guideline states (CG 53): "The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions." We must ensure that biomedical research into ME/CFS reflects the prevalence and seriousness of the illness.

Much more biomedical research needs to be done and ME Research UK is dedicated to funding the best research we can.

Trustees' Report

Objectives and activities

ME Research UK'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.

Achievements and Performance



The most significant aspect of our charity and the core of our charitable purposes and aims is the provision of funding for biomedical research.

ME Research UK is heartened by the geographic spread of applications for funding world-wide and also the quality of the applications themselves. In particular, this year was notable not only for the breadth of areas of research for which applications were received but also the fact that applications have been forthcoming from researchers who have not previously submitted applications for financial support from ME Research UK. Through the provision of funds we aim to -

- Be an accessible source of finance for scientifically sound biomedical research from researchers (normally) at the beginning of their careers;
- Fund projects, the results of which produce findings to enrich the research-world's understanding of ME/CFS;
- Generate data for larger studies or to build upon for applications to central funding e.g. Medical Research Council;
- Encourage new researchers into biomedical ME/CFS research.

Trustees' Report

ii. Increased funding for ongoing project

Project no. 37

Prof. Faisel Khan, University of Dundee

A Study Examining Nrf2 Antioxidant Gene Expression and its Role in Combatting Oxidative Stress

Additional funding of £10,495

We have agreed to provide additional funds to enable Prof. Khan to obtain high quality (in terms of RNA yield) samples from the UK ME/CFS Biobank in order that he can continue with his funded project.

iii. Ongoing Projects

Ongoing projects	Original commitment
	£
A study examining Nrf2 antioxidant gene expression and its role in combatting oxidative stress. Prof F Khan, The Institute of Cardiovascular Research.	72,448
University of Dundee, UK	
Two dimensional (2D) sequencing and machine learnings 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.	49,724
The Australian National University, Acton, Australia	
The role of autoantibodies in ME/CFS. Dr Madlen Löbel & Prof. Carmen Scheibenbogen, Institute of Medical Immunology.	70,460
Charité University Medicine Berlin, Berlin, Germany	
Investigating abnormalities in AMPK activation. Dr Audrey Brown, Institute of Cellular Medicine.	85,518
Newcastle University, UK	
Exploring the Association Between CFS and IBS Through Immune and Microbiome Analysis: a feasibility study, Prof. Yiannakou.	35,900
University Hospital of North Durham, UK	

Trustees' Report

b) Completed Projects

Prof Nijs' project completed in the period with the investigator submitting a final report.

Project no. 41

Prof. Jo Nijs, Vrije Universiteit Brussel

Epigenetics of the Brain Derived Neurotrophic Factor Gene and its Relevance for Pain in ME/CFS: An Explorative Study

£44,859

Brain-derived neurotrophic factor (BDNF) is a protein produced by neurons and immune cells which is known to increase the sensitivity of the central nervous system and may therefore contribute to the development of hypersensitivity to pain in people with ME/CFS. Prof. Nijs hypothesised that BDNF (as well as epigenetic changes to the *BDNF* gene) may help to explain the symptoms of ME/CFS, and also that this relationship may be affected by daily physical activity levels. The team measured serum levels of BDNF in 27 women with the illness and 27 healthy control subjects, as well as epigenetic modifications (specifically methylation changes) of the *BDNF* gene. In addition, pain thresholds were assessed in response to hot and cold stimuli delivered to the skin. The measurements were repeated a few days later, and daily physical activity levels were monitored between the assessments. The main finding was that BDNF levels were higher in ME/CFS patients than in controls and were correlated with measures of central sensitisation and with pain thresholds. However, there were no differences in *BDNF* methylation. A publication reporting these findings is currently in preparation.

c) Projects Reported in Scientific Publications

We received updates on projects which ended in the current reporting year.

Project no. 25

Prof. Jo Nijs, Vrije Universiteit Brussel

Comparison of the CDC 1994, London and Canadian Criteria for the Diagnosis of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome with Multiple Sclerosis: Focus on Neurocognitive Performance, Physical Recovery, Physical Activity and Autonomic Manifestations

£41,588

Prof Nijs project yielded five publications between 2013 and 2016. These have variously reported: reduced cognitive performance in women with ME/CFS, which did not correlate with pain severity (as it does in other chronic pain conditions); an association between cognitive performance and physical fitness (but not physical activity level) in women with ME/CFS; delayed recovery of upper limb muscle function following an exercise test in patients with ME/CFS plus fibromyalgia but not in those with ME/CFS alone; recovery of upper limb muscle function was a predictor of cognitive performance in ME/CFS patients; and little clinical difference between patients fulfilling the Canadian ME criteria and those fulfilling the older ME criteria (comorbid fibromyalgia was associated with worse symptoms and more dysfunction).

Trustees' Report

Project no. 36

Prof. Julia Newton, Newcastle University

Programme Grant – Biomedical investigation of ME/CFS

£100,000

Prof Newton's final report for this project details the variety of work that has been completed under ME Research UK's first programme grant, including projects looking at the prevalence, severity and potential for research in people with severe ME. There have been five publications as a result of this work, with possibly another to come. These have variously reported: impaired cellular bioenergetics (including lower oxidative phosphorylation) in ME/CFS patients; increased brain natriuretic peptide levels in ME/CFS, which correlated with lower cardiac volumes; evidence of susceptibility to a specific type of deconditioning due to cardiovascular and central nervous system vulnerabilities; a review of the limited research focused on patients with severe ME/CFS; and questionnaire findings highlighting the potential for severely affected individuals to be more involved in research despite their physical limitations.

Six papers were published in the charity year 2017/18 acknowledging the support of ME Research UK.

- 1. Strassheim VJ, Sunnquist M, Jason LA, Newton JL. Defining the prevalence and symptom burden of those with self-reported severe chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a two-phase community pilot study in the North East of England. BMJ Open, 2018 September 19; 8(9):e020775.
- 2. Wilson RL, Paterson KB, McGowan V, Hutchinson CV. Visual aspects of reading performance in myalgic encephalomyelitis (ME). Frontiers in Psychology, 2018 August 17; 9:1468.
- 3. Brown AE, Dibnah B, Fisher E, Newton JL, Walker M. Pharmacological activation of AMPK and glucose uptake in cultured human skeletal muscle cells from patients with ME/CFS. Bioscience Reports, 2018 May 8; 38(3):BSR20180242.
- 4. Tomas C, Newton J. Metabolic abnormalities in chronic fatigue syndrome/myalgic encephalomyelitis: a mini-review. Biochemical Society Transactions, 2018 April 17; 46(3):547-53.
- 5. Malfliet A, Pas R, Brouns R, De Win J, Hatem SM, Meeus M, Ickmans K, van Hooff RJ, Nijs J. Cerebral Blood Flow and Heart Rate Variability in Chronic Fatigue Syndrome: A Randomized Cross-Over Study. Pain Physician 2018 Jan; 21(1):E13-E24.
- 6. Lacerda EM, Kingdon CC, Bowman EW, Nacul L. Using a participatory approach to develop and implement the UK ME/CFS Biobank. Fatigue: Biomedicine, Health & Behavior 2018; 6(1):1-4.

Trustees' Report

Publications, Education and Awareness Raising

During 2017/18, 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 (MEResearchUK) strives to balance, on the one hand, postings relating to fundraising activities of our active supporters, with summaries of the most important worldwide research into ME/CFS and news of ME Research UK funded projects. In this way, those affected by ME/CFS can be kept abreast of recent developments. This 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 7000 'likes' – an increase of 16% from 2016-17 – and is viewed

regularly world-wide. It has steadily increased the audience for postings, created a community of regular commentators and provided a new platform from which we can connect to supporters both old and new. It is hoped that the newly more active twitter account will further drive the successful dissemination of our research news and that it will act as a further avenue to engage more fully with potential donors and create a new community of supporters.

Structure, Governance and Procedures

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 Director of Research & Communications.

The Board of Charity Trustees, after an open and nationally advertised recruitment process, were delighted to appoint Simon Phillips as ME Research UK's first CEO.

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

The performance of the CEO is overseen by the Board of Charity Trustees through reports and briefings presented by him at quarterly board meetings, and as part of the planning and budgeting process.

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.

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

The Board of Charity Trustees is acutely aware that applicants must contribute towards the good management of the charity and ought to enhance the capabilities of the Board. The Board of Charity Trustees therefore considers applications against the skill-set required for the proper functioning and evolution of the charity. The Board may set up a working group to recruit new Trustees who may be sought by open advertisement.

As part of the process of renewal and revitalisation of the charity, the Trustees were delighted to assume two new Trustees, namely Jonathan P J Davies and Mrs Lesley J Carr, following an open application process featuring both on-line and print advertising for applicants. Both Jonathan and Lesley's skill-sets are such that they add significantly to the depth of the Board of Charity Trustees.

The Trustees also report the resignation of Dr Stephen A Logan as Trustee of ME Research UK and wish to thank him publically for his contribution to the organisation - the Board was enriched by his charity knowledge and experience and is grateful for his insightful input.

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 Committee, utilising a Standardised scoring system to facilitate consistent decision-making, all applications are subject to Peer Review (including review by external experts). In the current year, a number of grant applications were unsuccessful either because, upon Peer Review and Scientific Advisory Committee input, they were deemed to fall out-with ME Research UK's charitable objectives or that their research methodology or submitted expenses did not meet the requisite standards. Through careful scrutiny of applications - the scientific basis of the submission, the itemised costs and ME Research UK strives to ensure proper and rigorous safeguards for the stewardship of funds under its control.

ME Research UK's Standard Grant Conditions provide that all payments of research funding are dependent upon satisfactory proof of research progress. Longer term projects i.e. those in excess of 1 year, are subject to regular (normally 6 monthly) review. The charity therefore ensures that grant monies which have been given are utilised in line with the charity's purposes and that progress merits payment of further instalments of financial assistance.

ME Research UK endorses the position of the Association of Medical Research Charities as regards university funding, and ME Research UK-sponsored projects are conducted in accordance with the principles outlined in the Declaration of Helsinki, and approved by local research ethics committees.

Trustees' Report

Grant making Objectives

Through funding studies at recognised Institutions world-wide, ME Research UK funded-projects enrich the scientific literature of ME/CFS and have the ultimate aim of helping those affected directly or indirectly by ME/CFS and those who may develop ME/CFS in the future. The research we fund helps lay the foundation for further biomedical 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 biomedical 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. 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 Committee which assesses the application, the peer review results (which include a standardised scoring system), and the charity's research objectives to arrive at a decision.

ME Research UK only funds projects at established institutions - such as universities, research centres and NHS hospitals (or equivalent overseas) - to ensure that, in the case of non-compliance with the terms of the research award, charity funds are protected and recovered.

By careful, structured and objective consideration of applications and a prudent approach to payment of research monies, ME Research UK ensures high standards of care of the funds entrusted to it. Details of the application process, together with relevant forms are available on the charity's website - www.meresearch.org.uk.

Monitoring Achievement

Research is assessed by the completion of approved research projects within the planned timescale for the project and of publication of the results in peer reviewed journals. Longer term consequences of the research are more difficult to assess but published papers build a critical mass of information in the scientific literature. Also, our funding lays the foundation for future work by allowing researchers to acquire pilot data on which to base applications to larger, often governmental, funding bodies. ME Research UK strives to repeat the success of Prof. Julia Newton, Dr Wan Ng and colleagues at Newcastle University who, in 2012, were awarded almost £1 million by the UK's Medical Research Council. Their successful application for funding was under a call for 'Understanding the Mechanisms of CFS/ME' and resulted in funding for 2 biomedical projects. At the time, Prof. Newton acknowledged ME Research UK for providing "the pilot/seed corn funding for four distinct projects from 2006 to 2011, which have allowed us to accumulate the data on which these successful applications to the MRC were based".

The Trustees monitor closely the feedback from Breakthrough and the data on uptake and use of Facebook and Breakthrough, which shows 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 1750 voluntary hours were donated by members i.e. the Trustees of ME Research UK, and 154 voluntary hours were donated by other volunteers.

Google Ads (formerly Google AdWords) enables the charity to advertise free via Google searches. The value of this donation in kind is approximately \$14,478 (£10,819) and has been recognised in the accounts.

Trustees' Report

Key management personnel remuneration

A new Chief Executive Officer was appointed on 10 September 2018. Previously, no key management personnel of the charity received any remuneration. The Chief Executive Officer has been delegated responsibility under the terms of a Schedule of Delegation approved by the Board of Trustees. The Board have formal meetings on a quarterly basis, but occasionally more frequently via Skype. The Chief Exective Officer's salary is reviewed annually and set by the Board of Trustees.

Financial review

The total funds held at the year-end were £490,128 (2017: £324,533), including £125,743 of restricted funds (2017: £66,125). 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 on page 18.

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 17th October 2018 the Trustees adopted an updated Risk Register and the items recorded therein will remain under scrutiny.

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

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

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

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

Trustees' Report

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 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 biomedical 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 taken and will continue to take, all opportunities to source new project opportunities.

Reserves policy

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

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

As the Trustees do not commit to funding research projects until the full costs have been raised, the Trustees minimise financial risk. Trustees continue to monitor their Reserves Policy in implementation of OSCR's general advice to Scottish charities. Within Unrestricted Funds, three months' operating expenses 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 9 April 2019 and signed on its behalf by:

Mrs Sue Waddle Vice-Chair/Trustee

Statement of Trustees' Responsibilities

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

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

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

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

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 2018 which are set out on pages 17 to 31.

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 acordance 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 Regulations

have 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

10 April 2019

Statement of Financial Activities for the Year Ended 31 October 2018 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds	Restricted funds £	Total 2018 £	Total 2017 £
Income and Endowments fro			~	~	~
Donations and legacies	2	193,351	68,287	261,638	210,845
Other trading activities	3	7,015	-	7,015	7,618
Investment income	4	2,287	1,458	3,745	2,852
Total Income		202,653	69,745	272,398	221,315
Expenditure on:					
Raising funds	5	(27,981)	(152)	(28,133)	(39,969)
Charitable activities	6	(66,637)	(10,495)	(77,132)	(212,984)
Total Expenditure		(94,618)	(10,647)	(105,265)	(252,953)
Gain on investment assets		(1,538)		(1,538)	2,005
Net income/(expenditure)		106,497	59,098	165,595	(29,633)
Transfers between funds		(520)	520		-
Net movement in funds		105,977	59,618	165,595	(29,633)
Reconciliation of funds					
Total funds brought forward		258,408	66,125	324,533	354,166
Total funds carried forward	20	364,385	125,743	490,128	324,533

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

The funds breakdown for 2017 is shown in note 20.

(Registration number: SC036942) Balance Sheet as at 31 October 2018

	Note	2018 £	2017 £
Fixed assets			
Tangible assets	13	557	167
Investments	14	36,657	38,196
		37,214	38,363
Current assets			
Stocks	15	1,193	1,305
Debtors	16	29,698	12,664
Cash at bank and in hand		614,109	648,551
		645,000	662,520
Creditors: Amounts falling due within one year	17	(126,698)	(254,236)
Net current assets		518,302	408,284
Total assets less current liabilities		555,516	446,647
Creditors: Amounts falling due after more than one year	18	(65,388)	(122,114)
Net assets		490,128	324,533
Funds of the charity:			
Restricted funds		125,743	66,125
Unrestricted income funds			
Unrestricted funds		364,385	258,408
Total funds	20	490,128	324,533

The financial statements on pages 17 to 30 were approved by the Trustees, and authorised for issue on 9 April 2019 and signed on their behalf by:

Mrs Sue Waddle Vice-Chair/Trustee

Mr Jonathan PJ Davies Secretary/Trustee

Notes to the Financial Statements for the Year Ended 31 October 2018

1 Accounting policies

General Information

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

Registered Office:

The Gateway North Methven Street Perth PH1 5PP

Summary of significant accounting policies and key accounting estimates

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

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

Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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

Exemption from preparing a cash flow statement

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

Going concern

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

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.

Notes to the Financial Statements for the Year Ended 31 October 2018

Investment income

Investment income is recognised on a receivable basis.

Other income

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

Expenditure

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

Raising funds

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

Charitable activities

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

Grant expenditure

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

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

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

Grant provisions

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

Support costs

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

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.

Notes to the Financial Statements for the Year Ended 31 October 2018

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

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			
	General £	Restricted funds	Total 2018 £	Total 2017 £
Donations and legacies;				
Donations from companies, trusts and similar proceeds	672	_	672	911
Donations from individuals	131,952	59,799	191,751	187,422
Legacies	44,639	1,000	45,639	500
Gift Aid reclaimed	16,088	7,488	23,576	22,012
	193,351	68,287	261,638	210,845

Notes to the Financial Statements for the Year Ended 31 October 2018

3 Income from other trading activities

	Unrestricted funds		
	General £	Total 2018 £	Total 2017 £
Trading income;			
Other trading income	7,015	7,015	7,618
	7,015	7,015	7,618

Notes to the Financial Statements for the Year Ended 31 October 2018

4 Investment income

	Unrestricted funds			
	General £	Restricted funds	Total 2018 £	Total 2017 ₤
Income from dividends;				
Dividends receivable from other listed investments	1,265	_	1,265	1,197
Interest receivable and similar income;			,	,
Interest receivable on bank deposits	1,022	1,458	2,480	1,655
	2,287	1,458	3,745	2,852

5 Expenditure on raising funds

a) Costs of generating donations and legacies

		Unrestricted funds			
		General	Restricted funds	Total 2018	Total 2017
	Note	£	£	£	£
Donations		25,660	152	25,812	37,411

b) Costs of trading activities

		Unrestricted Total		Total
		General	2018	2017
		£	£	£
Costs of goods sold	Note	2,321	2,321	2,558
		2,321	2,321	2,558
			2,321	2,3.

Notes to the Financial Statements for the Year Ended 31 October 2018

6 Expenditure on charitable activities

		Unrestricted funds			
	Note	General £	Restricted funds £	Total 2018 £	Total 2017 £
Grant funding of activities		_	10,495	10,495	137,778
Staff costs		36,286	-	36,286	36,600
Allocated support costs	7	25,551	-	25,551	37,706
Governance costs	7	4,800		4,800	900
		66,637	10,495	77,132	212,984

Grant funding of activity

	Total 2018	Total 2017
	£	£
Grant funding Returned Grant funding	10,495	191,878
	<u>-</u> _	(54,100)
	10,495	137,778

Grant funding of £54,100 was withdrawn due to the decision not to proceed with the specific project.

Notes to the Financial Statements for the Year Ended 31 October 2018

7 Analysis of governance and support costs

	Basis of allocation	Other support costs	Total 2018 £	Total 2017 £
Accommodation	actual cost	5,940	5,940	5,864
Breakthrough costs	actual cost	18,422	18,422	29,720
Other	actual cost	1,189	1,189	2,122
		25,551	25,551	37,706

Governance costs

	Unrestricted funds		
	General £	Total 2018 £	Total 2017 £
Independent examiner's fee	900	900	900
Legal fees	3,900	3,900	
	4,800	4,800	900

Notes to the Financial Statements for the Year Ended 31 October 2018

8 Grant-making

Grants payable at 1 November 2017	374,260
Grants paid	(195,824)
New grants committed	10,495
Grants payable at 31 October 2018	188,931

Grants paid and payable

		Grants	Grants	Pay	able
		paid	committed		
Institution	Title of project	2018	2018	2018	2017
University of Newcastle	2 Year Program Grant: Biomedical Basis of ME/CFS	16,925	-	-	16,925
University of Dundee	Insights into Pathophysiology of CFS/ME	3,854	10,495	48,358	41,717
The Australian National University	Two dimensional sequencing and machine learning to ME cohort for enhanced diagnosis	24,862	-	12,431	37,293
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
Charité University, Berlin	The role of autoantibodies in ME/CFS	35,230	-	35,230	70,460
University of Newcastle	Investigating abnormalities in AMPK activation	28,506	-	57,012	85,518
University Hospital of North Durham	Exploring the association between CFS and IBS through immune and microbiome analysis	-	-	35,900	35,900
		195,824	10,495	188,931	374,260

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

9 Net incoming/outgoing resources

Net incoming resources for the year include:

	2018	2017	
	£	£	
Independent examiner's remuneration	900	900	
Depreciation	445	168	
	1,345	1,068	

Notes to the Financial Statements for the Year Ended 31 October 2018

10 Trustees remuneration and expenses

Five Trustees were reimbursed for travelling expenses totalling £3,727.71 during the year (2017 - £1,262.21). No Trustees, nor any persons connected with them, have received any remuneration from the charity during the year.

11 Staff costs

The aggregate payroll costs were as follows:

	2018 £	2017 £
Staff costs during the year were:		
Wages and salaries	48,414	60,817
Social security costs	1,355	3,330
	49,769	64,147
	2018	2017
	No	No
Charitable activities	1.2	1
Fundraising	-	1
Governance	0.5	1
	1.7	3

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

The total remuneration (including taxable benefits and employer's pension contributions) of the key management personnel for the year was £6,168 (2017 - £Nil).

Notes to the Financial Statements for the Year Ended 31 October 2018

12 Taxation

No corporation tax was charged during the year (2017: £nil). ME Research UK is a registered charity and has been accepted as a charity for tax purposes.

13 Tangible fixed assets

Furniture and	
equipment	Total
£	£
5,695	5,695
835	835
(613)	(613)
5,917	5,917
5,528	5,528
445	445
(613)	(613)
5,360	5,360
557	557
167	167
	5,695 835 (613) 5,917 5,528 445 (613) 5,360

Notes to the Financial Statements for the Year Ended 31 October 2018

14 Fixed asset investments

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	Listed investments £	Total
Cost or Valuation		
Cost brought forward	38,196	38,196
Revaluation	(1,539)	(1,539)
At 31 October 2018	36,657	36,657
Net book value		
At 31 October 2018	36,657	36,657
At 31 October 2017	38,196	38,196

The market value of the listed investments at 31 October 2018 was £36,657 (2017 - £38,196).

All investment assets were held in the UK.

15 Stock

Stock	2018 £ 1,193	2017 £ 1,305
16 Debtors		
	2018	2017
Prepayments	£ 29,698	£ 12,664
17 Creditors: amounts falling due within one year		
	2018 £	2017 £
Other creditors	123,543	252,146
Accruals	3,155	2,090
	126,698	254,236
18 Creditors: amounts falling due after one year		
	2018	2017
Other creditors	£ 65,388	£ 122,114

Notes to the Financial Statements for the Year Ended 31 October 2018

19 Obligations under lease	and hire	purchase	contracts
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					2018	2017
					£	£
Land and buildings	8					
Within one year					2,179	2,179
20 Funds						
	Balance at 1 November 2017 £	Incoming resources	Resources expended £	Transfers £	Other recognised gains/(losses)	Balance at 31 October 2018 £
Unrestricted funds						
General Unrestricted funds	258,408	202,653	(94,618)	(520)	(1.520)	264.205
Restricted funds	230,400	202,033	(94,018)	(520)	(1,538)	364,385
Restricted funds	66,125	69,745	(10,647)	520		125,743
Total funds	324,533	272,398	(105,265)	-	(1,538)	490,128
	Balance at 1 November 2016 £	Incoming resources	Resources expended £	Transfers £	Other recognised gains/(losses)	Balance at 31 October 2017 £
Unrestricted funds						
General Unrestricted funds	316,651	171,972	(115,120)	(117,100)	2,005	258,408
Restricted funds Restricted funds	37,515	49,343	(137,833)	117,100		66,125
Total funds	354,166	221,315	(252,953)		2,005	324,533

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 fund are held in Restricted Funds to cover the charity's grant-making obligations, and to effect minor adjustments.

Notes to the Financial Statements for the Year Ended 31 October 2018

21 Analysis of net assets between funds

	Unrestricted funds		
	General £	Restricted funds £	Total funds
Tangible fixed assets	557	-	557
Fixed asset investments	36,657	-	36,657
Current assets	330,326	314,674	645,000
Current liabilities	(3,155)	(123,543)	(126,698)
Creditors over 1 year	-	(65,388)	(65,388)
Total net assets	364,385	125,743	490,128

22 Related party transactions

Controlling entity

The charity is controlled by the Trustees of the charity.

Related party transactions

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

Prof Faisel Khan

Insights into Pathophysiology of CFS/ME

The above Project was paid funding of £3,854 and awarded additional funding of £10,495 during the year (2017 - paid funding of £11,073). £48,358 remains payable at 31 October 2018 (2017 - £41,717). This is recognised in grants payable at the year-end. Prof Khan joined the Board after the decision was made to award this Project a grant and was not involved in the decision to award additional funding.