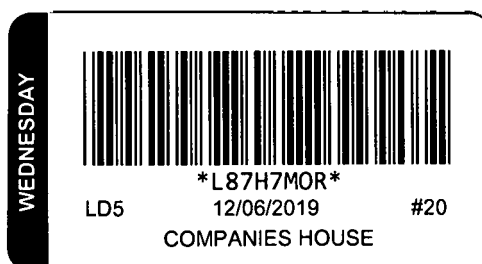




# Annual Report and Consolidated Financial Statements

For the year ended 31 December 2018



## HRH message

In 2018, I marked my 10th year as Royal Patron of the MND Association and over the course of the year I was delighted to attend six events, across England, Wales and Northern Ireland, in support of people affected by MND.

Every visit focused on key areas of the Association's work - improving care and support, funding and promoting research, and campaigning and raising awareness. Each visit highlighted the importance of volunteers, the foundation of the Association's work, whether they were supporting rural communities in Wales, helping people with MND record their voices in London or providing much needed extra resource working alongside health and social care professionals in Gloucestershire and Norfolk.

The importance of collaboration was also evident from meeting guests, especially those researchers and clinicians looking into the causes of MND. At a research dinner in London I learnt about the latest findings in UK science, before I joined more than 1,200 delegates from across 40 countries at the Association's 29th International Symposium on ALS/MND - which was hosted in Glasgow by MND Scotland - where we heard about the latest global developments.

I would like to congratulate the Association's staff, supporters and volunteers for their longstanding commitment and dedication to supporting those affected by this devastating disease. Although such focus is sadly still needed as much today as it was when the Association was founded back in 1979, I trust that the difference made through your actions, and the improvements you make to the lives of people living with MND and their families, will sustain and encourage your efforts in the coming year.

Thank you for your contribution and I wish you all every success in the future.

HRH The Princess Royal

## Message from the Chair

Ensuring people living with and affected by MND have access to the care and support they need, when they need it, has been one of the Association's main priorities during 2018.

In June, the Association opened its North Midlands MND Care Network at the Royal Stoke University Hospital – the 22nd care centre to have been developed in partnership with the NHS. Our care centres now offer multidisciplinary care to more than 3,800 people living with MND across England, Wales and Northern Ireland - care which has been proven to extend life expectancy in those affected by this terrible disease.

We also understand that MND can have a devastating impact on the lives of children with close relatives who are living with MND and we have been listening carefully to their needs. New information resources have been developed and we have been working hard to ensure families have access to the care services they need, important work which will continue during 2019 and beyond.

We continue to offer practical help and support to people living with MND through the loan of a wide range of equipment including communication aids and voice-banking equipment, as well as through support grants which, in 2018, totalled more than £1 million.

Our campaigners have been working alongside the Association's members to improve access to welfare benefits – a major area of concern to many people affected by MND. Our *Scrap 6 Months* campaign, which calls for a change in the definition of terminal illness for the purpose of accessing fast-track benefits, has received widespread support, with more than 12,000 people signing our online petition. We continue to listen to people living with MND about their need for accessible housing and adaptations and 850 people took part in our engagement survey last summer.

Meanwhile, we continue to take important steps forward in MND research, working closely with our partners around the world.

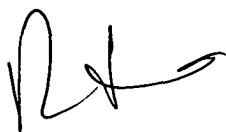
Our International Symposium on ALS/MND was held in Scotland in December and brought together 1,250 of the world's leading researchers, encouraging collaboration among experts from 40 countries.

Researchers, whose work is funded by the Association, are currently involved in a number of key projects and clinical trials aimed at increasing our understanding of what causes MND, paving the way for potential new treatments and ultimately, a cure.

None of this work would be possible without the tireless support and dedication of our volunteers, fundraisers, campaigners and supporters. I am very proud of all our achievements this year and I would like to thank the whole MND community for coming together to help us make it happen.

Thanks to their efforts, the Association remains in a strong position to take on any challenges that may lie ahead as we continue our work to support people affected by MND and all those who care for them.

Richard Coleman  
Chair, Board of Trustees



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## Trustees' Report

### Strategic report

The trustees present their report and accounts for the year ended 31 December 2018. The accounts have been prepared in accordance with the Accounting and Reporting by Charities: Statement of Recommended Practice (SORP) 2015 and are in accordance with the Companies Act (2006) and relevant accounting standards.

### About MND

What we do matters because of the nature of MND:

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord
- It attacks the nerves that control movement so muscles no longer work. It does not usually affect the senses such as sight, sound and feeling
- Around 35% of people with MND experience mild cognitive change causing difficulties with planning, decision-making and language

- A further 15% of people show signs of frontotemporal dementia (FTD) resulting in more pronounced behavioural change, which may interfere with their ability to function on a day to day basis
- MND can leave people locked in a failing body, unable to move, talk, swallow and eventually breathe
- A person's lifetime risk of developing MND is around 1 in 300
- It affects people from all communities
- Six people per day are diagnosed with MND in the UK
- It affects up to 5,000 adults in the UK at any one time
- More than 80% of people with MND will experience communication difficulties, including, for most, a complete loss of their voice
- It kills six people per day in the UK, this is just under 2,200 people per year
- MND has no cure

## i) Objectives and activities

### Our vision

*A world free from motor neurone disease.*

### Our mission

We improve care and support for people with MND, their carers and families.

We fund and promote research which leads to new understanding and treatments and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

### About us

The MND Association (the Association) was founded in 1979 by a group of volunteers with experience of living with, or caring for, someone with MND.

Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are focused on MND care, research and campaigning.

### Our values

- People with MND, their families and carers are at the heart of everything we do
- We collaborate, and value everyone's contribution
- We achieve excellence through personal commitment and on-going improvement

- We respect and respond to people's diverse needs, backgrounds and views
- We achieve our aims through building open and transparent relationships

#### Our charitable objects as stated in our Articles of Association

The Association exists for the relief of persons who are, or who are suspected of being, affected by motor neurone disease and associated conditions (the beneficiaries) by seeking to ensure that such persons, their carers and families receive such help and assistance as is calculated to relieve their need.

The Association commissions, undertakes, promotes, monitors and manages research into all aspects of motor neurone disease and its associated conditions and causes and works towards their prevention and cure and to publish and disseminate the useful results for the benefit of the public.

#### Public benefit

The trustees consider that the Association's charitable objects meet the 'purposes test' for public benefit, as set out in the Charities Act 2011, and that the goals, progress and achievements in this report demonstrate the public benefit deriving from Association activities.

The trustees refer to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning its future activities. In particular, the trustees consider how planned activities will contribute to the aims and objectives that have been set.

#### Our reach

People with MND are at the very heart of everything we do and the Association offers information and support to the approximately 4,570 people who are living with MND in England, Wales and Northern Ireland. We are committed to supporting their carers and family members too. We also work with and provide education to health and social care professionals (HSCPs), to enable them to provide the very best possible support to people affected by MND.

Our skilled volunteers and staff are committed to improving the standard of care that people living with MND receive both now and in the future. Together, they fundraise, campaign and provide support for people living with, and affected by the disease. We also work with other organisations and partners, including MND Scotland, with whom we have a close relationship.

Local support is provided by our network of 89 branches and groups, where people living with MND, their carers and families can access vital information and help and meet other members of the MND community.

We actively campaign and lobby the Government in Westminster, the Welsh Assembly, the Northern Ireland Assembly and local authorities, to ensure the needs of people affected by MND are being met. We do this in collaboration with our network of more than 5,000 committed campaigners and focus our efforts on those decision-makers who are best placed to make the biggest difference to people with MND.

To maximise our voice and extend our reach, we campaign in coalition with other charities, through the Neurological Alliance, the Care and Support Alliance, the Association of Medical Research Charities, with MND Scotland and others.

We are an active member of the International Alliance of ALS/MND Associations and we organise the world's largest annual research conference on MND – the International Symposium on ALS/MND.

Our social media platforms are vital in helping us to connect with our members and the wider MND community and to communicate the impact of our work. As at 31 December 2018 we had 37,599 likes on Facebook, an increase of 7.4% on 2017. We also received just over 10.6 million impressions – the number of times our posts are displayed to people. On Twitter, we increased our followers by 6.7% to 28,206 and received more than five and a half million impressions over 12 months. Our website received 1,668,742 total page views and our *Thumb Print* magazine, which is also available online, was sent to 8,600 Association members.

## ii) Achievements and performance in 2018

### Improving care and support

The Association helps to provide care and support for people living with MND and those closest to them. By working together and listening to the needs of those affected by MND we will continue to make a difference by providing direct support and by influencing, informing and educating health service, hospice and local authority employed staff.

### Children and young people service development

We have been working to improve access to services for children and young people affected by MND, developing our information resources and creating an outcomes tool to measure our impact.

We have listened carefully to the needs of children and parents and by working together with HSCPs and our branches and groups we have agreed the development of a range of pilot projects in Milton Keynes, West Yorkshire, Manchester and Northern Ireland that will launch during 2019.

### Communication and wheelchair support services

The communication aids co-ordinator role allows us to support the provision of communication aids for people living with MND, helping people living with MND across England, Wales and Northern Ireland.

We are funding a full-time speech and language therapy post at the Royal Hospital for Neuro-disability for two years to increase awareness and information on options for voice banking for people living with MND.

Our work supporting the provision of the correct wheelchair for people living with MND continues to gain momentum through the role of the wheelchair support services co-ordinator and the MND Wheelchair Champions programme. Thirteen clinicians from local NHS wheelchair services attended a pilot training event in November with a full review of this pilot and our services supporting wheelchair provision planned in 2019.

### Transforming MND Care Audit

This audit is based on The National Institute for Health and Care Excellence (NICE) guideline on MND which was published in 2016 following extensive campaigning by the Association. The audit allows HSCPs who care for people living with MND to measure the quality of their service and, if necessary, to make improvements. During the year, 53 teams or services registered for the 2018 version of the audit and data was received from 42 teams or services. A summary of the collated results was published in the report *The State of MND Care* and was distributed widely to HSCPs, Royal Colleges and professional bodies. This document also gave examples of good practice and demonstrated how some teams or services had implemented improvements as a result of the audit. Feedback received from HSCPs who completed the audit was taken into account when developing a revised version of the tool for 2019.

### **MND Connect helpline**

Our helpline answered 8,562 calls offering advice to people with or affected by MND, Association staff, volunteers and HSCPs. In addition, a further 2,900 'call-backs' were made to keep in touch with those people who requested additional and on-going support. In April, MND Connect once again achieved the Helpline Standards quality standard which recognises best practice in helplines. The majority of those contacting MND Connect were looking for more information about MND, including details about symptoms, progression and treatment. Of those who took part in our most recent survey, 93% said that using MND Connect had helped them to resolve their issue and 72% said getting in touch with MND Connect had improved their confidence when it came to dealing with the issues surrounding MND.

### **Providing practical support**

We know our grant support programme is a much-valued source of financial support for many people living with, and affected by, MND providing tangible help when they most need it. Increased awareness of the grants together with external influences, such as rising pressures on local authority and NHS budgets, means the number of people turning to the Association for support has increased. These grants are provided in line with clear guidelines, which are reviewed annually by branch and group volunteers, trustees and staff and publicised on our website.

In 2018, we provided £1.5 million (2017: £1.3 million) of support grants supporting 1,801 (2017: 1,070) people with MND. In addition, a total of 1,529 people living with MND had at least one piece of equipment on loan, including iPads with apps and voice-banking equipment such as laptops, headset microphones and voice amplifiers. We awarded 224 carers' grants totalling £90,000 and 247 children and young person's grants totalling £54,000, during the year. We are extremely grateful to the *My Name's Doddie Foundation*, which was set-up by Scottish rugby legend Doddie Weir after he was diagnosed with MND in 2017, for supporting this important work.

### **Continuing Healthcare funding**

Some people with long-term complex health needs, such as MND, qualify for free social care arranged and funded solely by the NHS Continuing Healthcare (CHC) - which helps people living with MND to cope with the effects of the disease at home. The Association successfully lobbied for the House of Commons Public Accounts Committee (PAC) to undertake an inquiry into CHC. In response to the PAC's recommendations, the Department of Health consulted on a new CHC Framework for England, and we were invited to participate. The new Framework came into force in October and contains some significant improvements.

### **Welfare Benefits Advice Service**

This advice service is provided via telephone, email and webchat in England and Wales by a Citizens Advice Service and by email and phone by Advice NI in Northern Ireland. Where calls cannot be taken by the external providers they are dealt with by MND Connect. In 2018 the service provided direct advice to more than 1,300 people with or affected by MND and identified more than £2.3 million of benefits they were eligible to claim. It also provided support to more than 50 HSCPs dealing with benefits enquiries and referred more than 160 people for advice on other topics. In 2018 the service was partly funded by the One Family Foundation and we are incredibly grateful for their support.

### **England**

As a direct result of our work, the Warwickshire North Care Commissioning Group (CCG) now funds a new part-time MND Care Co-ordinator. The North Midlands MND Care Network based at the Royal Stoke University Hospital opened on 1 June, providing services to 80 people with MND across

Staffordshire. There are plans for new clinics in Stafford and Crewe to serve parts of Cheshire. A new full-time MND care co-ordinator has been recruited and is funded by the Association through a four-year grant.

#### **Northern Ireland**

A pilot project run by the Northern Ireland branch and the Communication Advice Centre (CAC) for Northern Ireland, to provide equipment to people affected by MND on an extended loan basis, has led to the Public Health Agency making changes to its Augmentative and Alternative Communication (AAC) provision. As of April 2019, when a person is assessed for a device, they will have immediate access to a communication aid. A respiratory physiotherapy pilot project funded by the Northern Ireland branch for 18 months, started in July. The pilot will gather data about the impact of the service for people with MND with assurances of ongoing funding already in place should agreed outcomes be achieved.

In March, we launched the new Enhancing MND Care Practice in Northern Ireland Award. Funded by the Northern Ireland branch these awards support HSCPs caring for people living with MND to engage in a range of learning and development activities essential to the further development of care services.

#### **Wales**

People with MND across North Wales have continued to benefit from the success of the region's MND Care Co-ordination Service, after Betsi Cadwaladr University Health Board announced in September that it had agreed to continue to fully fund the service. Launched by the MND Association in February 2017 with £120,000 of funds from the Ice Bucket Challenge and a strong, collaborative partnership with colleagues working in the NHS, the service has been delivered by two part-time care co-ordinators and has made a huge difference to the lives of people living with MND, giving them a single point of contact for MND services in the region.

#### **Education**

Almost 350 professionals attended our ten masterclasses on respiratory management in MND. The need for this type of education was identified via a survey of all HSCPs in contact with the Association. Nine regional events were facilitated by respiratory experts from the Specialists in Long Term Ventilation at Home group using a combination of theoretical and practical approaches. Interviews carried out since the event demonstrate an increase in knowledge and understanding and changes to practice, particularly in cough management. We held two masterclasses on cognitive impairment and the evaluation was excellent including evidence of changes in practice.

#### **Bereavement support**

We have been developing the ways in which the Association can continue to support people affected by MND by offering post bereavement care. Several focus groups have been held across the Association with former carers and a final report is due to be considered by the Association in early 2019.

#### **Care Centres**

In 2018 we supported 3,828 people through our Association-funded MND care centre network, developed in partnership with the NHS. This represents 83.8% of the people living with MND of whom we are aware. We are committed to ensuring all people with MND have access to one of our MND Care Centres or similar high-quality multidisciplinary care and support as close to their home as possible.

### **Support volunteer roles**

Our network of 305 Association visitors (AVs), Association visitor co-ordinators and care service navigators supported 1,214 people with MND. Our branches and groups provide support groups for people living with MND, carers and bereaved carers in locations throughout England, Wales and Northern Ireland. We have been working with our volunteers to improve our network of support and have set up new groups in Coventry and Warwickshire and the Black Country as well as in Wyre and Fylde and North East Lincolnshire.

### **Care information and advice**

We launched several new care information resources. We created a suite of animated films including *What is MND?*, *What is Kennedy's disease?* and *What is voice and message banking?* – this resource was endorsed by the Royal College of Speech and Language Therapists. We launched a recipe app to accompany our guide *Eating and drinking with motor neurone disease* and published a guide for coping with bereavement, *Finding your way with bereavement*, which features images and quotes from people affected by MND.

We have further developed the range of material available to HSCPs. We published a new guide for professionals called *Multidisciplinary team working for MND*. Three existing professional guides were revised including *Motor neurone disease: a guide for GPs and primary care teams*, which has been endorsed by the Royal College of General Practitioners.

Overall, we issued more than 26,800 pieces of care information to people living with, or affected by, MND during the year and a further 45,000 copies of publications were downloaded from our website. We issued 10,700 pieces of information directly to HSCPs, with a further 11,400 downloads from the website.

### **Competency framework for progressive neurological conditions**

The *Competency framework for progressive neurological conditions* was launched – resulting from a partnership between the Association, MS Trust and Parkinson's UK. The framework was developed in consultation with allied health professionals (AHPs), including occupational therapists and speech and language therapists. It aims to recognise the activities and responsibilities of AHPs working with patients with progressive neurological conditions. It has additional sections which focus specifically on Parkinson's disease, multiple sclerosis and motor neurone disease.

Accessibility to these key roles is a critical factor in assuring good care for people living with any of these neurological conditions and those who care for them. Through this resource we hope to increase knowledge about specialist AHP neurology roles along with an appreciation of their importance and how the most effective team can be constructed by recruiting or retaining the appropriate staffing levels and associated skills. We hope this will contribute to the provision of good care for people living with MND.

### **Rightcare Pathway**

We have developed a new Rightcare Pathway for progressive neurological conditions, in collaboration with NHS Rightcare, the MS Society, MS Trust and Parkinson's UK. The pathway is expected to be launched in Summer 2019 and will help to ensure that people living with MND have access to the care they need.

### **The Massive Online Open Course (MOOC) on MND**

The MOOC on MND is an online resource which has been developed by the Association to help AHPs and trainee AHPs explore the key factors in the effective operation of a multi-disciplinary team for the treatment and care of people living with MND. It is based on the NICE guideline on MND and has

been endorsed by the Association of Palliative Care Social Workers, Royal College of Speech and Language Therapists, British Dietetic Association and Association of Chartered Physiotherapists in Respiratory Care. A total of 85 participants signed up to the first module. This important work means that MDT members will be well-placed to provide co-ordinated care as specified within the NICE guideline.

#### **Funding and promoting research**

The fight against MND is a global one and we will continue to work closely with our international partners around the world to develop new collaborative opportunities to accelerate progress. We published our latest research strategy, which outlines how we will develop our research activities over the next four years, to ensure we continue delivering significant and measurable advances.

The value of our whole research grant portfolio on 31 December 2018 was £16,048,367 and we were funding 90 projects on that date.

During 2018 we awarded:

- Eight new biomedical project grants
- Three clinical and healthcare project grants (including one through our joint funding programme with Marie Curie)
- Two Non-Clinical Fellowships
- One Senior Clinical Fellowship, via our joint funding programme with the Medical Research Council (MRC)
- A further eight small grants

#### **International Symposium on ALS/MND**

In December, the 29th International Symposium on ALS/MND, the largest scientific conference dedicated to MND in the world, was held in Scotland. The event was organised by the Association and hosted by MND Scotland, bringing together 1,250 of the world's leading researchers and clinicians to share information about their work. Regular updates from the Symposium were made available through *The Periodic Table of MND Research* – a web-based information tool designed to bring the science discussed at the Symposium to life for people living with, and affected by, MND. Within three weeks of being launched, the periodic table and its contents had been viewed by 53% more people than the previous year's Symposium news pages with a 173% increase in the number of pages read. Content focused on clinical trials, videos of individual researchers and news of the platform presentations proved to be among the most popular.

#### **The ALS Reproducible Antibody Platform (ALS-RAP)**

This project, launched in January, is a partnership involving the Association, the ALS Association (USA) and ALS Canada with each funder contributing \$200,000 (£153,000) to the research programme, plus a further \$250,000 (£191,000) 'in kind' donation from an industry partner. It is co-ordinated by the Structural Genomics Consortium, a collaboration involving several leading universities. The ALS-RAP aims to ensure that researchers around the world have access to the highest quality antibody-based research tools. By the end of 2018, the consortium had established a development and testing pipeline looking at antibodies for over 20 different inherited causes of MND. They also reported on their evaluation of commercially available antibodies for C9orf72, the most common known genetic cause of MND, to provide the research community with robust advice to use in their research studies.

#### **Modifying Immune Response and Outcomes in ALS (MIROCALS)**

MIROCALS is an innovative clinical trial of interleukin-2 for controlling neuro-inflammation in people

newly-diagnosed with MND. This is an EU-funded project, with additional funding from the Association, generously supported by the Garfield Weston Foundation and the JP Moulton Charitable Foundation. The target for the MIROCALS team in the UK has risen from 30% of the number of people to be recruited into the clinical trial to 50%. This means that both France and the UK now each have a target of recruiting 108 people living with MND into the trial. Participating clinics have been added in Glasgow and Manchester, bringing the total number of UK clinics to seven and greatly increasing the opportunities for people living with MND to become involved. At the end of 2018, the original recruitment target of 216 had been reached, but recruitment is continuing due to a higher than anticipated dropout in the initial 'run in' phase.

#### **MND Collections**

We created a system that allows our cell lines, which are donated by people living with MND, to be made available to researchers across the world, including commercial companies. We signed our first agreement permitting a company to use the cells for drug screening. We are funding a project to convert blood cells from donors with inherited forms of MND into induced pluripotent stem cells, which can then be turned into motor neurones, and other brain cells, for research purposes. The first batch of these lines, created at King's College London, was and transferred to our MND Collections resource at Porton Down, administered by Public Health England. We will extend the use of MND Collections, comprising DNA, cell lines and data through more active promotion of these important resources to the research community and will fund research that seeks to further understand the biological basis of MND.

#### **Project MinE**

Project MinE aims to map the genetic code of at least 15,000 people living with MND as well as 7,500 control subjects and then analyse the data. The third major stage of the Association's commitment to this international genetic research programme has been activated, with up to 300 samples sent for sequencing by the end of 2018. This number brings us close to our total target of sequencing up to 2,200 genomes – almost 10% of the total worldwide target of 22,500 genomes.

#### **Clinical and healthcare studies**

The Association funds 16 MND studies, which are registered by the NHS and allow researchers to recruit people affected by MND to take part in a wide range of projects. Among these is the COMMEND study, which looks at the use of Acceptance and Commitment Therapy, a form of psychotherapy which improves the psychological health of people living with MND when used alongside established multi-disciplinary care. Another project being funded is VOTECO2ALS, which is looking at a new hand-held device that can be used by a person living with MND at home to improve the effectiveness of Non-Invasive Ventilation (NIV). NIV is proven to improve life expectancy for people living with MND.

#### **MND Register**

The MND Register is a research project which will be used to help researchers understand where people with MND live, ensure sufficient services exist and identify any potential MND 'hotspots'. The information generated will help plan the care for people living with MND and tell researchers more about what might be causing the disease. At the end of 2018, more than 1,100 people with MND had been recruited to the register, through 23 participating clinics, with another 15 clinics initiating plans to join. In addition, more than 120 people registered themselves online at [www.mndregister.ac.uk](http://www.mndregister.ac.uk). We are grateful for the generous support of the Betty Messenger Charitable Foundation and a family trust that wishes to remain anonymous in funding this project.

### **Analysis of Diaphragm Pacing Trials**

In collaboration with the ALS Association and Muscular Dystrophy UK, the Association agreed to jointly fund a detailed review of data from Diaphragm Pacing trials. An open label trial, a type of clinical trial in which the researchers and patients know the treatment is being administered, has been held in the USA and indicated that diaphragm pacing is effective. Two trials in Europe where the participants were randomly assigned to receive diaphragm pacing or standard treatment have shown that diaphragm pacing might be detrimental. The analysis of the trial data may result in guidance on when this intervention may be considered for use and when it should be avoided.

### **Investing in talent**

The Association funded two new Non-Clinical Fellowships (one Junior and one Senior) and a Senior Clinical Fellowship, in collaboration with the Medical Research Council, from our Lady Edith Wolfson Fellowship Programme. Of the 12 MRC/MND Association Fellowships awarded over the past decade, all but one have continued their careers as MND clinician-scientists. To date, two have been awarded tenured lectureships and one a professorial appointment. The two major International Young Investigator awards in MND research were both won in 2018 by Lady Edith Wolfson Fellows as part of our Lady Edith Wolfson Fellowship programme. Dr Russel McLaughlin (Trinity College Dublin, one of our Senior Non-Clinical Fellows) won the European Network for the Cure of ALS (ENCALS) Young Investigator Prize; Dr Rickie Patani (University College London, one of our MRC/MND Association Senior Clinical Fellows) won the Paulo Gontijo Prize which was presented at the Association's International Symposium on ALS/MND.

Thanks to the generous support of a donor family, we were able to establish a Professorial post in Clinical Neurology and Neuroscience at the University of Oxford. The position was awarded to Dr Martin Turner, a leading international expert on the disease.

### **Campaigning and raising awareness**

We campaign and raise awareness to ensure people living with MND and those closest to them, get the support they need, when they need it.

### **Raising awareness**

Our awareness-raising film *The Ride* was launched in September. The devastating effects of MND are depicted in this hard-hitting film which was the centrepiece of our #TakeOverMND campaign. *The Ride*, which was developed with award-winning creative agency Don't Panic, was rolled out across social media and online platforms and marked a new, bolder approach to awareness raising by the Association. The film has had more than one million Facebook views, it was shared thousands of times and prompted people to tell their own stories too. In November, creative production agency Projection Artworks used the *Motor neurone disease takes over lives* artwork from our #TakeoverMND campaign and projected it onto buildings in Soho, Charing Cross and Shoreditch.

On 23 August, a documentary called *Grayson Perry: Rites of Passage* was broadcast on Channel 4, featuring a family whose lives had been touched by MND. Roch Maher, and his wife Deirdre, were interviewed by world-renowned artist Grayson Perry about Roch's experience of living with MND. Sadly, Roch died shortly after filming ended, but we are extremely grateful to Roch, Deirdre and their family for agreeing to be involved in this important documentary.

### **Accessible housing and adaptations**

Our engagement programme about accessible housing and housing adaptations for people living with MND closed in July. Around 850 people participated and we communicated the findings via an infographic and articles on all our communication channels. We sent Freedom of Information (FOI)

requests for information on Disabled Facilities Grants (DFGs) policy and practice to local authorities in England and Wales and to the Northern Ireland Housing Executive and commissioned an analysis of the findings which have been fed into campaign planning for 2019. We intend to release the results in 2019. These showed that the time taken to access housing adaptations was the most commonly mentioned challenge and we are now looking at campaigning to speed up the process for getting adaptations completed as part of a public campaign to launch in summer 2019.

#### **Website development**

We have redeveloped the Association's website. This important work focused on the user experience including navigation, content, using video to share information and making the website work better on mobile devices. The development also looked at security, accessibility for those with disabilities, performance such as page load times and compatibility with Google. The new website launched in May 2019 and has provided us with a solid foundation upon which we can further innovate to support people affected by MND.

#### **Football and MND**

In August, former professional footballer Len Johnrose announced that he had been diagnosed with MND and since then we have been incredibly grateful for the support of Len and his family in raising funds and awareness. In mid-September Bolton Wanderers' footballer Stephen Darby retired from the club following his diagnosis of MND. We are working closely with Len, Stephen and the Professional Footballers' Association to raise awareness within the footballing community of this devastating disease.

#### **Champion the Charter**

As at 31 December 2018, 79 councils had adopted the Association's MND Charter, a five-point document that sets out what good care for people living with MND looks like. We continue to work with a number of councils on actions following their signing of the Charter, including Cambridgeshire County Council which is developing a plan to ensure the Charter is taken on board across the council and Worcestershire County Council, which met with the local branch to discuss support for people living with MND. All five CCGs in Norfolk signed the Charter in October and have undertaken a number of follow-up actions including promoting our Red Flag tool, designed to help GPs improve referrals to neurology departments and reduce the time it takes to receive a diagnosis.

#### **All-Party Parliamentary Group (APPG) on MND**

We provided the secretariat for the APPG, which met three times in 2018, discussing disability benefits and research. At the October meeting, the group focused on MND research. More than 1,000 supporters emailed their MP about the meeting and 21 MPs attended.

#### **Improving welfare benefits**

After active campaigning by the Association over a sustained period, The Department for Work and Pensions (DWP) announced it will introduce ongoing awards for Personal Independence Payments (PIP) claimants with progressive conditions on the highest rates of benefits, with a light touch review at the end of ten years. This essentially scraps reassessments for people with MND on the highest rates of PIP and was a major campaigning achievement in 2018. The Association has also been working with the DWP on the development of new guidance for DWP case managers to implement the ongoing PIP awards.

On Global MND Awareness Day, 21 June, the Association launched its new campaign *Scrap 6 Months* to reform the definition of terminal illness for the purpose of accessing fast-track benefits, by removing the requirement for 'a reasonable expectation of death within six months' from

legislation. We supported Madeleine Moon MP's Private Members' Bill *Access to Welfare (Terminal Illness Definition) Bill 2017-19*, which proposes to remove the six-month time limit and replace it with a clinical judgment made by an appropriate health professional. We issued a press release highlighting the findings from a report on the impact of the new benefit, Universal Credit, on people living with MND.

We responded to a Social Security Advisory Committee (SSAC) consultation on DWP's plans to roll out Universal Credit to existing claimants currently in receipt of existing so-called legacy benefits, and our submission was cited extensively by the SSAC in its recommendations to Government. 125 MPs signed a letter to the Secretary of State for Work and Pensions in support of the Bill. More than 50 MPs attended a parliamentary drop-in event in November, organised to promote the Bill and raise awareness of the issue. In addition, the Work and Pensions Select Committee issued a report in December which recommended that the Government remove the six-month definition in favour of a clinical judgement by a medical practitioner, in line with the Bill. The Minister, Sarah Newton MP, wrote to the Association in December stating that the DWP would shortly be engaging with disability charities, clinicians and other stakeholders to discuss the wording around terminal illness and improve understanding of the Special Rules for Terminal Illness process. Although our longer-term campaigning goal remains a change in the law, it may be possible to obtain some useful clarifications to guidance in the short term.

#### **The work of our patrons and supporters**

We have been incredibly grateful for the continuing support of The Princess Royal during 2018, Her Royal Highness's 10th year as the Association's Royal Patron. It was a very busy 12 months, with Her Royal Highness attending six events on our behalf. In just five weeks during January and February, The Princess made three visits - to Aberystwyth to meet our Support Volunteers Network, to Norwich to the launch of the Norfolk MND Care and Research Network and to London to highlight our work with communication aids and voice-banking. In June, The Princess joined volunteers and healthcare professionals in Cheltenham to celebrate our work across the West of England. In October she attended our annual Research Dinner to hear the latest developments in MND research. The Princess ended the year in Glasgow, supporting both the Association and MND Scotland, for whom The Princess is also a patron, by welcoming delegates from more than 40 countries to the 29th International Symposium on ALS/MND. In addition, The Princess met with our incoming and outgoing Chairs Richard Coleman and Alun Owen at Buckingham Palace.

In March, the Association was extremely saddened to learn of the deaths of our patrons Professor Stephen Hawking and Sir Roger Bannister.

Professor Hawking had been a passionate supporter of the Association's work since the very beginning and we were fortunate to have him as one of our Patrons for so many years. He was a generous supporter and was invaluable in helping to raise awareness of MND all over the world, perhaps most memorably through the film *The Theory of Everything*. The media coverage which followed Professor Hawking's death was testament to his remarkable life and we remain incredibly grateful to the Hawking family for their continued support.

Sir Roger Bannister was famous around the world as the first man to run a mile in less than four minutes. After retiring from running he became a consultant physician and a leading neurologist. Sir Roger always maintained that his achievements as a neurologist far outshone his time on the track and it was for this reason he was invited to become a patron in 2008.

### **Conferences and events**

The Association's AGM and Annual Conference in July was a success with 130 delegates attending. A notable highlight was the introduction of a Virtual Reality experience which received positive feedback from many people living with and affected by MND. We held four regional conferences, including our first in Northern Ireland, which, in total, attracted 271 delegates including 51 people living with MND.

### **The Hawking Annual MND Lecture**

In partnership with the Royal College of Nursing, this lecture brings the latest thinking in the field of MND to a wide audience.

The 2018 lecture, led by Professor Eneida Mioshi, Chair of Dementia Care, Faculty of Medicine and Health Sciences at the University of East Anglia, introduced the audience to her research and explored the useful practical steps that health professionals might use in their practice to provide the best person-centred care.

### **Supporting local campaigns**

Work continues to resolve the acute gap in local respiratory services in Sussex. All three Sussex branches are involved with the Association's *Every Breath* campaign and 120 campaign network members emailed their decision-makers. Thanks to local people affected by MND who helped to raise awareness, 12 Sussex-based MPs are mounting pressure for a solution from CCGs across the county. Regional staff have met with decision-makers at all three trusts and we hope that a service will be in place soon.

### **Progress against strategy**

We have completed the second year of our five-year strategy *Going further together towards a world free from MND 2017-2021* and the trustees continue to regularly review our progress.

Our performance indicators show that at the end of 2018 we were hitting our targets in the vast majority of our strategic objectives, which cover the following areas:

- Advancing research
- Ensuring quality health and care
- Strengthening professionals' ability to treat and care for people affected by MND
- Working together
- Raising awareness
- The difference we make

You can see achievements against these goals by visiting

[www.mndassociation.org/2018achievements](http://www.mndassociation.org/2018achievements). The trustees will continue to monitor our progress in the months and years to come to ensure the Association continues to do all it can to achieve these important strategic objectives.

### **Equality, Diversity and Inclusion (EDI)**

We launched our EDI strategy, *Reaching out*. During the year, the Association has created a team of ambassadors to ensure that EDI is championed across the organisation and created an equality impact assessment tool to ensure all new and existing products and services are truly accessible. Among other achievements, we have:

- included equality commitment clauses in employment contracts to ensure everyone shares the same commitment to EDI

- become a Mindful Employer to ensure our policies and practices reflect the needs of staff. In October, the Association signed the Charter for *Employers who are Positive About Mental Health*. The Charter is a voluntary commitment which provides us with easier access to information, local support, mental health awareness training and other resources to help us to support staff.
- designed and delivered training around EDI so that members of staff understand what our commitment to EDI means to them and the way we work
- created a process for undertaking access audits of venues to ensure ones we use are fully accessible.

We would like to thank

Everyone who is living with or affected by MND, including those who generously support our work, either by volunteering, campaigning, raising or donating money, or by sharing their personal experiences in order to help us raise awareness and funds. Their courage and dedication continue to inspire our work every day.

Our 9,384 members, including many people living with MND, who are the driving force behind our work. They influence our strategy, our activities and how we spend our money to support people living with MND. We will continue to find new ways to seek our members' views to ensure they inform and influence our work.

Our volunteers, who are involved in all aspects of the Association from providing local support in people's homes, organising our branches and groups, running our helpline, contributing to our forums, raising money and awareness, campaigning - to governing the charity, and so much more.

All our passionate and committed fundraisers who each year raise millions of pounds to support our work by organising and taking part in a wide range of fundraising events and challenges.

All our donors and supporters who have donated generously to our appeals, left money in legacies, set up Fightback and Tribute Funds and contributed in countless other ways.

All the trusts and foundations, companies and individuals who made significant contributions to care and research projects during the year.

All the individuals and families who have continued their transformative support and wish to remain anonymous. Their support has funded key care and research programmes.

We would also like to thank:

Our President Professor Sir Colin Blakemore FMedSci HonFRCP HonFRSM HonFRSB FRS for his dedication to the Association.

Our Patrons Chris Broad, Joel Cadbury, Benedict Cumberbatch CBE, The Rt Hon the Lady Finlay of Llandaff FRCP FRCGP, The Baroness Greenfield CBE, Charlotte Hawkins, James Niven, Richard Noble OBE, Eddie Redmayne OBE and Jeremy Vine for generously supporting our work.

Our Ambassadors Joss Ackland CBE, Gina Bellman, Taron Egerton, Olivia Lee, and Natalie Pinkham for helping to raise awareness of the Association.

The many people affected by MND who shared their experiences to help raise money and awareness including:

Our growing online community on Twitter, Facebook and other social media channels who do so much to help us raise awareness of MND and actively encourage others to support us.

Our staff based in Northampton, London and around England, Wales and Northern Ireland, who use their skills and professionalism to further the Association's work and share our vision of a world free from MND.

#### Congratulations to

The Association's Director of Research Development, Dr Brian Dickie, who was presented with The International Alliance Humanitarian Award by HRH The Princess Royal at the Association's International Symposium on ALS/MND in recognition of his significant contribution to people affected by MND.

#### Remembering

All those members of the MND family we sadly lost this year. As we remember their courage and their contribution to the work of the Association, they will continue to inspire our fight against MND and remind us of the need to do everything we can to support those living with the disease and those closest to them. Here we pay tribute to just some of the many members of the MND community who died this year. Our thoughts are with them all.

Volunteer Olga Bannister who died in June 2018, just days after being presented with the British Empire Medal in recognition of her 17 years of work supporting people living with MND in South Yorkshire.

Alan Davidson, founder of The Alan Davidson Foundation who died from MND in August 2018. We are incredibly grateful to the Foundation for continuing to support our work.

Roch Maher who died from MND in April 2018. Roch spent many years campaigning on behalf of the Association to raise awareness and improve care and support for all those affected. He supported the Association's campaigning at Westminster by attending meetings of the All-Party Parliamentary Group on MND and played a key role in establishing the NICE guideline on MND.

Our trustee and friend Janis Parks who died in April 2019. Janis had been a volunteer for the MND Association for more than 20 years and was a founder member of the Association's West London and Middlesex branch. She became a trustee in 2014 and dedicated much of her life to supporting people living with MND in both her national and local roles.

### iii) Future plans and priorities

#### Improving care and support

We will continue to work with our Care Centres, Care Networks and other NHS services to support them to complete our improved 2019 Transforming MND Care Audit and Patient Experience Survey, and to use their results to continue to develop their services. We will be looking at how this tool can support different types of teams to improve standards of care.

We will work with our Care Centres and networks to increase recruitment to the MND Register for England, Wales and Northern Ireland.

We will be recruiting volunteers to our Carers' Champions trial. These Champions will provide information about support for carers and bereaved carers of people with MND in their local area. We will pilot several new support volunteer roles that provide direct support to people affected by MND.

We will be supporting more branches and groups to establish support groups for people living with MND, carers and bereaved carers.

We will launch our new web hub for children aged between four and 10 and we will continue to develop resources for children including an information guide for children aged between eight and 10 and an animated video for use in schools.

We will develop our technology think tank, working with people living with MND and external organisations to create a platform for technology innovation to help people living with MND in their daily lives.

#### Research

We will support research centres to achieve their recruitment target to the MIROCALS clinical drug trial, in addition to facilitating recruitment of UK participants to a new European trial.

In collaboration with MND Australia, we will facilitate international collaboration in MND research and clinical management through hosting the 30th International Symposium on ALS/MND in Perth, Australia in December 2019.

We will fund new and innovative studies in fundamental science, clinical science and healthcare research, with a proportion of our funding targeted to joint collaborations with partner organisations, in order to maximise our funding impact.

We will continue to develop our web and social media activities about our research projects to provide timely, relevant and accurate information to our members and supporters.

#### Campaigning and raising awareness

We will launch a new campaign focusing on improving access to adapted and accessible homes for people with MND.

As part of our equality, diversity and inclusion strategy, *Reaching Out*, we will be working with our volunteers to explore how they can reach out to new communities and supporters.

In 2019 the MND Association marks its 40th anniversary and we will be hosting a series of events to mark this unique occasion. In addition, the Association will use its 40th anniversary to demonstrate the progress being made in MND research and caring for people who are living with MND.

#### Fundraising approach

We undertake fundraising activity to our supporters via direct mail, email and direct contact at events, managed centrally and by our branches and groups. We are registered with the Fundraising Regulator and have signed up to the fundraising preference service, which allows people to control the nature and frequency of direct marketing communications that they receive from fundraising organisations. We fundraise in line with the Code of Fundraising Practice and adhere to data protection law. We are committed to ensuring that we are completely open and transparent about

our fundraising and spending. As members of the Fundraising Regulator's self-regulatory scheme we comply with its principles in all of our fundraising:

- We will commit to high standards
- We will be clear, honest and open
- We will be respectful
- We will be fair and reasonable
- We will be accountable and responsible.

When we benefit from commercial companies raising funds on our behalf through the sale of products, we operate within a written agreement to ensure their activities are not harmful to the Association. Trustees regularly review the fundraising strategy and are made aware of any significant new activities and/or contracts where values need to be carefully aligned.

We received 12 complaints about our fundraising activity in 2018 and all were promptly resolved without the need for escalation to the Fundraising Regulator. Complaints are taken very seriously and regularly reviewed by the Board of Trustees. However, these 12 represent a tiny fraction of our outgoing fundraising communications.

#### iv) Financial review

The charity is a company limited by guarantee and is registered in England and Wales. These financial statements are for the group which comprises both the Association and its wholly owned trading company Motor Neurone Disease (Sales) Ltd. The results for the year are set out in the Consolidated Statement of Financial Activities, formatted in accordance with the Accounting and Reporting by Charities: Statement of Recommended Practice (SORP).

#### Financial performance

The trustees are pleased to report on a satisfactory financial performance for 2018. The Association had planned for a significant deficit budget in the year to continue the momentum generated by the Ice Bucket Challenge while drawing down surplus reserves. However, with a strong income performance in the year, we were able to maintain planned levels of spend on our charitable activities while delivering a modest surplus of £60,000 (2017: deficit £178,000). This has increased overall reserves to £10.3 million (2017: £10.2 million).

Restricted reserves of £1.8 million increased in year by £100,000 and now represent 17.2% of total reserves (2017: 16.4%). The non-restricted reserve remains at £8.5 million and now represents 82.8% (2017: 83.6%) of overall reserves. This equates to around 7.9 months of general expenditure, well ahead of the current group reserves policy of four to six months.

A decrease in cash and bank deposits to £19.2 million (2017: £20.5 million) at 31 December 2018 is the result of the planned further draw down of Ice Bucket Challenge monies from designated reserves and payments towards the committed research programme funded from the restricted reserve. The trustees are pleased to report that cash flows from fundraising activities remain resilient and cash balances are healthy.

#### Income

We continue to generate income from a broad range of fundraising activities and 2018 was another successful year for the Association's fundraising and income generating teams.

Total income for the year was £18.7 million (2017: £19.0 million).

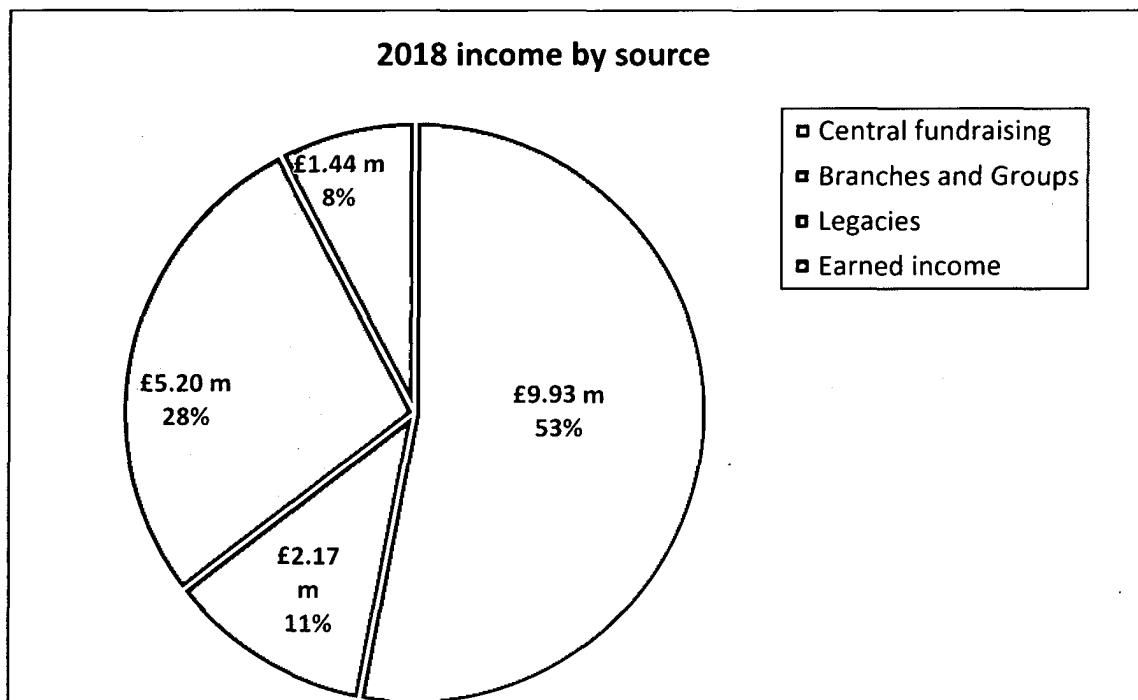
The Association's fundraising team had a very successful year raising £9.9 million (2017: £10.5 million) from individuals and communities. This represents 53% of our total income (2017: 55%).

Of this, our 89 branches and groups raised £2.17 million in the year (2017: £2.41 million). This is an outstanding achievement enabling the Association to confidently provide our extensive range of local services to people living with and affected by MND. The trustees would like to thank and congratulate all our volunteers and supporters for their dedication, commitment and success throughout the year.

Fundraising through major donors, trusts and foundations and corporate partners generated £3.6 million (2017: £4.0 million).

It was a strong year for legacies with £5.2 million raised (2017: £4.9 million), representing a substantial 28% of total income. This included £86,000 given directly to branches and groups. Once again, this was ahead of expectations and the trustees wish to recognise the incredible generosity and very personal commitment of our legacy givers to supporting those living with MND now and in the future.

#### Sources of income



#### Fundraising highlights

For every £1 spent directly on central fundraising in 2018, £3.58 (2017: £3.68) of income was generated. When central legacy income and expenditure is included, this figure increases to £5.17 for every £1 spent.

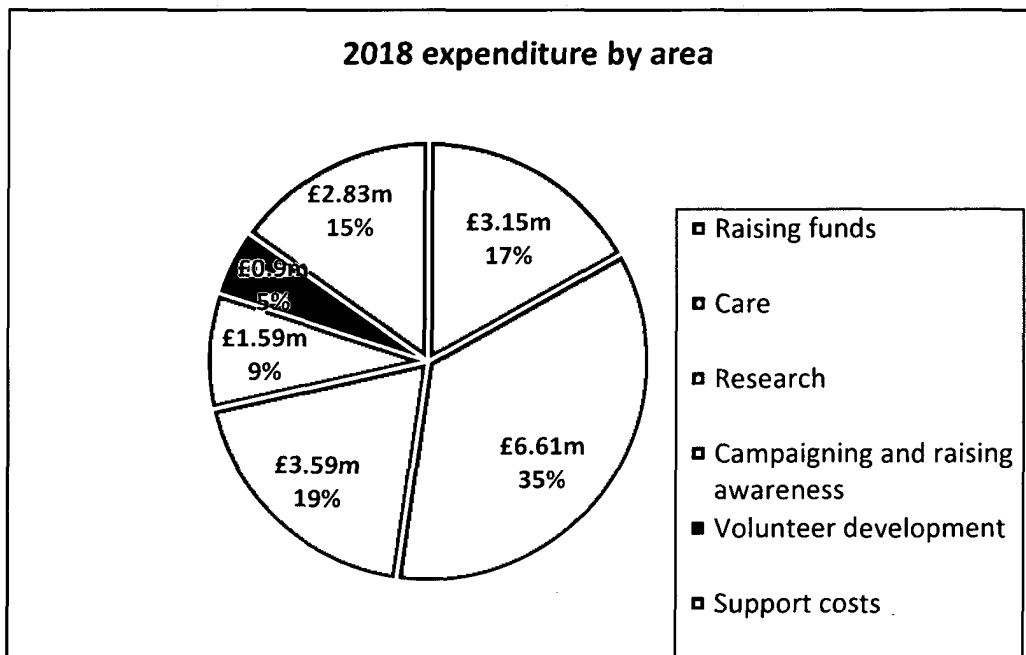
Our fundraising highlights this year include:

- Once again, our fantastic MND community rose to the challenge raising more than £4.1 million to support people affected by MND. The Royal Parks Run had an exceptional year with 160 runners including corporate teams raising over £200,000
- The Wolfson Foundation pledged £750,000 over two years towards The Lady Edith Wolfson Fellowship Programme. This exceptional donation marks more than three decades of support from the Wolfson Foundation and represents their largest single donation to the Association
- The Broad Appeal Ball was the Association's biggest and most successful fundraising ball in our history, generating a net profit of £200,000 with funds split equally across care and research programmes
- The Linbury Trust pledged a substantial donation of £200,000 in memory of the ballerina Annette Page who died from MND in 2017. The donation will go towards the Association's biggest ever research programme, Project AMBRoSIA which is seeking to identify biomarkers for MND
- The J P Moulton Charitable Foundation supported the Association for the first time, donating £108,000 towards the MIROCALS clinical drug trial
- The Heaton-Ellis Trust continued their generosity by supporting research into familial forms of MND at King's College London
- The My Name's Doddie Foundation entered into a generous two-year partnership to help fund elements of our Care Support Grants Programme. In 2018, the Foundation donated £50,000 to help people living with MND adapt their homes as well as funding respite activities for carers
- In September, the London City Swim Foundation, sponsored by Intertrust, held its second open water swimming event at the Royal Victoria Docks. More than 330 swimmers including five people with MND took part in the event, raising more than £140,000 to support Project AMBRoSIA
- Our thanks to The Freshfield Foundation, The William and Frank Brake Family Trusts and the Bruce Wake Charitable Trust for their enduring support of the Association across many projects
- Investec created an extraordinary Charity of the Year partnership with us for 2018–2019 with the aim of raising £100,000 for research

- The Christmas Lifeline Appeal featuring our Communication Aids work was our most successful appeal in 2018 raising more than £166,000 and exceeding our target by 64%
- The Alan Davidson Foundation donated £60,000 as a result of the successful HD5K Run in Hyde Park in May and a further grant of £106,000 to support our care programme
- City v MND: The David Setters' Trophy Cricket event delivered another memorable day's Cricket in the City and raised vital funds for our Research Fellowship Programme
- Our Charity of the Year Partnership with Sainsbury's Non-Food Division raised £36,000 in 2018 through a variety of staff-led fundraising activities.

### Expenditure

Total expenditure in 2018 was £18.7 million (2017: £19.1 million). Expenditure on core charitable activities was £12.7 million (2017: £13.3 million) meaning that 68% of every pound spent was on the Association's core work (2017: 69%)



The table overleaf shows where the money was spent on our core work compared to the previous year:

Fundraising activities (excluding support costs) cost £3.15 million in the year representing 16.7% of total expenditure (2017: £3.10 million - 16.2%). The remaining £2.8 million of support costs is 15.2% of total expenditure (2017: £2.8 million - 14.5%).

	Volunteer development	Care £000	Research ** £000	Campaigning and raising awareness £000	Total 2018 £000	Total 2017 £000
Patient care and grants	-	1,486	-	-	1,486	1,298
Care centre grants	-	1,292	-	-	1,292	1,072
Equipment loan service	-	465	-	-	465	438
Wheelchair services	-	168	-	-	168	175
Communication aids	-	208	-	-	208	135
Research grants and donations	-	-	2,800	-	2,800	3,627
International Symposium	-	-	336	-	336	476
Campaign and awareness costs	-	-	-	414	414	453
Other costs *	26	695	66	27	814	863
Staff and related costs	586	2,295	388	1,146	4,415	4,423
Volunteer support	286	-	-	-	286	308
<b>Total 2018</b>	<b>898</b>	<b>6,609</b>	<b>3,590</b>	<b>1,587</b>	<b>12,684</b>	
<b>Total 2017</b>	<b>944</b>	<b>6,199</b>	<b>4,520</b>	<b>1,605</b>		<b>13,268</b>

\* Other costs include irrecoverable VAT, publicity, information, education and other departmental running costs

\*\* In 2017 a £1m donation was made to the international research initiative project MinE, which was partly funded by IBC funds. See also note 6.

### Restricted funds

As at 31 December 2018 restricted funds stood at £1.8 million (2017: £1.7 million). Of this total, modest amounts are being held centrally for research and care programmes, but £1.3 million (2017: £1.2 million) is being held locally by branches for use in specific geographical areas, on particular types of expenditure. This includes a number of legacies which are restricted to local use.

Where restricted funds are not currently allocated to specific projects or activities the reserves are reviewed periodically to ensure they are utilised in accordance with the donors' stated wishes as soon as is practicable.

### Designated funds

At 31 December 2018 designated funds stood at £1.9 million (2017: £3.4 million). Of the £7.2 million of Ice Bucket Challenge monies raised in 2014/15 a further £900,000 was spent in the year leaving just £800,000 to spend through to 2021. All of these funds are fully allocated to programmes across care, research, campaigning and volunteering. The remaining £1.1 million (2017: £1.7 million) of designated funds relates to our continuing commitment to the MND Care Centre Network.

### Unrestricted funds

Following another excellent year of fundraising our unrestricted reserves have increased in the year to £6.6 million (2017: £5.1 million) while we have been able to maintain our planned spending levels. As at 31 December 2018, the total of unrestricted and designated reserves was £8.5 million (2017: £8.5 million) exceeding our current policy of maintaining four to six months of general expenditure. The planned programme of activities for 2019 within care, research and campaigning is expected to bring reserves closer to our policy.

## v) Principal risks and uncertainties

### Risk management

The trustees acknowledge their responsibility for the Association's systems of internal control and risk management and recognise that such a system is designed to actively manage and minimise the risk of failure to achieve the Association's objectives. The Board delegates some appropriate financial powers to the Finance and Audit Committee as detailed in the Scheme of Delegation.

The Association has a cautious risk appetite across all of its principal risks. The trustees review the key risk indicators for each principal risk area on a regular basis through the delegated Committees of Finance and Audit, Governance, Care and Engagement. Trustees monitor that appropriate action is being taken where risk does not align with appetite.

There is a comprehensive organisation risk register for the Association that is reviewed and signed off at each Board meeting. In addition, risk registers are held for major project activities and managed through formal Project Boards sponsored by an executive director and usually with trustee representation. The trustees are satisfied that all significant strategic and operational risks have been identified, reviewed and actions established to manage and mitigate those risks.

The following major categories of risk are relevant to the Association:

#### Reputational risk

Retaining the Association's reputation is paramount. Due to the diverse nature of our activities this risk relates to a number of areas including our extensive research programme, the provision of care through our care centre networks or through our Association Visitor network, and the extensive activities of our 2,400 volunteers across England, Wales and Northern Ireland.

The risks associated with our extensive research programme include scientific fraud and misuse of resources, in addition to controversy over research policies and methods, such as the use of animals or embryonic stem cells. We have clear policies, procedures and guidance including terms and conditions for all grants requiring appropriate licensing to be in place. There is also a peer review process that provides a robust system of governance and quality assurance.

We are a signatory to the Concordat on Openness in Animal Research which sets out how organisations report the use of animals in scientific, medical and veterinary research in the UK. Signatories to the Concordat have agreed to be more open about their use of animals in research, and to abide by their four commitments. All of the UK-based research institutions that we fund are also signatories to the Concordat. Together we ensure that these commitments are met and that we are transparent in the use of animals in research.

Our extensive MND Care Centres and Care Networks are a significant and ongoing investment by the Association to provide co-ordinated multi-disciplinary care for people living with MND. The grant funding is governed by a contract that includes service objectives, which are reviewed regularly and discussed through a steering group process. New Care Centres or Networks are subject to site visits by a group including trustees and staff from the Care directorate, to ensure best practice and governance processes are in place. In 2018, each Care Centre/Network assessed its services against the standards in the NICE guideline on MND and this provided the Association with a source of assurance of quality.

The Association visitors (AV) network is reliant on the skill and involvement of volunteers, with risks including maintaining up to date skills and data protection. These risks are mitigated through an in-depth AV training programme, an AV support framework and focused recruitment processes addressing local need. Our extensive volunteer base is also managed through relevant policies, procedures and training.

#### Financial risk

Voluntary donations and associated fundraising activities provide over 90% of the Association's income. To mitigate this risk, we have in place a robust fundraising strategy supporting multi-year budgets and financial plans reflecting the nature and level of risk (see Fundraising Risk below). In addition, we maintain a broad portfolio of income generating activities and, where possible, seek multi-year commitments from our generous supporters.

There is additional financial risk arising from increased demand from people with MND who are unable to access equipment and services on a timely basis through national and local statutory service commissioning. This is mitigated, where possible, by campaigning and driving local and national policy changes. The *NICE guideline on MND*, published in February 2016, was a significant move in this direction. We also have clear criteria, agreed by trustees, which state we do not fund services or equipment which are a statutory responsibility, except in exceptional circumstances.

With a significant level of cash reserves the Association takes a low risk approach to investments with financial institutions through agreed parameters of credit ratings and low risk, easy access investment products. Our investments are reviewed regularly by the Finance and Audit Committee.

#### Fundraising risk

We continue to ensure compliance with the Code of Fundraising Practice and data protection laws whilst maintaining a broad portfolio of activities. We are committed to ensuring that we are completely open and transparent about our approach to fundraising. We worked hard in 2018 to ensure compliance across the Association with the new data protection laws (GDPR) which came into force in May 2018 and will continue to do this through 2019. We are committed to protecting and respecting the personal data of all those that we work with and support.

#### External environment risk

The Association supports people living with MND across England, Wales and Northern Ireland. Recent structural changes in the NHS, and the constraints on health services, local authority and financial support budgets, have led to geographical variation in service availability. In order to mitigate this risk, we actively campaign throughout the three nations to ensure that the delivery of care for people living with MND is provided by the appropriate agency, in the right place and at the right time.

The trustees recognise the uncertainties resulting from the Brexit vote. In particular, the potential risks to voluntary and corporate fundraising, UK participation in EU-funded research and the availability of skilled health and social care staff to support people living with MND. We continue to monitor developments carefully and take precautionary action where we can.

#### Legal and regulatory risk

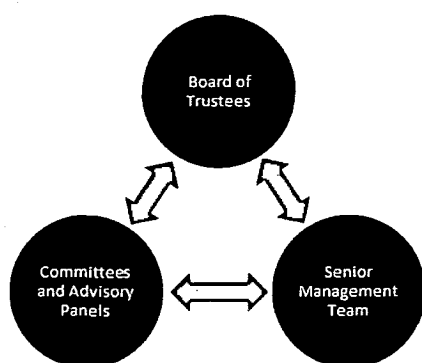
The Association must comply with a range of legal and regulatory requirements including charity law, data protection, new fundraising standards, health and safety and safeguarding. To mitigate these risks the Association has robust and embedded processes and policies, which are complemented by regular and rigorous review at both delegated committee and, where appropriate, Board meetings.

# Structure, Governance and Management

## Structure

The Association was originally formed on 6 October 1979 and was incorporated as a company limited by membership guarantee in 1986. The Association is governed by its *Articles of Association* and in the event of it being wound up, every member is liable for an amount not exceeding £1 to facilitate the payment of the debts and liabilities of the Association. At 31 December 2018, there were 9,384 members.

## Governance



Our governance structure is designed to ensure that:

- there is strong representation from people living with and affected by MND
- there are strong connections to research teams and HSCPs
- the Association is advised by a breadth of specialist organisations and people
- the Association receives comprehensive information and advice to support decision-making
- the Association has flexible mechanisms for engagement with people affected by MND and our supporters.

### The Board of Trustees

The Board (members of which are directors under company law) is the governing body of the Motor Neurone Disease Association. It comprises a maximum of 16 trustees: the Chair plus up to a maximum of 10 elected and five co-opted trustees, with the majority always being directly elected by the membership. It ordinarily meets in formal session four times a year.

Election of trustees is by ballot of members and carried out by an independent scrutineer. In accordance with the Companies Act 2006, members may register an electronic vote, a postal vote, or can appoint a proxy to vote on their behalf. Elected trustees serve for a maximum of two consecutive three-year terms and must stand for re-election at the end of their first term. The recruitment and selection of co-opted trustees is overseen by the Governance Committee and all appointments are the responsibility of the Board. Co-opted trustees serve two-year terms and can serve a total of six years which can, but do not have to be consecutive, with the Board considering their reappointment at the end of their first and second terms. The Board encourages people with

personal experience of MND to stand for election. During 2018 the Board included two trustees living with MND, nine current or previous primary carers and four trustees with family experience of the disease.

All elected and co-opted trustees are provided with a comprehensive induction to the Association, which includes briefings on the roles and duties of trustees. They receive subsequent development and training through internal coaching and external providers.

Every two years, the Board carries out a skills audit to enable it to identify gaps and plan for future recruitment, with the latest audit having been carried out in 2018. The Board also carries out a Board Effectiveness Review on a bi-annual basis within which trustees' views are sought on a range of aspects of individual and collective performance that are recognised as contributing to effective governance. Conclusions are debated and, as necessary, improvement action plans are developed and put on place.

The Board seeks to maintain and improve its governance arrangements, and in 2018 used the Charity Governance Code to benchmark its structure and processes against the Code's recommended practices. Although compliant in almost all areas, an action plan has been developed to ensure appropriate improvements are made during 2019.

#### **Committees of the Board**

A number of committees and panels advise the Board on issues relevant to the aims, objectives and good governance of the Association. There are formal terms of reference, minimum skill sets and required number of trustees for each committee, which are regularly reviewed by the Governance Committee before Board approval. Minutes from each committee are supplied to the full Board. The committees are as follows:

##### **Care Committee**

This committee reviews all aspects of the Association's work relating to improving care and providing support for people with MND, their carers and families. This encompasses both direct support and highlighting areas where campaigning is needed to maintain best practice in the delivery of health and social care across the three nations. It reviews risk and approves grant funding to support the work of MND Care Centres and Networks, up to an agreed limit, with grants above that limit being approved by the Board.

##### **Engagement Committee**

This committee reviews strategic activities, policy, and effectiveness relating to the Association's volunteers. This includes all aspects of volunteering including recruitment, retention, empowerment, any potential risks and the development of existing and emerging roles. Two young volunteers are also co-opted on to the committee in recognition of the Association's strategic aim to increase participation by younger people.

##### **Finance and Audit Committee**

This committee provides stewardship of all financial aspects of the charity's activities. The committee scrutinises and evaluates the annual budget prior to Board approval. It ensures that the appropriate financial controls and regulatory requirements are adhered to and advises the Board accordingly. The committee is responsible for the annual internal audit plan, oversight of the external auditor's report and the improvement plans resulting from it and reviewing financial and fundraising risks. The committee also recommends the annual pay award for all employees, which includes the Senior Management Team (except the Chief Executive), to the Board for approval.

### **Governance Committee**

This committee ensures that the Association can achieve its charitable aims and strategic priorities by undertaking regular reviews of its governance structures and procedures. The committee also monitors compliance within the Association and ensures that high standards of governance are maintained and risks, where possible, are mitigated.

### **Remuneration Committee**

This committee is responsible for the annual review of the salary and other benefits of the Chief Executive. The committee also oversees the remuneration packages of members of the senior management team assisted by sector benchmarking and advises on communication of this information to members of the wider public in line with best practice.

### **Biomedical and Healthcare Research Advisory Panels**

These panels assess applications for funding for biomedical and healthcare research in accordance with guidelines from the Association of Medical Research Charities (AMRC) and in line with the Association's research strategy. Those proposals meeting the criteria are then scored, prioritised and recommended to the Board for approval.

Membership of the sub-committees of the Board is generally restricted to trustees. However, to enhance their skill set and benefit from expert input, the Care and Engagement committees can co-opt up to two non-trustee members.

The relative responsibilities of the Board and the Executive are formalised in the Association's Scheme of Delegated Authority. A parallel Scheme of Financial Delegation sets out spending authority which is delegated to the Executive or remains the responsibility of the Board. The Chief Executive and senior management team attend meetings of the Board of Trustees and the relevant committees/advisory panels.

During 2016, a Clinical Advisory Board (CAB) was established with extensive external membership offering specialist clinical expertise. The CAB is chaired by a consultant neurologist and covers a range of areas, which includes identifying opportunities for the development and implementation of best practice guidelines in clinical care, advice on the development of education programmes for HSCPs and assisting the Association to develop a vision and associated strategy for care for the next five to ten years. The CAB provides advice to the Senior Management Team on clinical issues relating to motor neurone disease, which in turn informs decision making at the Care Committee.

### **Additional external partnerships**

The Association is involved with a variety of external partnerships to work collaboratively and in consultation over a number of cross organisational areas. These include, but are not restricted to, the End of Life Coalition, the Neurological Alliance, the Association of Medical Research Charities and The National Council for Volunteering Organisations.

### **Branches, groups and affiliates**

At 31 December 2018, the Association had 89 branches and groups and two affiliates (based in Jersey and the Isle of Man). Each branch and group sign a charter annually called *Agreement for working together*, which sets out the parameters of the powers delegated to them by the Board. Branches and groups, whose financial results are included in these statements, are governed by the Board. The two affiliates are excluded from the consolidation as they are not part of the Association. Branches and groups provide unique support to people affected by MND at local level and also fundraise and campaign on their behalf. They raise and spend money locally, in line with guidelines

which are reviewed annually by a group in which volunteers are in the majority. Association staff support them by providing advice and guidance on recruitment and support of volunteers and local structure, organisation and management of their activities.

#### Environmental impact

The Association initiates and monitors changes to process and practice that reduce its environmental impact. An example of this is its choice of fleet vehicles, where the vehicles must be fit for purpose, cost effective and have excellent environmental credentials. Money saved through environmental efficiencies can be diverted into achieving the charity's strategic objectives.

#### Management

The Board takes responsibility for governance and strategy and mandates the Chief Executive and the Senior Management Team to conduct operational management within clearly defined policies. A robust and formal reporting structure together with the attendance of the Chief Executive and Senior Management Team at Board of Trustees and board committee meetings helps to ensure that appropriate checks and balances are maintained.

The Chief Executive and Senior Management Team report in writing to the Board and these reports are scrutinised and discussed by trustees at their meetings. The Chief Executive provides a written overview of performance against agreed priorities to each meeting of the Board. The Board uses a range of information and key performance indicators and the risk register to measure the degree of success achieved by the Association in meeting its aims and objectives.

#### Safeguarding and whistleblowing

The MND Association is committed to meeting the needs of people living with MND, their families and carers. For that reason, we have specific safeguarding and whistleblowing policies and procedures for our staff and volunteers to follow, as well as a safeguarding board. This ensures everyone is safeguarded and treated properly, in accordance with our values. This means that concerns can be raised confidentially, we take any evidence of malpractice very seriously and support anyone in raising genuinely held concerns. We regularly review these policies and they are backed up by mandatory staff and volunteer training. Our Board of Trustees regularly review our risk in relation to safeguarding issues and we implement actions as required.

#### Grants

Grants are awarded for both research projects and care services:

**Research** – We award project and programme grants, PhD studentships and clinical research fellowships.

Application and decision-making processes, including comprehensive peer review, are published on the Association's website. These processes conclude with formal approval or rejection of applications by the Board.

**Care** – We provide grants to existing and new specialist MND Care Centres and Networks. At 31 December 2018 the Association was providing financial support to 22 such centres and networks. Once a potential site for a new Care Centre has been identified, a formal application is made to the Association. Each application is subject to a rigorous process of audit against the *Transforming MND Care* audit tool and other criteria. Applications are referred for review and recommendation to the Care Committee and then presented to the Board for final approval or otherwise. Performance is monitored annually for existing Care Centres, with a full grant renewal process every four years.

### Investment policy

Investments are held to cover reserves for the management of risk and for future investment opportunities. The investment objective is to provide resources to cover short term demands arising from sudden or unexpected events that could influence fundraising income. The trustees take a prudent approach to risk, holding the Association's investments in cash deposits, near cash and general recognised cash equivalents (including but not limited to Certificates of Deposit and other short-term investments). Counter party limits and acceptable credit ratings are set by the Finance and Audit Committee. Any investment donated to the Association will ordinarily be sold at the earliest opportunity, unless there is a specific request from the donor for the shares to be held as fixed asset investments.

### Group reserves policy

The trustees have adopted a robust and flexible reserves policy to meet the changing needs of the charity. This states that the general reserve should be in the range of four to six months' general expenditure represented in cash and readily realisable investments, held centrally and within branches.

## Statement of Trustees' Responsibilities and Corporate Governance

Trustees, who are also directors of the Association for the purposes of company law, are responsible for preparing the *Trustees' Report* and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group and of the incoming resources and application of resources, including the income and expenditure, of the charitable group 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 judgments and accounting 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
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in operation.

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company and the group's transactions and disclose with reasonable accuracy at any time the financial position of the charitable group and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the charitable company's constitution. They are also responsible for safeguarding the assets of the charitable company and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable group's website. Legislation in the United Kingdom

governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

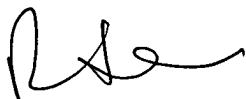
So far as each of the trustees is aware at the time the report is approved:

- there is no relevant audit information of which the company and the group's auditors are unaware, and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

#### Re-appointment of auditors

The appointment of auditors is reviewed annually with Haysmacintyre LLP having indicated its willingness to be reappointed as statutory auditor and as such a resolution of reappointment will be proposed for consideration at the Annual General Meeting of members convened for 13 July 2019.

This *Trustees' Report*, prepared in accordance with the Charities Act 2011 and the Companies Act 2006 was approved by the Board of Trustees on XX including in their capacity as company directors, the strategic report contained therein, and signed on its behalf by:



Richard Coleman  
Chair, Board of Trustees

XX 18<sup>th</sup> May, 2019

## Organisational information and financial statements

#### President

Professor Sir Colin Blakemore FMedSci HonFRCP HonFRSM HonFRSB FRS

#### Board of Trustees

Chair: Alun Owen (*until July 2018*)

Chair: Richard Coleman (*from July 2018*)

Vice Chair: Charlotte Layton (*until July 2018*)

Vice Chair: Janet Warren (*from July 2018*)

Honorary Treasurer: Tim Kidd

Emma Adams

Wendy Balmain

Susan Edwards

Alan Graham MBE (*from July 2018*)

Charlotte Layton

Lindsey Lonsborough (*until July 2018*)

Janis Parks (*until April 2019*)

Steve Parry-Hearn (*until November 2018*)

Siobhán Rooney

Dr Peter Scott-Morgan (*from July 2018*)

Dr Nikhil Sharma

Dr Heather Smith  
Katy Styles

**Senior management team**

Sally Light, Chief Executive  
Linda Allen, Director of Fundraising  
Dr Brian Dickie, Director of Research Development  
Neil Fray, Director of Finance (*from 22 January, 2018*)  
Nick Goldup, Director of Care Improvement  
Chris James, Director of External Affairs  
David Oldham, Interim Director of Finance (*from 8 July 2017 to 22 January 2018*)  
Chris Wade, Director of Engagement

**Secretary**

Jo Darby

**Registered office**

David Niven House  
10-15 Notre Dame Mews  
Northampton  
NN1 2BG

**Professional advisers**

**Statutory auditors**

Haysmacintyre LLP  
10 Queen Street Place  
London  
EC4R 1AG

**Solicitors**

Bates, Wells and Braithwaite London LLP  
2-6 Cannon Street  
London  
EC4M 6YH

**Bankers**

Lloyds Bank plc  
Public and Community Sector  
3rd Floor  
25 Gresham Street  
London  
EC2V 7HN

Barclays Bank plc  
4 Waterside Way  
The Lakes  
Northampton  
NN4 7XD

# Independent auditor's report to the members of Motor Neurone Disease Association

## **Opinion**

We have audited the financial statements of Motor Neurone Disease Association for the year ended 31 December 2018 which comprise the Consolidated Statement of Financial Activities, the Group and Charity Balance Sheets, the Statement of Cash Flows, and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 December 2018 and of the group's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

## **Basis for opinion**

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

## **Responsibilities of trustees for the financial statements**

As explained more fully in the trustees' responsibilities statement set out on page 30, the trustees, who are also the directors of the charitable company for the purposes of company law, are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the group's and the parent charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group or the parent charitable company or to cease operations, or have no realistic alternative but to do so.

## **Auditor's responsibilities for the audit of the financial statements**

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered

material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

#### **Conclusions relating to going concern**

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

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

#### **Other information**

The trustees are responsible for the other information. The other information comprises the information included in the Trustees' Annual Report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

#### **Opinions on other matters prescribed by the Companies Act 2006**

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

- the information given in the Trustees' Annual Report (which includes the strategic report and the directors' report prepared for the purposes of company law) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the strategic report and the directors' report included within the Trustees' Annual Report have been prepared in accordance with applicable legal requirements.

#### **Matters on which we are required to report by exception**

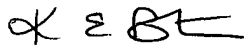
In the light of the knowledge and understanding of the group and the parent charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Annual Report (which incorporates the strategic report and the directors' report).

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept by the parent charitable company, or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

#### **Use of our report**

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an Auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Kathryn Burton (Senior Statutory Auditor)  
 10 Queen Street Place  
 For and on behalf of Haysmacintyre LLP,  
 Statutory Auditors  
 London  
 EC4R 1AG

20th May 2019

# Motor Neurone Disease Association

Charity No. 294354

Company No. 02007023

## Consolidated Statement of Financial Activities (incorporating an income and expenditure account)

For the year ended 31 December 2018

	Notes	Unrestricted Funds £000	Restricted Funds £000	Total Funds 2018 £000	Total Funds 2017 £000
<b>Income and endowments from:</b>					
Donations and legacies:	1a				
Donations		8,201	3,692	11,893	12,774
Legacies		3,932	1,264	5,196	4,856
Charitable activities		-	-	-	-
Other trading activities	1b	1,444	-	1,444	1,230
Investments	1c	166	-	166	155
Other	1d	45	-	45	(60)
<b>Total income</b>		<b>13,788</b>	<b>4,956</b>	<b>18,744</b>	<b>18,955</b>
<b>Expenditure on:</b>					
Raising funds		3,961	-	3,961	3,898
Charitable activities:					
Care		5,944	1,636	7,580	7,151
Research		612	3,189	3,801	4,728
Campaigning and raising awareness		2,087	14	2,101	2,110
Volunteer development		1,191	30	1,221	1,262
<b>Total expenditure</b>	4	<b>13,795</b>	<b>4,869</b>	<b>18,664</b>	<b>19,149</b>
<b>Net (loss)/ gain on investments</b>	12b	<b>(20)</b>	<b>-</b>	<b>(20)</b>	<b>16</b>
<b>Net income/ (expenditure)</b>		<b>(27)</b>	<b>87</b>	<b>60</b>	<b>(178)</b>
<b>Net movement in funds</b>		<b>(27)</b>	<b>87</b>	<b>60</b>	<b>(178)</b>
<b>Reconciliation of funds:</b>					
Total funds brought forward		8,524	1,677	10,201	10,379
<b>Total funds carried forward</b>	18a, 19	<b>8,497</b>	<b>1,764</b>	<b>10,261</b>	<b>10,201</b>

All movements on reserves and recognised gains and losses are shown above, and all activities are continuing.

The movement on restricted funds is shown in note 18a.

# Motor Neurone Disease Association

Charity No. 294354  
Company No. 02007023

## Balance Sheet As at 31 December 2018

	Notes	Group		Charity	
		2018 £000	2017 £000	2018 £000	2017 £000
<b>Fixed assets</b>					
Intangible assets	11	16	26	16	26
Tangible assets	11	294	266	294	266
Investments	12b	-	2,282	-	2,282
		<u>310</u>	<u>2,574</u>	<u>310</u>	<u>2,574</u>
<b>Current assets</b>					
Stocks	13	33	31	-	-
Debtors	14	4,780	4,371	4,744	4,408
Investments	15	11,126	10,528	11,126	10,528
Cash at bank and in hand		8,366	7,976	8,283	7,884
		<u>24,305</u>	<u>22,906</u>	<u>24,153</u>	<u>22,820</u>
<b>Creditors: amounts falling due within one year</b>	16a	11,092	10,539	11,040	10,496
<b>Net current assets</b>		<u>13,213</u>	<u>12,367</u>	<u>13,113</u>	<u>12,324</u>
<b>Total assets less current liabilities</b>		<b>13,523</b>	<b>14,941</b>	<b>13,423</b>	<b>14,898</b>
<b>Creditors: amounts falling due after more than one year</b>	17	3,262	4,740	3,262	4,740
<b>Net assets</b>	19	<u>10,261</u>	<u>10,201</u>	<u>10,161</u>	<u>10,158</u>
<b>Accumulated funds</b>					
Restricted funds	18a	1,764	1,677	1,764	1,677
Designated funds	18a, 18b	1,863	3,408	1,863	3,408
Unrestricted funds:					
Unrestricted funds	18a	6,591	5,073	6,534	5,073
Funds retained in subsidiary	12a	43	43	-	-
		<u>10,261</u>	<u>10,201</u>	<u>10,161</u>	<u>10,158</u>

The financial statements on pages 36 to 60 were approved and authorised for issue by the Board of Trustees on 18 May 2019, and were signed on its behalf by:



Tim Kidd  
Treasurer



Richard Coleman  
Chair

The net movement in funds for the Association for the year ending 31 December 2018 was £60,000 (2017 : £(178,000) ).

As permitted by Section 408 of the Companies Act 2006, no separate Statement of Financial Activities or Income and Expenditure account has been presented for the charity alone.

**Motor Neurone Disease Association**  
**Statement of Cash Flows**  
For the year ended 31 December 2018

	Notes	2018 £000	2017 £000
<b>Cash flows from operating activities:</b>			
Net income/ (expenditure) for the reporting year		60	(178 )
Adjustments for:			
Depreciation and amortisation charges	11	153	175
Loss/ (gain) on investments		20	(16 )
Dividends and interest from investments	1c	(166 )	(155 )
Loss on disposal of fixed assets	11	1	-
Increase in stock	13	(2 )	(3 )
(Increase)/ decrease in debtors	14	(409 )	1,091
Decrease in creditors	16a,17	(925 )	(131 )
<b>Net cash used in operating activities</b>		<b>(1,268 )</b>	<b>783</b>
<b>Cash flows from investing activities:</b>			
Cost of additions to investments	12b	(58 )	(2,092 )
Movement in cash held as investment	12b	2,000	2,000
Proceeds from sales of investments	12b	85	99
Dividends and interest from investments		166	155
Purchase of fixed assets	11	(172 )	(110 )
<b>Net cash used in investing activities</b>		<b>2,021</b>	<b>52</b>
<b>Change in cash and cash equivalents in the reporting year</b>		<b>753</b>	<b>835</b>
<b>Cash and cash equivalents at the start of the year</b>		<b>18,504</b>	<b>17,669</b>
<b>Cash and cash equivalents at the end of the year</b>		<b>19,257</b>	<b>18,504</b>

**Analysis of cash and cash equivalents**

Group	Balance 1 January 2017 £000	Cash flow changes £000	Balance 1 January 2018 £000	Cash flow changes £000	Balance 31 December 2018 £000
<b>Net cash</b>					
Short term deposits	12,065	(1,537)	10,528	339	10,867
Bank current accounts	5,601	2,368	7,969	394	8,363
Cash in hand	3	4	7	20	27
<b>Net funds</b>	<b>17,669</b>	<b>835</b>	<b>18,504</b>	<b>753</b>	<b>19,257</b>

## Motor Neurone Disease Association

### Statement of Accounting Policies

#### Legal Status

The Association is a company limited by guarantee not having a share capital, incorporated in England and Wales (company number: 02007023) and a charity registered in England and Wales (charity number: 294354). The charity's registered office address is 10-15 Notre Dame Mews, Northampton NN1 2BG. The members undertake to contribute to the assets of the company in the event of it being wound up, either whilst members or within one year of the membership ceasing. The maximum contribution required from each member is £1. There were 9,536 members at 31 December 2018 (31 December 2017: 9,277).

#### Principal accounting policies

The principal accounting policies adopted, judgements and key sources of estimation of uncertainty in the preparation of the financial statements are as follows:

##### a) 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), and the Companies Act 2006.

The Motor Neurone Disease Association 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 note(s).

##### b) Critical accounting judgements and key sources of estimation uncertainty

In the application of the accounting policies, trustees are required to make judgement, estimates, and assumptions about the carrying value of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period, or in the period of the revision and future periods if the revision affected current and future periods.

The key area that is deemed to be material for these financial statements is as follows:

Accruing for income derived from legacies is a material estimate for the Association. The key estimates include the valuation of residual estates due to the Association and assessing the probability of receipt.

##### c) Preparation of the accounts on a going concern basis

The trustees consider there are no material uncertainties about the charity's ability to continue as a going concern and regularly review potential risks making strategic changes as and when required. The review of the charity's financial position, reserves levels and future plans gives trustees confidence that the charity remains a going concern for the foreseeable future.

# Motor Neurone Disease Association

## Statement of Accounting Policies (continued)

### d) Consolidated financial statements

Consolidated financial statements have been prepared for the charity and its wholly owned subsidiary, Motor Neurone Disease (Sales) Limited. The results of this subsidiary have been included in the Consolidated Statement of Financial Activities on a line by line basis with the results of the charity.

In accordance with the exemption afforded by section 408 of the Companies Act 2006 a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared. The surplus of the parent charity was £3,000 (2017: deficit £247,000).

### e) Income

Other than income for events and conferences, income is recognised when the charity has entitlement to the funds, any performance conditions attached to the item(s) of income have been met, it is probable that the income will be received and the amount can be measured reliably.

Income for events and conferences is recognised in the Consolidated Statement of Financial Activities in the financial period when the event takes place. Income relating to events occurring in a future accounting period is deferred until the event takes place.

Income from government and other grants, whether 'capital' grants or 'revenue' grants, is recognised when the charity has entitlement to the funds, any performance conditions attached to the grants have been met, it is probable that the income will be received and the amount can be measured reliably and is not deferred.

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the charity that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material (see note 14).

### f) Investment income

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

Other investment income is recognised when receivable and the amounts can be measured reliably.

### g) Fund accounting

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charity's work or for specific projects being undertaken by the charity.

# Motor Neurone Disease Association

## Statement of Accounting Policies (continued)

### h) Expenditure and irrecoverable VAT

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Other than relevant salaries and support costs, expenditure includes under the following activity headings:

- Costs of raising funds includes cost of goods sold and cost of hosting fundraising events
- Care spend includes the costs of grants made to our Care Centre Network and to individuals
- Research spend is represented by grants made to third parties in respect of biomedical and healthcare research. Single or multi-year grants are accounted for when the trustees have agreed to pay the grant without condition
- Campaigning and raising awareness costs include the costs of advertising, promoting and lobbying to ensure that the activities of the MND Association (the 'Association') are as effective as possible
- Volunteering costs are those incurred in supporting our large network of volunteers.

Irrecoverable VAT is charged as a cost against the activity for which the expenditure was incurred.

### i) Allocation of costs incurred in respect of more than one activity

Governance and the support costs of general management, finance, payroll administration, information and communications technology, human resources and facilities provision which support the charity's activities and raising funds are all apportioned in proportion to the staff head counts. The costs of conference and event organisation are shared equally between the four areas which use these services. The allocation of governance and support costs is analysed in note 5.

### j) Operating leases

Costs in respect of operating leases are charged on a straight line basis over the lease term.

### k) Intangible fixed assets

Represents expenditure on software licences which confer the right to use software owned by a third party and are measured at cost less accumulated amortisation and any accumulated impairment losses.

Amortisation is charged so as to allocate the cost of intangibles less their residual values on a straight line basis over their estimated useful economic life at the following rates :

Software licences	4 years
-------------------	---------

### l) Tangible fixed assets

Individual assets or group of integral assets costing less than £750 are written off to the Consolidated Statement of Financial Activities as expenditure. All other equipment is capitalised at purchase price, including irrecoverable VAT, where applicable.

Equipment is depreciated on a straight line basis over its estimated useful economic life at the following rates. Depreciation is charged at half the full annual rate in the year of acquisition, and again by half in the year of disposal.

Fixtures and fittings	5 years
Computer and other equipment	2 years
Computer software	4 years

# Motor Neurone Disease Association

## Statement of Accounting Policies (continued)

### m) Investments

Investments are a form of basic financial instruments and are initially shown in the financial statements at market value. Movements in the market values of investments are shown as unrealised gains and losses in the Statement of Financial Activities.

Profits and losses on the realisation of investments are shown as realised gains and losses in the Statement of Financial Activities. Realised gains and losses on investments are calculated between sales proceeds and their opening carrying values or their purchase value if acquired subsequent to the first day of the financial year. Unrealised gains and losses are calculated as the difference between the fair value at the year end and their carrying value. Realised and unrealised investment gains and losses are combined in the Statement of Financial Activities.

Fixed asset investments comprise donated shares, which were valued at market value at the date of gift and credited as income in the Statement of Financial Activities. In line with the trustees' investment policy, donated shares are sold at the earliest opportunity unless there is a request by any donor to hold these shares as long term investments.

Shares held at the year end are carried in the balance sheet at fair value as at that date.

### n) Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

### o) Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments with a short maturity of three months or less from the date of acquisition or opening of the deposit or similar account.

### p) Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

### q) Stocks

Stocks are stated at the lower of cost and net realisable value. In general, cost is determined on a first in first out basis and includes transport and handling costs. Net realisable value is the price at which stocks can be sold in the normal course of business after allowing for the costs of realisation. Provision is made where necessary for obsolete, slow moving and defective stocks.

### r) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount.

# Motor Neurone Disease Association

## Statement of Accounting Policies

### s) Long term liabilities

FRS 102 requires long term liabilities to take into account the time value of money and liabilities have therefore been discounted back to their present value at the reporting date.

### t) Employee benefits

The Motor Neurone Disease Association contributes to a group personal pension scheme, the assets of which are administered by Standard Life. It is a *defined contribution scheme*. All contributed costs are accounted for on the basis of charging the cost of providing pensions over the period when the charity benefits from the employees' services. The charity has no further liability under the scheme.

Short term benefits including holiday pay are recognised as an expense in the period in which the service is received.

Termination benefits are accounted for on an accrual basis and in line with FRS 102.

### u) Taxation

As a registered charity, the Association benefits from being exempt from corporation tax on its charitable income.

The Association is not registered for VAT purposes. This is due to the fact that the majority of the charity's income is outside the scope of VAT, and thus to the extent that VAT is suffered on its purchases of goods and services, the Association is unable to reclaim this VAT which is allocated to the category of expenditure to which it relates.

The subsidiary company, as a trading company, is subject to corporation tax on the profits retained, after due allowance for the Gift Aid payment made to the Association. It is also registered for VAT.

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

Income			
<b>1a</b>	<b>Donations and legacies</b>		
		<b>2018</b>	<b>2017</b>
		<b>£000</b>	<b>£000</b>
	Individuals	3,819	4,282
	Community and other fundraising	3,668	4,062
	Appeals	1,365	1,284
	Charitable foundations (see note 2)	1,459	959
	Corporate donations	682	1,224
	Tax recovered	900	963
		<u>11,893</u>	<u>12,774</u>
	Legacies	5,196	4,856
		<u>17,089</u>	<u>17,630</u>

Income from legacies represents amounts received and receivable in the year where there is probability of receipt. See also note 14.

<b>1b</b>	<b>Other trading activities</b>		
		<b>2018</b>	<b>2017</b>
		<b>£000</b>	<b>£000</b>
	Charity-organised fundraising	475	309
	Merchandise sales	168	128
	Conferences and events	795	784
	Advertising	6	8
	Information leaflets	-	1
		<u>1,444</u>	<u>1,230</u>

<b>1c</b>	<b>Investments</b>		
		<b>2018</b>	<b>2017</b>
		<b>£000</b>	<b>£000</b>
	Bank interest	156	144
	Dividends	10	11
		<u>166</u>	<u>155</u>

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### Income (continued)

1d Other

	2018 £000	2017 £000
Costs recovered from the International Alliance	19	18
Research and development tax credit	-	(97)
Other	26	19
	<u>45</u>	<u>(60)</u>

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### 2 Grants receivable from Charitable foundations

During the year, the following grants of £5,000 and above were receivable:

	2018 £000
The Heaton-Ellis Trust	200
Alan Davidson Foundation	166
J P Moulton Charitable Foundation	77
Wolfson Foundation	75
My Name'S Doddie Foundation	50
The Linbury Trust	50
The Freshfield Foundation	40
OneFamily Foundation	28
Bruce Wake Charitable Trust	25
William Brake Charitable Trust	25
The Goldcrest Charitable Trust	20
London City Swim Foundation	17
Edith Murphy Foundation	15
The Enid Linder Foundation	14
Mullock Charitable Trust	12
The Elizabeth and Prince Zaiger Trust	12
Peacock Charitable Trust	11
Frank Brake Charitable Trust	10
P F Charitable Trust	10
The Eveson Charitable Trust	10
The Harebell Centenary Fund	10
The Jordan Charitable Foundation	10
The Welton Foundation	10
Lloyds Bank Foundation for England and Wales	9
The L and R Gilley Charitable Trust	9
Sylvia Aitken Charitable Trust	8
The Zochonis Charitable Trust	8
The Thomas and Rosemary Greenhalgh Charitable Trust	7
BP Foundation	6
Santander Foundation	6
The Ofenheim Charitable Trust	6
The Sir John Riblat Family Foundation	6
The Nora Milburn Charitable Trust	5
Annandale Charitable Trust	5
Chaldon Charity Trust	5
John James Bristol Foundation	5
Margaret Giffen Charitable Trust	5
Pilkington Charities Fund	5
Schroder Charity Trust	5
The 29th May 1961 Charitable Trust	5
The Berni Family Trust	5
The Billmeir Charitable Trust	5
The Biss Davies Charitable Trust	5
The D'Oyly Carte Charitable Trust	5
The Edith Lilian Harrison 2000 Foundation	5
The Florence Shute Millennium Trust	5
The Foster Wood Foundation	5
The G C Gibson Charitable Trust	5
The Inman Charity	5
The Jones 1986 Charitable Trust	5
The Kirby Laing Foundation	5
The Light Fund	5
The Oldhurst Trust	5
The Pixel Fund	5
The Simon Gibson Charitable Trust	5
The Steel Charitable Trust	5
The Swire Charitable Trust	5
Anonymous grants and other individual grants of less than £5,000	372
<b>TOTAL</b>	<b>1,459</b>

Please refer to previous year's Financial Statement for comparative figures

## Motor Neurone Disease Association

### Notes to the Consolidated Financial Statements For the year ended 31 December 2018

#### 3 Net income for the year

This arises after charging:

	2018 £000	2017 £000
Auditors' remuneration:		
External audit	23	22
Other services	4	-
Operating lease rentals:		
motor vehicles	189	185
land and buildings	130	130
other	14	17
Depreciation and amortisation of owned assets	153	175
Loss on disposal of fixed assets	1	-

#### 4 Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2018 £000	Total 2017 £000
Care and care centres	3,832	2,778	970	7,580	7,151
Research	847	2,743	211	3,801	4,728
Campaigning and raising awareness	1,587	-	514	2,101	2,110
Volunteering	898	-	323	1,221	1,262
<b>Costs of charitable activity</b>	<b>7,164</b>	<b>5,521</b>	<b>2,018</b>	<b>14,703</b>	<b>15,251</b>
Raising funds	3,148	-	813	3,961	3,898
<b>Total resources expended 2018</b>	<b>10,312</b>	<b>5,521</b>	<b>2,831</b>	<b>18,664</b>	
<b>Total resources expended 2017</b>	<b>11,367</b>	<b>5,004</b>	<b>2,778</b>		<b>19,149</b>

#### 5 Support costs

Governance and support costs are allocated to activities in proportion to the numbers employed in each area, except for the costs of conference and event provision, which are split equally between the main areas of usage, as follows:

	Care £000	Care grants £000	Research £000	Research grants £000	Campaigning and raising awareness £000	Volunteering £000	Raising funds £000	Total 2018 £000	Total 2017 £000
Management	87	4	15	2	46	27	79	260	259
Governance	61	2	10	1	32	19	56	181	207
Finance	130	5	22	2	69	41	118	387	416
Information and communications technology	250	10	42	5	132	78	227	744	748
Facilities	252	10	43	5	133	79	230	752	653
Human resources	114	4	19	2	60	36	103	338	320
Conferences and events	42	-	42	-	42	43	-	169	175
	<b>936</b>	<b>35</b>	<b>193</b>	<b>17</b>	<b>514</b>	<b>323</b>	<b>813</b>	<b>2,831</b>	<b>2,778</b>

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### 6 Grants payable

Grants were awarded during the year as follows:

	2018 £000	2017 £000
Grants to institutions	4,035	3,712
Grants to individuals	1,486	1,292
	<u>5,521</u>	<u>5,004</u>
Donations to institutions	-	1,013
	<u>5,521</u>	<u>6,017</u>

note 4

Grants made to, and for, individuals affected by motor neurone disease are for expenses such as respite care, building adaptations and equipment rental. These grants benefited a large number of individuals throughout the Association's network across England, Wales and Northern Ireland.

During the year, no charitable donations (2017: £1,012,668) were made as a contribution towards Project MinE, a major international research programme. This project is being co-ordinated from the Netherlands with in excess of 16 countries worldwide participating, with the aim of analysing the DNA of 15,000 people with MND.

	2018 £000	2017 £000
Balance at start of year	13,284	13,888
Awarded in year	5,521	6,018
Paid in year	<u>(5,984)</u>	<u>(6,622)</u>
Balance at end of year	<u>12,821</u>	<u>13,284</u>
Falling due within one year (note 16a)	9,559	8,544
Falling due after more than one year (note 17)	<u>3,262</u>	<u>4,740</u>
	<u>12,821</u>	<u>13,284</u>

### Commitments

In addition to the expenditure recognised in the accounts, the Group and Charity has outstanding commitments to fund the MND Care Centre Network. Full payment of Care Centre grants is contingent on the outcome of annual reviews and therefore only 12 months of liability has been recognised at the year end.

Group and Charity	2018 £000	2017 £000
Payable within one year	350	200
Payable in years two to five	<u>1,150</u>	<u>2,145</u>
	<u>1,500</u>	<u>2,345</u>

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### 6 Grants payable (cont.)

During the year, grants were payable to the following institutions:

	2018 £000
Kings College London	473
University of Oxford	433
University of Liverpool	290
University Of Sussex	268
University Of Sheffield	259
University of Nottingham	254
University of St Andrews	237
University of York	191
University of Bath	155
The University Hospital Wales	126
Plymouth Hospitals NHS Trust	99
Marie Curie	95
University Hospital Southampton NHS Foundation Trust	72
Cambridge University Hospitals NHS Foundation Trust	72
The James Cook University Hospital	71
Hope Hospital	71
Leeds General Infirmary	70
University of Edinburgh	68
North Bristol NHS Trust	68
Walton Centre for Neurology and Neurosurgery	64
Birmingham Neuroscience Centre	58
Barts Health NHS Trust	54
University Hospital of North Midlands NHS Trust	54
Norfolk & Norwich University Hospitals NHS Foundation trust	50
John Radcliffe Hospital	50
Belfast Health and Social Care Trust	43
Nottingham University Hospital	41
Royal Preston Hospital	40
School Of Biomedical Sciences	38
University College London	35
Newcastle General Hospital	27
Imperial College London	10
University Hospital Jena, Germany	10
Institute Of Neurology	10
Other < £10,000	79
	<b>4,035</b>

Please refer to previous year's Financial Statement for comparative figures

## Motor Neurone Disease Association

### Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

#### 7 Staff costs, the cost of key management personnel and trustee remuneration and expenses

The employment costs of all employees were:

	2018 £000	2017 £000
Gross wages and salaries	6,070	5,958
Social security costs	644	594
Other pension costs	436	413
Medical insurance	56	56
	<u>7,206</u>	<u>7,021</u>

The total number of employees whose emoluments for the period (not including pension contributions) exceeded £60,000 relates to seven of the eight members of the senior management team. These emoluments are identified as follows:

	2018	2017
£90,000 - £99,999	1	1
£80,000 - £89,999	1	-
£70,000 - £79,999	5	2
£60,000 - £69,999	-	2

Employers pension contributions for the higher paid employees above are £43,964 for the year ended 31 December 2018 (2017: £34,092).

The trustees devolved the day-to-day running of the Association to the 8 members of the senior management team, who served in the year, as identified on pages 30 and 31 of these accounts. As such, this body is identified as the key management personnel of the Association and included above are the following payments specifically to this group:

	2018 £000	2017 £000
Gross wages and salaries	549	545
Benefits-in-kind	4	12
Pension costs	44	62
Social security costs	62	42
	<u>659</u>	<u>661</u>

#### Trustee remuneration and expenses

	2018 £000	2017 £000
Reimbursement directly to trustees	18	19
Payment to third parties in respect of trustee expenses	13	19
	<u>31</u>	<u>38</u>

Number of trustees holding office during the year

17 19

The charity trustees neither received nor waived any emoluments during the year (2017: £nil). Trustee expenses in the year include travel and subsistence expenses totalling £31,401 (2017: £38,020). These expenses were all incurred in the course of their duties and were reimbursed, or paid directly to third parties on their behalf as shown above. Trustee indemnity insurance is held at a cost of £535 (2017: £521).

There were no transactions during the year between the Group and any related party

#### 8 Staff numbers

The average headcount number of employees and full-time equivalent (FTE) for the year is shown below:

	2018 headcount	2017 headcount	2018 FTE	2017 FTE
Care	67	66	62	64
Research	14	12	12	11
Campaigning and raising awareness	34	34	31	32
Volunteering	20	20	20	19
Raising funds	60	58	59	56
	<u>195</u>	<u>190</u>	<u>184</u>	<u>182</u>

Staff numbers above include an appropriate apportionment of support staff.

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### 9 Pension costs

The Association operates defined contribution personal pension schemes for employees. The assets of the schemes are held separately from those of the Association in funds independently administered by Standard Life. The amounts paid to the funds represent contributions from both the employer and employees. The employer's contributions in the year were £436,121 (2017: £412,910). There are no other ongoing obligations arising. Amounts outstanding at period end were £63,892 (2017: £64,347).

### 10 Taxation

The Association is a registered charity and is exempt from corporation tax, income tax and capital gains tax as all its income is charitable and is applied for charitable purposes.

The subsidiary company is liable for corporation tax on the profits retained. This was £nil in 2018 (2017: £nil).

### 11 Fixed assets

Group and Charity	Motor vehicles £000	Computers, fixtures, fittings and equipment £000	Total tangible fixed assets £000	Total intangible fixed assets * £000
<b>Cost</b>				
At 1 January 2018	8	624	632	47
Additions	-	172	172	-
Disposals	-	(166)	(166)	(2)
<b>At 31 December 2018</b>	<b>8</b>	<b>630</b>	<b>638</b>	<b>45</b>
<b>Depreciation and amortisation</b>				
At 1 January 2018	4	362	366	21
Charged in the year	3	141	144	9
Eliminated on disposal	-	(166)	(166)	(1)
<b>At 31 December 2018</b>	<b>7</b>	<b>337</b>	<b>344</b>	<b>29</b>
<b>Net book value</b>				
At 31 December 2018	1	293	294	16
At 31 December 2017	4	262	266	26

\* Intangible fixed assets comprises purchased software licences.

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### 12 Fixed asset investments

#### 12a Motor Neurone Disease (Sales) Limited

The Association owns a wholly owned subsidiary company, Motor Neurone Disease (Sales) Limited, which is registered in England and Wales (Company number: 01989172) at David Niven House, 10-15 Notre Dame Mews, Northampton NN1 2BG. This subsidiary operates mail order catalogues selling promotional clothing, gifts and cards and runs Challenge and other fundraising events. All taxable profits are donated to the Association each year under Gift Aid. Audited accounts are filed with the Registrar of Companies, and below is a summary of its trading results for the 12 months ended 31 December 2018:

#### Motor Neurone Disease (Sales) Limited Income Statement

	2018 £000	2017 £000
Turnover	319	305
Cost of sales	(236)	(217)
Gross profit	83	88
Administration costs	(25)	(18)
Profit before interest and tax	58	70
Net interest payable	(1)	(1)
Profit on ordinary activities before tax	57	69
Corporation tax	-	-
<b>Profit for the financial period</b>	<b>57</b>	<b>69</b>

The aggregate of the assets, liabilities and funds was:

	2018 £000	2017 £000
Assets	263	245
Liabilities	(163)	(202)
Funds (representing 2 ordinary shares of £1 each)	100	43

The investment held by the Charity of £2 (2017: £2) represents shares in the subsidiary company at cost.

The parent charity's gross income and results for the year are as follows:

	2018 £000	31 Dec 2017 £000
Gross income	18,478	18,752
Surplus/ (deficit) for the year	3	(247)

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### 12 Fixed asset investments (continued)

#### 12b Other fixed asset investments

##### Group and Charity

	Bank deposits £000	Investment portfolio £000	Total 2018 £000	Total 2017 £000
Market value at 1 January 2018	2,000	282	2,282	2,266
Additions to investments at cost	-	58	58	2,092
Disposal proceeds	(2,000)	(85)	(2,085)	(2,099)
Unrealised (loss)/ gain	-	(30)	(30)	14
Realised gain	-	10	10	2
	-	235	235	2,275
Cash held in investment portfolio	-	24	24	7
<b>Fair value at 31 December 2018</b>	-	259	259	2,282
Re-categorise as current asset	-	(259)	(259)	-
<b>Fair value at 31 December 2018</b>	-	-	-	2,282
Historical cost at 31 December 2018	-	-	-	236

### 13 Stocks

	Group		Charity	
	2018 £000	2017 £000	2018 £000	2017 £000
Purchased goods for resale	33	31	-	-

### 14 Debtors

	Group		Charity	
	2018 £000	2017 £000	2018 £000	2017 £000
Loan to subsidiary company	-	-	50	50
Amounts due from subsidiary company	-	-	39	89
Legacies	3,638	3,652	3,638	3,652
Other debtors	278	200	245	158
Income tax reclaimable	438	124	437	124
Prepayments	426	395	335	335
	4,780	4,371	4,744	4,408

The legacies debtor excludes notified legacies where measurement or probability of entitlement were not confirmed at the year end. As such, there is a contingent asset of £381,000 at the year end (2017: £381,000) for legacies notified but not recognised as income for the year.

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### 15 Current asset investments

The total of current asset investments £11,126,045 (2017: £10,527,778) is constituted by fixed term and other bank and building society deposits with maturity dates within 12 months plus other investments which will be converted to cash with 12 months of the Balance Sheet date.

### 16a Creditors: amounts falling due within one year

	Group		Charity	
	2018	2017	2018	2017
	£000	£000	£000	£000
Accruals for grants payable	9,559	8,544	9,559	8,544
Trade creditors	563	505	535	490
Accruals and deferred income (note 16b)	406	987	372	947
Finance leases	-	28	-	28
Payroll taxation and social security	152	157	152	157
Provisions and other creditors (note 21)	412	318	422	330
	<u>11,092</u>	<u>10,539</u>	<u>11,040</u>	<u>10,496</u>

### 16b Analysis of deferred income

	Group		Charity	
	2018	2017	2018	2017
	£000	£000	£000	£000
Deferred income at 1 January 2018	19	22	-	-
Released during the year	(19)	(22)	-	-
Deferred during the year	18	19	3	-
Deferred income at 31 December 2018	<u>18</u>	<u>19</u>	<u>3</u>	<u>-</u>

### 17 Creditors: amounts falling due after one year

	Group		Charity	
	2018	2017	2018	2017
	£000	£000	£000	£000
Research grants	3,262	4,740	3,262	4,740
	<u>3,262</u>	<u>4,740</u>	<u>3,262</u>	<u>4,740</u>

The future value of payments due after more than one year above is discounted using an appropriate discount rate of 1.6% (2017: 1.1%).

Research grants due as at 31 December 2018 is shown after a reduction of £125,169 (2017: £125,119) as a result of discounting the future value of payments.

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements For the year ended 31 December 2018

### 18a Statement of funds

Group and Charity	Balance at 1 January 2017 £000	Income £000	Expenditure £000	Balance at 1 January 2018 £000	Income £000	Expenditure £000	Balance at 31 December 2018 £000
<b>Unrestricted funds:</b>							
General funds	1,550	14,064	(10,498)	5,116	13,151	(11,633)	6,634
Designated funds:							
Care Centre grants	3,027	(222)	(1,081)	1,724	637	(1,292)	1,069
IBC funded projects:							
Research	941	-	(455)	486	-	(136)	350
Care	997	-	(424)	573	-	(258)	315
Campaigning and raising awareness	504	-	(119)	385	-	(330)	55
Volunteering and new opportunities	981	-	(741)	240	-	(166)	74
note 18b	6,450	(222)	(2,820)	3,408	637	(2,182)	1,863
<b>Total unrestricted funds</b>	<b>8,000</b>	<b>13,842</b>	<b>(13,318)</b>	<b>8,524</b>	<b>13,788</b>	<b>(13,815)</b>	<b>8,497</b>
<b>Restricted funds:</b>							
Research	1,045	2,967	(3,822)	190	3,177	(3,189)	178
Care	292	1,244	(1,221)	315	1,123	(1,220)	218
Volunteering	116	7	(123)	-	30	(30)	-
Branches and Groups	926	875	(629)	1,172	591	(416)	1,347
Campaigning	-	20	(20)	-	35	(14)	21
<b>Total restricted funds</b>	<b>2,379</b>	<b>5,113</b>	<b>(5,815)</b>	<b>1,677</b>	<b>4,956</b>	<b>(4,869)</b>	<b>1,764</b>
<b>Total funds</b>	<b>10,379</b>	<b>18,955</b>	<b>(19,133)</b>	<b>10,201</b>	<b>18,744</b>	<b>(18,684)</b>	<b>10,261</b>

Charity	Balance at 1 January 2017 £000	Income £000	Expenditure £000	Balance at 1 January 2018 £000	Income £000	Expenditure £000	Balance at 31 December 2018 £000
<b>Unrestricted funds:</b>							
General funds	1,507	14,064	(10,498)	5,073	13,094	(11,633)	6,534
Designated funds	6,450	(222)	(2,820)	3,408	637	(2,182)	1,863
note 18b	7,957	13,842	(13,318)	8,481	13,731	(13,815)	8,397
<b>Restricted funds</b>	<b>2,379</b>	<b>5,113</b>	<b>(5,815)</b>	<b>1,677</b>	<b>4,956</b>	<b>(4,869)</b>	<b>1,764</b>
<b>Total funds</b>	<b>10,336</b>	<b>18,955</b>	<b>(19,133)</b>	<b>10,158</b>	<b>18,687</b>	<b>(18,684)</b>	<b>10,161</b>

Included in unrestricted resources expended above is (£20,000) representing the net movement on investments

## Motor Neurone Disease Association

### Notes to the Consolidated Financial Statements For the year ended 31 December 2018

#### 18a Statement of funds (continued)

Restricted funds are utilised as follows:

Research	for grant payments to be made enabling various research projects to continue
Care	for wheelchairs, communication aids and other care equipment
Volunteering	Department of Health funding aimed at delivering choice and personalisation through a new volunteer role and also specific funding for volunteer training
Branches and Groups	for care for people with MND within local areas
Campaigning	for raising awareness of MND across England, Wales and Northern Ireland

#### 18b Designated funds

Designated funds represent:

	2018 £000	2017 £000
i) the amounts committed by the Association in respect of grants payable for the MND Care Centre Network not reflected in the Consolidated Statement of Financial Activities	1,069	1,724
ii) the trustees previously also designated the IBC monies of £7.2m together with additional reserves for the following specific activities:		
Research projects	350	486
Care	315	573
Campaigning and raising awareness	55	385
Engagement of volunteers and to fund emerging new opportunities	74	240
	<u>1,863</u>	<u>3,408</u>

#### 19 Analysis of net assets between funds

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Group:				
Fund balances at 31 December 2018 are represented by:				
Fixed assets	-	-	310	310
Net current assets less long-term liabilities	<u>1,764</u>	<u>1,863</u>	<u>6,324</u>	<u>9,951</u>
Total net assets	<u>1,764</u>	<u>1,863</u>	<u>6,634</u>	<u>10,261</u>

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2018 are represented by:				
Fixed assets	-	-	310	310
Net current assets less long-term liabilities	<u>1,764</u>	<u>1,863</u>	<u>6,224</u>	<u>9,851</u>
Total net assets	<u>1,764</u>	<u>1,863</u>	<u>6,534</u>	<u>10,161</u>

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Group:				
Fund balances at 31 December 2017 are represented by:				
Fixed assets	-	-	2,574	2,574
Net current assets less long-term liabilities	<u>1,677</u>	<u>3,408</u>	<u>2,542</u>	<u>7,627</u>
Total net assets	<u>1,677</u>	<u>3,408</u>	<u>5,116</u>	<u>10,201</u>

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2017 are represented by:				
Fixed assets	-	-	2,574	2,574
Net current assets less long-term liabilities	<u>1,677</u>	<u>3,408</u>	<u>2,499</u>	<u>7,584</u>
Total net assets	<u>1,677</u>	<u>3,408</u>	<u>5,073</u>	<u>10,158</u>

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### 20 Leasing commitments

#### a Finance leases

At 31 December the Group and Charity had the following future minimum lease payments under finance leases:

	2018 £000	2017 £000
Not later than one year	-	28
Later than one year and not later than five years	-	-
Later than five years	-	-
	<u>-</u>	<u>28</u>

#### b Operating leases

At 31 December the Group and Charity had the following future minimum lease payments under non-cancellable operating leases:

	2018 £000	2017 £000
Within one year	271	325
Between two to five years	157	359
Over five years	-	-
	<u>428</u>	<u>684</u>

The charge to the Statement of Financial Activities is £333,000 (2017: £332,000)

### 21 Provisions for liabilities and charges

Charity	Leasehold dilapidations £000	Bad debts £000	Obsolete stock £000	Total £000
At 1 January 2018	142	2	-	144
Additions	118	21	-	139
Utilised	-	-	-	-
<b>Balance at 31 December 2018</b>	<b>260</b>	<b>23</b>	<b>-</b>	<b>283</b>

Group	Leasehold dilapidations £000	Bad debts £000	Obsolete stock £000	Total £000
At 1 January 2018	142	2	17	161
Additions	118	21	12	151
Utilised	-	-	-	-
<b>Balance at 31 December 2018</b>	<b>260</b>	<b>23</b>	<b>29</b>	<b>312</b>

These amounts have been included within Provisions and other creditors in note 16a.

# Motor Neurone Disease Association

## Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

### 22 Financial instruments - assets and liabilities

Charity	2018 £000	2017 £000
Financial assets	23,818	24,767
Financial liabilities	(14,149)	(15,079)
Net financial assets measured at amortised cost	<u>9,669</u>	<u>9,688</u>

Group	2018 £000	2017 £000
Financial assets	23,846	24,763
Financial liabilities	(14,201)	(15,123)
Net financial assets measured at amortised cost	<u>9,645</u>	<u>9,640</u>

Financial assets include cash, investments, loans receivable, trade debtors, accrued income and other debtors.

Financial liabilities include deferred income, trade creditors, other creditors, grants payable and accruals.

# Motor Neurone Disease Association

Charity No. 294354

Company No. 02007023

## 23 Consolidated Statement of Financial Activities (incorporating an income and expenditure account) For the year ending 31 December 2017

	Notes	Unrestricted Funds £000	Restricted Funds £000	2017 £000
<b>Income and endowments from:</b>				
Donations and legacies:	1a			
Donations		8,216	4,558	12,774
Legacies		4,301	555	4,856
Charitable activities	1b	-	-	-
Other trading activities	1c	1,230	-	1,230
Investments	1d	155	-	155
Other	1e	(60)	-	(60)
<b>Total income</b>		<b>13,842</b>	<b>5,113</b>	<b>18,955</b>
<b>Expenditure on:</b>				
Raising funds		3,898	-	3,898
Charitable activities:				
Care		5,301	1,850	7,151
Research		906	3,822	4,728
Campaigning and raising awareness		2,090	20	2,110
Volunteer development		1,139	123	1,262
<b>Total expenditure</b>	4	<b>13,334</b>	<b>5,815</b>	<b>19,149</b>
<b>Net gains/ (losses) on investments</b>	12b	<b>16</b>	<b>-</b>	<b>16</b>
<b>Net income/(expenditure)</b>		<b>524</b>	<b>(702)</b>	<b>(178)</b>
<b>Net movement in funds</b>		<b>524</b>	<b>(702)</b>	<b>(178)</b>
<b>Reconciliation of funds:</b>				
Total funds brought forward		8,000	2,379	10,379
<b>Total funds carried forward</b>	18a, 19	<b>8,524</b>	<b>1,677</b>	<b>10,201</b>

## Motor Neurone Disease Association

### Notes to the Consolidated Financial Statements

For the year ended 31 December 2018

#### 24 Prior year figures

##### 24a Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Activities undertaken directly	Grant funding of activities (note 6)	Support costs (note 5)	Total 2017 12 months
	£000	£000	£000	£000
Care and care centres	3,826	2,373	952	7,151
Research	1,889	2,631	208	4,728
Campaigning and raising awareness	1,605	-	505	2,110
Volunteering	944	-	318	1,262
<b>Costs of charitable activity</b>	<b>8,264</b>	<b>5,004</b>	<b>1,983</b>	<b>15,251</b>
Raising funds	3,103	-	795	3,898
<b>Total resources expended 2017 (12 months)</b>	<b>11,367</b>	<b>5,004</b>	<b>2,778</b>	<b>19,149</b>

##### 24b Support costs

Governance and support costs are allocated to activities in proportion to the numbers employed in each area, except for the costs of conference and event provision, which are split equally between the main areas of usage, as follows:

	Care	Care grants	Research	Research grants	Campaigning and raising awareness	Volunteering	Raising funds	Total 2017 12 months
	£000	£000	£000	£000	£000	£000	£000	£000
Management	87	3	15	2	46	27	79	259
Governance	69	3	12	1	37	22	63	207
Finance	140	5	24	3	73	44	127	416
Information and communications technology	251	10	42	5	133	78	229	748
Facilities	219	9	37	4	116	69	199	653
Human resources	107	4	18	2	57	34	98	320
Conferences and events	44	-	44	-	43	44	-	175
	<b>917</b>	<b>34</b>	<b>192</b>	<b>17</b>	<b>505</b>	<b>318</b>	<b>795</b>	<b>2,778</b>

##### 24c Analysis of net assets between funds

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
<b>Group:</b>				
Fund balances at 31 December 2017 are represented by:				
Fixed assets	-	-	2,574	2,574
Net current assets less long-term liabilities	1,677	3,408	2,542	7,627
<b>Total net assets</b>	<b>1,677</b>	<b>3,408</b>	<b>5,116</b>	<b>10,201</b>
<b>Charity:</b>	<b>£000</b>	<b>£000</b>	<b>£000</b>	<b>£000</b>
Fund balances at 31 December 2017 are represented by:				
Fixed assets	-	-	2,574	2,574
Net current assets less long-term liabilities	1,677	3,408	2,499	7,584
<b>Total net assets</b>	<b>1,677</b>	<b>3,408</b>	<b>5,073</b>	<b>10,158</b>