







# Annual Report and Financial Statements

For the year ended 31 January 2012



# BUCKINGHAM PALACE

Last spring I visited the Euan MacDonald Centre for Motor Neurone Disease Research at the University of Edinburgh where I learnt more about the stem cell research programme funded by the MND Association, which has pulled together research expertise from Edinburgh, London and New York. The results of this programme will have a powerful impact in shaping the future of MND research and embracing future international research collaboration.

In November, I attended a lecture at Oxford University to mark the establishment of the Professorship in Motor Neuron Biology. This new MND Association-supported position is the first of its kind in the UK and will play a pivotal role in developing our understanding of MND.

The Care and Research Centres in both Oxford and Edinburgh are examples of how provision of timely, high quality multidisciplinary disease management which enables quality and quantity of life for people living with the disease now, can be married with innovative world class research, with the potential to deliver effective treatments in the future. They also serve to illustrate how dedicated people and excellent teamwork can produce outstanding results.

I congratulate the MND Association on its significant achievements in 2011 and look forward to the coming year as it continues to drive research while providing care and support for people living with MND, their families and carers.

**HRH The Princess Royal** 

## Introduction

I am proud to be part of an organisation that urges people to be 'incurable optimists'. We seek to follow the lead of people with MND in finding hope in the face of terrible adversity and turning that hope into action.

Here at the Association, our sense of optimism endures, even though 2011 put that feeling under huge pressure, with the economic downturn contributing to profoundly challenging times. Less disposable cash, the rising costs of living, and cuts to public spending – while these affect all of us, they have an impact on people with MND more than most. This means the need for our support has never been more sharply felt – and the challenges in meeting this need never greater.

The Annual Report and Financial Statements tell the story of how we have continued to rise to the challenges of MND in 2011. The Trustees are most grateful for the efforts of our generous supporters, donors and our dedicated and committed volunteers and staff – working together to deliver our twin mission areas of care and research, and to bring us further along the journey to a world free of MND.

Mark Todd

Chair – Board of Trustees

# The challenges of MND

#### Motor Neurone Disease:

- Is a fatal neurological disease that leaves people trapped in a failing body, unable to walk, talk or feed themselves
- Kills five people every day in the UK, most within two to five years, and half within 14 months of diagnosis
- · Can affect any adult at any age
- Affects 5,000 people in the UK at any one time
- Has no cure

MND affects everyone differently, and the complex and unpredictable nature of the disease, as well as its usually rapid progression, makes it a devastating diagnosis. All of this makes MND a uniquely challenging disease – for the person with MND, their family and friends, and for all of the health and social care professionals and managers who provide and make decisions on care.

#### • A challenge for people and their families

"When I was diagnosed with MND, I thought my world was about to end. How would we manage - with two young children and a hefty mortgage. Would we have to buy a bungalow? Would my wife (who also worked full time) have to be my full time carer? It took us many weeks to come to terms with being given what can only be described as a death sentence, in fact even now some six months since formal diagnosis we still find ourselves in tears at the slightest thing. However I have learnt to get anything out of life you have to remain positive, and I now feel I should treat every day as though it could be my last." – John, 44, who lives with MND

#### A challenge for science

There are still few clues as to what causes MND, though we learn more all the time. It has traditionally been hard to 'model' the disease in the lab, making it difficult to investigate why motor neurones die, or why the disease progresses in different ways and at different rates, or to develop potential treatments. Less common than other neurodegenerative diseases, such as Alzheimer's, MND receives less attention from research organisations. Interest in the disease from the academic community, though greatly increased in recent years, is hampered by lack of funds and few pharmaceutical organisations are interested in developing a treatment for MND because of the high cost relative to a low return from subsequent sales.

#### A challenge for statutory services

MND is hard to diagnose, with no definitive test, insidious symptoms at first, and a lack of awareness amongst GPs who may only see one case in their entire careers. In addition, once diagnosis is made, people with MND often find it hard to access the proactive and well co-ordinated approach needed for their care – often with the help of up to 18 different health specialisms. Because MND is not always well understood by those working in statutory services, care can be poorly-planned and badly co-ordinated, leading to a negative impact on people's quality of life, medical crises, emergency admissions and prolonged hospital stays.

# Finding solutions – the MND Association

The MND Association was founded in 1979 by a group of volunteers who had personal experience of all these challenges. Our charitable objects:

- 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 and their families and carers receive such help and assistance as is calculated to relieve their need
- To commission, undertake, promote, monitor and manage research into all aspects of motor neurone disease and its associated conditions and causes and work towards their prevention and cure and to publish and disseminate the useful results for the benefit of the public.

These objects remain unchanged, and are translated into our vision and mission:

#### Vision

A world free of MND

#### Mission

We will fund and promote research to bring about an end to MND. Until then, we will do all that we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible, and die with dignity. We will also do all that we can to support the families and carers of people with MND.

Our Strategic Framework 2009-15 is our current strategic response to the challenges outlined above, and includes seven goals that guide all of our activities. Our outcomes and key activities during the financial year 2011/12, set against these seven goals, comprise the next part of this report.

Goal 1 is how we will increase our world-class research activity

Goal 2 is how we ensure **high quality care** and support to people with MND

Goal 3 is how we support carers and family members

Goal 4 is how our volunteers and staff work together

Goal 5 is how we influence and raise awareness

Goal 6 is how we **respond to change** in the external environment

Goal 7 is how we **raise and spend the money** we need to deliver our mission

# Rising to our challenges in 2011 and 2012 – Summary

Last year both challenged us, and provided opportunities, to make progress against our goals. Factors in the external environment, combined with the current economic downturn, continued to impact both directly on people with MND and on our ability to support them to achieve the highest quality of life.

#### Closing the gap

More people with MND than at any other time in our history came to us for financial assistance in 2011, both at local and national levels. While we budgeted accordingly to meet the rising demand, we found ourselves under ever increasing pressure, and took a considered decision to draw on our cash reserves to sustain our services.

This is unsustainable beyond the short term for any organisation, so in summer 2011 we began a programme of reform of our financial support and equipment loan services. These services are accessed by health and social care professionals on behalf of people with MND, and make a huge positive difference to someone's quality of life.

The programme focused on 'pushing back' to statutory services where they have a legal responsibility to provide support or equipment – following considerable evidence that we were being used as a 'surrogate' provider, allowing NHS and social services to step back from their own duties to people in need of help.

Thanks to this action, the large overspend we anticipated in this area in mid July had not come to pass by the end of the financial year, while our new processes ensured we continued to support people with MND within the resources available. Combined with other efficiency measures including a number of staff post reductions, we have started the new financial year with a balanced budget, and a renewed commitment to income generation including new sources of revenue beyond voluntary donations.

#### **Battling against cuts**

Our volunteers and staff joined thousands of disabled people and other charities on the Hardest Hit protest march in London, while we also launched our Cuts Watch campaign to help identify and support people with MND affected by cuts to funding and services. Our involvement in such high visibility campaigns, together with ongoing lobbying and engagement with the Government, sends a clear message to decision makers: stop the unfair cuts to benefits and services for disabled people, and restore services for people with MND.

## Progress against goals

#### Taking advantage of the accelerated pace of research

As the only national charity that funds and promotes global research into MND, we have played a key role in the recent exciting progress towards a world free of MND. As the pace of research accelerates, it challenges us to ensure we remain at the forefront of fostering collaborative partnerships, funding the 'best of the best' research and disseminating new knowledge about the disease.

In 2011, Association-funded researchers discovered a rogue sequence in the gene *C9orf72* that causes up to 40% of all inherited (familial) MND cases. This gene is also associated with some non-inherited forms of the disease, opening up new avenues of research that may have relevance to all forms of MND. Collectively, researchers have now identified almost two-thirds of the cause of familial MND.

This hugely significant finding was followed by yet more exciting news early in 2012, as Association-funded researchers announced they had for the first time used stem cells derived from adult skin to generate living human motor neurones that display key characteristics of MND. These diseased neurones offer huge potential. As a uniquely realistic laboratory model of the disease ('disease in a dish') they can allow the rapid screening of thousands of drugs, as well as furthering understanding of disease mechanisms.

#### **Our Chief Executive departs**

The Association was led by chief executive Dr Kirstine Knox. In April 2012, we were sad to announce that Kirstine was stepping down after almost seven distinguished years in the role, following her husband becoming seriously ill. Under her leadership the Association developed strongly in all areas and there is no doubt her tenure had a hugely positive impact, for which we are greatly indebted.

A priority for 2012 is the recruitment of her successor. In the meantime we would like to thank Alasdair McLeish for stepping into Kirstine's role on a temporary basis and the whole of the executive team for all their hard work and leadership through this period of transition.

The remainder of the Chair's report summarises all progress made in 2011/12 against our Strategic Framework goals.

# GOAL 1: To enable people with MND to participate in research should they so wish, and realise the benefits of national and international research

We are the leader in identifying and funding cutting edge MND research both in the UK and across the world. We have invested more than £18 million in research over the past decade and at the start of 2012 were supporting more MND research projects than any other UK funding agency.

#### Chromosome 9 discovery

As mentioned above, the most significant discovery of the past year – indeed for many years – was made by Association-funded researchers, who discovered a rogue sequence in the gene *C9orf72* that causes up to 40% of all inherited MND cases. The discovery also opens up new avenues of research that may have relevance to all forms of MND. Collectively, researchers have now identified almost two-thirds of the genes responsible for familial MND.

#### Research we fund and support

In 2011/12, our overall research portfolio reached £7.9 million including a total of 56 research projects.

We also received a record number of research grant applications. As a result 12 new research grants were approved and a commitment of £1.5 million will be made over the next three years. These projects include five PhD studentships and using a new zebrafish model of MND to screen over 2,000 potential new drugs.

Our rigorous review and governance process which ensures that we only fund research of the highest merit and relevance to MND – the 'best of the best' in MND research – was recognised by a Certificate of Good Practice by the Association of Medical Research Charities (AMRC).

We also support research through making available our unique resource of DNA samples provided by people with MND. We have 3,400 samples in our DNA bank and during 2011/12, approved eight applications from researchers to make use of these samples for vital MND research.

#### Partnership working

Partnership and collaboration on national and global levels are fundamental to research progress. We forge strong collaborative links with other research funders – governmental, industrial and charitable – around the world, combining financial and intellectual resource to focus on the common goal to defeat MND. With several of our collaborative initiatives, every £1 committed by the Association helps leverage another £2-£3 in partnership funding. Examples from 2011/12 include:

- The creation of a PhD Studentship post at the University of Reading, jointly funded by the MND Association and the university. The PhD project in turn builds on a larger research study, supported by a US-based funding agency, to develop new compounds for drug testing in MND;
- A partnership with Ataxia UK for a project at the University of Oxford to study the senataxin gene, which can cause either a form of MND or a type of cerebellar ataxia, dependent on how the gene is mutated. It was logical for the organisations to cofund a comparative research study into how senataxin works in health and disease.

#### Spreading the word

MND is not constrained by national boundaries, therefore to understand the disease it is essential that researchers around the world work together. Rapid and timely exchange of new knowledge is essential to continue to drive the pace of research.

In April 2011 we began a policy of 'Open Access' on all new research grants, which ensures that whenever new scientific findings are published, they are made available to the international research community, immediately and free of charge.

We play a major role in promoting and fostering international research collaboration through a number of events and meetings. The largest and most established of these is the International Symposium on ALS/MND which is organised every year by the Association. The symposium is regarded as the premier event in the MND research calendar and is the world's largest scientific and medical conference dedicated to the disease.

We held our 22nd symposium in 2011, in Sydney, Australia, which attracted over 600 delegates from 33 countries and 84 speakers from 12 countries.

#### Professorship in Motor Neuron Biology at Oxford University

Our Royal Patron, HRH The Princess Royal attended a lecture and reception at Oxford University to mark the establishment of the Professorship of Motor Neuron Biology, held by Prof Kevin Talbot. We have co-funded the establishment of this prestigious new post, the first in the UK, which will underpin the continued development of Oxford University as a world-class centre for MND research and treatment.

#### **Developing and testing treatments**

During 2011 we were involved in a number of initiatives:

- A 12-month safety and effectiveness trial of the drug dexpramipexole, involving over 800 people living with ALS, the most common form of MND, in 11 countries. The UK part of the trial involves 60 people with MND recruited from six of our Association-funded MND Care Centres.
- A pre-clinical study of an experimental drug called Cogane, under development by the biotechnology company Phytopharm, showed some significant improvements in muscle strength and motor neurone survival in MND-affected mice, even in later stages of the disease.
- The 'LiCALs' trial of lithium carbonate, was completed in early 2012. While the drug was shown to be safe and well tolerated, it did not have a positive impact on disease progression. However, a positive outcome of the trial was that several of our Care Centres who had never previously participated in clinical trials have now developed the necessary expertise that will permit their participation in future trials.
- Ongoing studies to evaluate potential treatments for MND symptoms: diaphragm pacing to help with respiratory symptoms and gastrostomy to support good nutrition.

# GOAL 2: To empower people with MND to achieve the highest quality of life possible and to die with dignity

The rapidly progressing nature of MND demands the fast provision of care and support services. We do all we can to ensure the complex needs of those living with the disease are met quickly to enable them to achieve the highest quality of life possible.

We work hard to ensure statutory services meet their obligations to provide the support those living with MND need and are entitled to. Where these services fail to deliver we strive to fill the gap.

In 2011 we were in touch with 2,853 people living with MND. More people affected by MND turned to us for our help than at any other time in our 32-year history.

# Our services – advice, information, equipment and financial support

**MND Connect**, our support and advice service run by staff and volunteers, dealt with nearly 8,000 calls and over 4,000 emails – 41% from those living with and affected by MND and 27% from health and social care professionals. Requests for support are becoming increasingly complex, with the Connect team more frequently involved in informal advocacy and influencing statutory services.

Our accurate, professional, accessible **care information** offers a lifeline to those affected by the disease to enable them to live through their diagnosis and achieve the best possible quality of life and die with dignity. In 2011/12, we issued 50,583 items of care information, including information sheets, Personal Guides and other printed literature. Our information for people living with MND has been accredited by the Department of Health's Information Standard.

Timely access to the right equipment, and financial help to secure it, enables those living with MND to maintain independence and dignity. In 2011/12 we:

- Loaned 790 riser-recliner chairs, 466 lightwriters, 139 suction units and 632 computer assistive technology devices, and 88 other items supporting 823 people with equipment needs.
- Agreed to 957 requests for financial support, totalling £680,423, in addition to a further £581,044 worth of financial support provided at a local level by our branches and groups. This means we spent more than £1.2 million on this type of support.

Our **online forum**, launched in December 2010, goes from strength to strength. With the support of staff and volunteer moderators, the forum provides a safe place for those affected by the disease to share experiences and support each other with the challenges of living with the disease. In 2011/12, 63,231 separate visits were made to the forum by 22,386 different individuals and 1,202 people registered on the forum. The most popular topics related to progression of the disease and clinical trials.

#### Our services - MND Care Centres and networks

We provide funding to a national partnership programme of MND Care Centres and networks across England, Wales and Northern Ireland. These centres and networks bring together dedicated professionals with a wealth of experience of caring for people living with MND.

The effective co-ordination of treatment for those living with MND significantly impacts on quality of life. It also helps to avoid medical crises, emergency admission and prolonged hospital stays, ensuring the best use of health and social services resources.

In December 2011 we expanded our programme by developing South Wales Network and in February 2012 opened our 19th MND Care Centre in Bristol. We will be working with the Department of Health regarding further expansion of the programme.

#### Ensuring care at a local level - some examples

Our Northern Ireland branch is funding a dedicated nurse for palliative and respiratory care over a three year period. Our Gloucestershire Branch funded a specialist MND post which has been so successful that it is now being funded by statutory services. Sue Ryder Care (St John's) Hospice in Bedfordshire secured funding for and recruited a specialist MND Co-ordinator. This need was identified at a mapping day organised by the Association in Bedfordshire the previous year, attended by people living with MND, carers, health professionals, consultants and commissioners.

Meanwhile, our 92 volunteer-led branches and groups throughout England and Wales continued to support people in their localities providing not only financial support but also opportunities for people with MND and their carers to meet with others in a similar situation for mutual support. Our network of 400 trained volunteer Association visitors provided ongoing support to people with MND and their carers, liaising with health and social care professionals on a regular basis and often attending multi-disciplinary team MDT meetings.

#### Education

MND is still little understood within the clinical and medical communities. We continue to offer high quality education and training opportunities for current and future health and social care professionals across England, Wales and Northern Ireland to enable them to provide the best possible care for those living with the disease. In 2011:

- In partnership with the MS Society, we developed a full-day training course on neurological conditions for third year medical students at Manchester University
- In the Bristol area 30 people attended our Vocational Training Scheme (VTS) for third year General Practitioners focusing on Neurology and MND. We also launched an E-learning module for General Practitioners, which has had 155 visitors
- We worked with Marie Curie Cancer Care (MCCC) to create a seven-week online learning module for Health Care Assistants (HCAs) designed to focus on increasing the knowledge and skills of staff caring for MND patients in a variety of care settings. By the end of 2012, almost 250 MCCC and MND Association nominated staff will have taken part. Evaluation of the pilot showed 17 of 19 participants rated the course as 'excellent'
- At Northampton University, we delivered MND awareness sessions to around 125 undergraduate nurses. A session for around 50 occupational therapists raised awareness of MND and focused on emerging roles for qualified occupational therapists
- Overall, at least 1,700 professionals participated in an Association education or awareness raising event including our annual study day for health and social care professionals.

Our education and awareness raising with GPs will receive a boost from 2012 following the development of a formal partnership with the Royal College of GPs, who have made MND the main focus of a Clinical Priority Programme.

#### **Communications aids**

Greater demand for more flexible communication aids led us in 2011 to commission a Communication Aids Review. This took into account the responsibilities of the statutory sector, the need to ensure these responsibilities are met and the most cost effective solutions in the current challenging economic environment. The project included a think-tank of experts and a user group of people living with MND.

One outcome has been the development of our MND Augmentative and Alternative Communication (AAC) Care Pathway and Guidelines for speech and language therapists.

We are confident that from 2012 we will provide an improved service, supporting the communication needs of those living with MND in a way that is timely, appropriate and of a high quality.

#### Wheelchairs

Founded in response to unacceptable challenges in access to NHS wheelchairs, our David Carleton Paget (DCP) Wheelchair Service operates from our MND Care Centre in Oxford. In 2011/12 the service spent £170,592, purchasing 47 new wheelchairs and supplying 233 wheelchairs. Over the year their support benefitted 300 people with MND.

We recently secured a three year grant of £500,000 from the Department of Health's Innovation, Excellence & Strategic Development Fund. The grant will be used to expand the geographical coverage of the MND Association's wheelchair service into the London region and the North East, as a 'qualified provider' under the Department's 'Any Qualified Provider' policy.

#### Standards of care

Care that meets agreed quality standards is vital if people with MND are to achieve the highest quality of life. In addition, when the right care management is in place it costs less to the tax payer, through reduced emergency admissions. The reality is that standards of care are still dependent on where people live. We continue to develop and influence standards of care on a national and local level.

For example, in 2011 we successfully campaigned to improve standards of care and awareness of MND at the Norfolk and Norwich University Hospital. We were contacted by a person who had lost a family member to MND and believed poor care had been received in the hospital at the end of life. The evidence was used to highlight concerns and as a result we have run awareness/training sessions at the hospital, including senior nurse training.

In Leicestershire, at the request of the Primary Care Trust, the local MND team, including Association representatives, developed a MND service specification for care homes and care agencies. Any agencies or care homes wishing to tender for contracts to deliver services to people with MND are required to fulfil the criteria outlined in the specifications.

#### Listening to people with MND

We believe our services, plans and activities for people with MND and affected by MND will be most successful if we involve these people in helping us design them. 2011/12 saw an increase in our 'user involvement' activity, including:

- Surveys gathering the views of people with MND, carers, and our broader membership on a variety of subjects from satisfaction with our care services, to what people thought should be our priorities for action in the next six years
- An independent qualitative research study asking people with MND their views on issues related to death and dying. The results are due to be published during 2012
- People with and affected by MND reviewed and made comments on drafts of a number of information products, from our new Carer's Pack, to information sheets on benefits and work. Over the course of the year this activity developed from three people who commented on our DLA application leaflet, to 15 reviewers of our revised information sheet on motoring. One member of the user reviewers' group told us: "It's so refreshing to see the initial proof followed by a version which has been significantly amended on account of feedback which has clearly been absorbed. All too often organisations consult but don't listen."

#### GOAL 3: To ensure the families and carers of people with MND have the opportunity to access support and information which enables them to have as high a quality life as possible.

The majority of care for those living with MND is provided by family members who often receive little or no support during the most challenging time of their lives. The effects of the disease can leave carers feeling emotionally and socially isolated. We know that carers are vital to people with MND and we strive to provide them with the best possible support.

#### Carers' strategy

We recognise that the needs of carers are often overlooked, which is why in 2011 we developed our first ever Carers' Strategy. The strategy will be implemented from 2012 and will focus on four strategic objectives:

- Raise the profile and promote recognition of carers of people with MND
- Provide information and opportunities to access training specifically aimed at carers to enable greater choice and control

- Build on the range and quality of support available to carers
- Campaign and influence Government and statutory services about the impact of caring for someone with MND.

#### Carers' pack

In December 2011 we launched our first carers' pack, Caring and MND: support for you. Research and development of the pack was shaped by the views of many carers including those who completed our 2011 Carers' Survey.

The pack provides a wealth of guidance and support for those caring for someone living with MND. It also provides our Association visitors (AVs) and staff with detailed information to help them assist those in a caring role.

In the first month we distributed 1,053 packs. In 2012 we will be creating a web resource for carers and a compact summary version of the pack.

#### **Online forum**

In 2011 we developed a dedicated area on our online forum for those who are caring, or have cared, for someone living with MND to share experiences and offer practical and emotional support. By 31 January 2012 there had been 6,274 views of the forum's Carers area homepage.

#### Improving knowledge and skills - the 'managing early' course

We ran this six-week course in partnership with St Peter's Hospice and Dorothy House Hospice Care in the Bath and Bristol region. The aim was to improve the knowledge and skills of people with MND and their carers, enabling them to better manage their condition and maximise their physical, psychological, social and emotional health. The course was attended by eight people and resulted in an increased knowledge about local services and improved knowledge of MND and its progression.

#### GOAL 4: To ensure the Association's staff and volunteers are working seamlessly to more effectively serve people with MND, their families and carers

The Association understands that we make the biggest difference for people with MND when we combine the efforts of our 3,000 active volunteers with those of our 140 paid staff members. Volunteers are the lifeblood of the Association – working with staff to fundraise, influence, raise awareness and provide direct support including information and financial help within their local areas. A number of volunteers also support our nationally co-ordinated activities, including campaigning, information production and as trustees overseeing the governance of the Association. The annual contribution of our volunteers in economic terms is estimated at £4.9 million.

#### Award winning volunteers

The exceptional commitment of our volunteers was recognised during 2011/12 with awards and honours for individuals who have dedicated themselves to supporting people affected by MND:

- Audrey Beall received an MBE for service with the East Dorset and New Forest Branch
- Alan Graham, former chairman of the Association, also received an MBE to recognise his contribution to the voluntary sector
- Andrew Norton of the Cambridgeshire Branch was recognised by Peterborough Council for his continued fundraising efforts
- Julia Franklin received a Community Heroes Award for fundraising from BBC Sussex and Surrey
- In May 2011 Olga Camm was awarded the Unsung Hero award at the age of 92 by Lancashire County Council for 25 years continued service with the Blackpool, Wyre and Fylde Branch. Sadly, Olga passed away in June 2012.

#### Embracing new technology

Digital media continues to dramatically change the way we communicate with people with MND and their families, and communication between staff and volunteers. Our staff work closely with volunteers to provide them with guidance and support to make best use of these channels. By the end of 2011/12, 13 branches and groups were using facebook, and two thirds had a website. By the end of 2012, we anticipate all branches and groups will have their own websites or web pages.

#### Association visitors (AVs)

Our trained, specialist volunteers provide essential front-line support for people with MND and their families, including providing emotional support, practical advice and information about the disease and the Association and signposting and informal advocacy. During 2011/12 the number of trained AVs topped 400 for the first time.

#### **Regional Discussion Forums**

Trustees and staff were once again committed to meeting volunteers face to face to improve communications and joint working. Three regional forums were held in the first half of 2011 with 33 volunteers representing 13 branches and groups accepting the opportunity to attend. The aim of the forums is to provide an opportunity for staff and trustees to meet and hear directly from representatives from our branches and groups the challenges being faced in local areas

#### Collaborative working to close the gap

The challenges of meeting the increased demands from growing numbers of people with MND for our support, coupled with the economic downturn and dramatic changes and cuts to statutory services, are shared by volunteers and staff alike. Everyone at the Association is seeking to meet this demand through raising further income, reducing costs and improving efficiency.

In Autumn 2011, we ran a series of Closing the Gap workshops with branches and groups to share our knowledge of challenges we face and tap into their great ideas and enthusiasm for helping us manage through tough times. We expect the results of this closer, collaborative working to emerge during 2012, though there are already examples of the differences made by branches and groups:

- 40 branches and groups contributed through the workshops to the development of new guidelines on financial support to people with MND, to promote equitable support to people with MND during a time of limited resources. In particular, seven branches and groups were directly involved in drafting guidance for all volunteers to use
- Examples of branches and groups being 'good neighbours' to each other, with more well-funded branches offering to help less well-off branches and groups to support people with MND, or directly helping people in those parts of England and Wales where there is no branch or group
- In South Wales, a number of branches and groups have joined forces to create the South West and South East Wales
   Planning Groups. They find ways to collaborate in providing support to people with MND, including in the Cwm Taff Local Health Board area, where there is no branch.

Meanwhile, our staff have also taken up the call to "close the gap" between the resources we have available and the rising demand for our services. The last year has been challenging with the loss of a number of staff posts across the Association and no pay award made in 2011.

We are proud that staff have continued to embrace a culture of continuous change and improvement at all levels. Work with external partners on process improvements and the use of new media have begun to deliver tangible benefits in all areas of our work. Staff have also contributed to staff groups designed to increase staff involvement in the development of the Association. Embedding a culture of flexibility and working within the context of a constantly changing external environment will be key to success as we plan for the future. We would take this opportunity to acknowledge all of the hard work by our volunteers and staff as we manage through these challenges. GOAL 5: To ensure that all our stakeholders are aware of the needs of people with MND, the Association's work on behalf of people with MND, and their role in delivering outcomes for people with MND

Getting – and keeping – MND at the top of the agenda of all those who can make a difference for people with the disease is key to the success of all of our activities.

#### Creating a powerful voice

2011/12 saw us step up our campaigning to make sure decision makers are aware of the issues affecting people with MND, and take action to ensure people with MND receive high quality services. We are working hard to create a powerful voice and empower people to campaign effectively on issues affecting people with MND nationally and locally. For example:

- In 2011/12, our supporters engaged with more politicians on MND issues than ever before in the Association's history
- In April 2011 we launched our campaigns website www.mndcampaigns.org and the MND Campaigners' Network – more than 100 people have joined
- 90 campaigners and branch and group members met with politicians at our reception events at the Houses of Parliament at Westminster and at Stormont
- More than 100 people attended Association-run campaigning workshops and sessions, empowering them with the skills and knowledge to campaign effectively on behalf of people with MND.

#### **Raising public awareness**

In November our message of 'incurable optimism' reached the House of Commons when 40 MPs and peers attended an exhibition of Patrick Joyce's paintings. Patrick set himself the challenge to paint the portraits of 100 incurable optimists before MND took away the use of his arms. Our public awareness campaign 'Patrick the Optimist' won best creative campaign at the Chartered Institute of Marketing's Marketing Excellence Awards.

Meanwhile, Alistair Banks took up the mantle to be the new face of 'incurable optimism' in 2011. His quest to fulfil a lifelong ambition of recording his own album – completed late last year – gained media coverage through interviews with Alistair on BBC Five Live and The Wright Show on TV's Five. His website **www.alistairtheoptimist.org** has had over 16,000 hits and the combined reach of editorial coverage for the campaign was over eight million people. Posters also appeared on the London Underground during MND Awareness Week in June 2011.

#### Lobbying nationally

We launched our first ever national Wales and Northern Ireland manifesto campaigns in the run up to Assembly elections in May 2011. More than 200 campaigners emailed their candidates urging them to pledge their support to MND. As a result:

- 74 Welsh Assembly candidates signed our pledge. Of these, 22 were elected, making up more than one third of the Assembly
- 40 candidates signed our pledge in Northern Ireland, of whom 11 were elected amongst the 108-strong Assembly.

In December, we joined forces with the Neurological Alliance, MS Society and Parkinson's UK to campaign for an end to the postcode lottery of care in England, following the publication of a damning National Audit Office (NAO) report on services for people with neurological conditions.

The report was written on our initiative, following an approach to the NAO, the Parliamentary watchdog on public spending. More than 1,200 campaign supporters contacted their MPs urging them to take action on the NAO report. The campaign continues. In June 2011 the All Party Parliamentary Group (APPG) on MND launched its report into access to specialist palliative care for people with MND at a reception in Parliament. Campaigners and branch and group volunteers wrote to MPs and primary care trusts urging them to implement the recommendations from the report.

Other lobbying activity:

- We responded to 26 consultation exercises by the Government and others
- The Health Secretary and Shadow Health Secretary both spoke at Association events in Parliament, and the Minister for Health spoke at our reception in Stormont. We also continued to influence positively with the Welsh Assembly.

#### GOAL 6: To ensure the Association remains focused on achieving outcomes for people with MND, whilst exploiting the opportunities for creating value that changes in the external environment can bring

Factors in the external environment continue to impact both on people with MND and on our ability to support them to achieve highest quality of life. Chief amongst these factors in 2011/12 were:

- The ongoing economic downturn, which has made fundraising more difficult
- Increasing demand for our services, caused by cuts and changes to health and social services and our own success in raising awareness of what we do
- Progress of legislation that fundamentally changes the way the NHS both commissions and delivers care.

#### 'Pushing back' on Statutory Services

The biggest challenge the Association faced during the year was how to meet the increasing demand on our services, and particularly the requests for financial assistance being made on behalf of people with MND. This rise in demand has been a trend over the past few years, and has led to us taking the considered decision in recent years to draw on our cash reserves so that we could sustain these services and not turn people away.

However, this was not a sustainable position in the longer term, as it was putting increasing pressure on both income generation and all other areas of spend such as funding care centres, supporting research and training volunteers to support people with MND.

In summer 2011 we embarked on a programme of reform of financial support and equipment loan services. This was with the aim of 'pushing back' to statutory services where they have a legal responsibility to provide support of equipment. There was considerable evidence that we were being used as a 'surrogate' provider, with health and social care professionals accessing our support rather than requesting funding as they should from local NHS or social services. This also reduced the chances of such services planning and budgeting properly for the needs of the MND population.

We commissioned guidance on statutory services responsibilities to help people affected by MND and the professionals who care for them know where to direct requests. And we developed criteria and guidance for our own financial support and equipment loan decision-making, based on knowledge of statutory services responsibilities. Our over-riding consideration was that people with MND should not be left disadvantaged, and implementation of these reforms was managed carefully.

Thanks to this action, the large overspend we anticipated in this area in mid July had not come to pass by the end of the financial year, while our new processes ensured we continued to support people with MND within the resources available to us. Combined with other efficiency measures including a number of staff post reductions, we have started the new financial year with a balanced budget, and a renewed commitment to income generation, including new sources of revenue beyond voluntary donations.

#### **Battling against cuts**

Our volunteers and staff joined thousands of disabled people and other charities on the Hardest Hit protest march in London, while we also launched our Cuts Watch campaign to help identify and support people with MND affected by cuts to funding and services. Our involvement in such high visibility campaigns, together with ongoing lobbying and engagement with the Government, sends a clear message to decision makers: stop the unfair cuts to benefits and services for disabled people, and restore services for people with MND.

# Income

#### 'Any qualified provider'

The right wheelchair can make all the difference to someone with MND. We have been awarded a Department of Health grant to expand our wheelchair service delivery model, currently based in Oxford, to help achieve national coverage. This is an example of how we can work within the new health environment to ensure quality services to people with MND, and receive statutory funding to do so, using the 'Any qualified provider' provision of the new Health and Social Care Act.

#### A leaner organisation

While we have good reason to be proud of our low running costs, compared with other charities, our recent financial challenges have caused us to look even more closely at how we can be as efficient as possible in our use of resources.

In September 2011 we embarked on a programme which resulted in us making £500,000 of savings, including losing a number of staff posts. Achieving a more balanced budget for 2012/13 resulted in further post closures. All of this requires us to find ways to do more with less.

Last summer we secured the support of Barclaycard plc to build our skills in undertaking business process re-engineering – that is, the mapping out of internal tasks and processes to understand and implement ways to improve these and eliminate waste. The pilot project, looking at income processing means we can thank people more promptly, and have the money in the bank more quickly to use for the benefit of people with MND. This work will continue in 2012.

# GOAL 7: By 2015, to generate an income of between £19 million and £20 million, of which 83% of Association expenditure is allocated to our charitable purpose.

Achieving our mission means both raising the income to fund our activities, and ensuring that this is used in ways that make the biggest difference for people with MND and those who care for them. This means on one side maintaining a broad portfolio of fundraising and income generating activities that are efficient and deliver suitable returns, and on the other, spending these donations as wisely and effectively as possible while continually finding ways to minimise our running costs.

#### Income

Overall income achieved as a result of the tremendous efforts of our volunteer and staff fundraisers in 2011/12 was £12.7 million – a 2.5% decrease on the previous year. This small decrease illustrates the challenges of securing income during times of ongoing economic uncertainty.

Traditionally, almost all of our income has come from three main sources: nationally-led fundraising; local fundraising by our 92 volunteer branches and groups; and income left in legacies. A breakdown of total income shown in the statutory accounts was as follows (with last year's figures as a comparison):

	2011/2012	2010/2011
National fundraising	£6.8 million	£6.9 million
Branches and groups	£2.2 million	£2.4 million
Legacies	£3.4 million	£3.3 million
Other income	£0.3 million	£0.4 million
Total	£12.7 million	£13.0 million

#### **National fundraising**

National fundraising accounted for more than half of total funds raised and showed a small decline year on year.

Some highlights:

- Our record number of 149 runners at the London Marathon raised £260,000.
- Our partnership with Midlands Co-operative Society raised £200,000 (for the second year in a row) the largest amount ever raised from one partnership with a company.
- Our annual raffle raised over £115,000.
- We received a £100,000 grant from the Garfield Weston Foundation to fund a three year research project using zebrafish to screen for new drugs to treat MND.
- Our Christmas appeal raised over £130,000
- Simon Adams, who died from MND in October 2011, was posthumously awarded fundraiser of the year at the 2011 Just Giving Awards, having raised over £300,000 between 2009 and the time of his death for the Association to fund research. This total continues to grow thanks to the efforts of his family and friends.

#### Local fundraising – branches and groups

Branch and group income was down 7 % on last year and our volunteers in branches and groups did well to hold up income levels as much as they did despite the economic downturn.

#### Legacies

Income from legacies shows a 6.5% increase of £210,000 to £3.4 million.

## Expenditure

Charitable expenditure, that is money directly spent for the benefit of people living with MND, was £11.9 million. This represented 81% of our total expenditure in 2011/12 compared to 79% last year.

Fundraising from national office accounted for 13% of our total spend, and for every £1 spent in this way during 2011/12 we generated **£3.60** in return.

#### Our mission - providing care

We spent £8.4 million on providing care and support. This is broadly the same as in 2010/11 despite our stronger stance of "pushing back" in non-urgent cases to statutory services where they have a legal obligation to provide support. It still represents a doubling of our spend on care over the last five years.

#### Our mission – funding research

£3.5 million of our charitable spend in 2011/12 was research related, an increase of 4.2% compared with last year. Since each research activity will normally last several years, and thanks to donors who provide funds specifically for this part of our mission, we hold over £500,000 of restricted reserves to ensure we can meet our current commitments in this critical area.

#### Future funding commitments

Much of the work we fund requires a certain level of committed funding over a number of years in order to go ahead. Our commitment to future funding for research projects, postgraduate studentships and MND care centres stood at the end of the financial year at £3.1 million.

#### Reserves

In 2011/12 we spent a total of £14.8 million against income of £12.7 million, drawing on our combined restricted and unrestricted reserves by some £1.9 million. This followed a similar draw down in 2010/11. Whilst some £0.9m of this draw down was from restricted funds, our general reserves have reduced and this is not a sustainable approach for any organisation. Unrestricted reserves now represent some five months of general expenditure.

With guidance from the Charity Finance Group, the Institute of Fundraising and the Association of Chief Executives of Voluntary Organisations (ACEVO), we have undertaken a thorough review of our income, expenditure and cash flow forecasting, and have revised our reserves policy to hold between four and six months general expenditure.

For 2012/13 we have set a balanced budget in an effort to maintain reserves. As well as efficiency and cost reduction programmes including reduced staff posts, we recognise that our current approach to income generation is unlikely to achieve the level of growth we need to meet our ambitious financial targets, and thus drive our mission activities of care and research. If we are to make the required 'step change' in our income, it is most likely to come from a changed approach where we identify and pursue new opportunities. We remain dependent on our traditional funding sources for most of our work, but the 2012/13 budget also includes targets for a range of new income-generating streams, including statutory grant funding.

#### Structure

The Association is constituted as a company limited by guarantee. Our Articles of Association are our governing documents. In the event of the Association being wound up, every member is liable for an amount not exceeding £1 to facilitate the payment of the debts and liabilities of the charity.

At time of writing, we have 7500 members.

The board of trustees comprises up to 10 elected trustees, five coopted trustees and an elected chair.

#### Trustees' responsibilities

The trustees (who are also directors of the Motor Neurone Disease 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 which 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 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 judgements and estimates that are reasonable and prudent
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and enable them to ensure that the financial statements comply with the Companies Act 2006. 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.

In so far as the trustees are aware:

- There is no relevant audit information of which the charitable company'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.

The trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charitable company's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

#### Appointment and development of trustees

Election of trustees is by postal ballot of our members and scrutinised by the Electoral Reform Society. In accordance with the Companies Act 2006, our members may also register an electronic vote, or can appoint a proxy to vote on their behalf.

Processes for recruitment and selection of trustees are regularly reviewed by the Governance Committee. The Board regards trustee induction and ongoing training and development as essential. Our principal in-house reference document, Governance Operating System Manual is a comprehensive guide to the role and responsibilities of Association trustees, governance procedures and processes, and good practice recommendations from the Charity Commission. The Board annually reviews the selection, induction and ongoing development of trustees.

The Board assesses its performance using an effectiveness audit covering processes, procedures and outcomes of Board meetings. This and the annual skills audit are being re-examined with a view to introducing a more independent and evidence-based process that further promotes individual and collective improvement and fosters best practice. Each trustee meets the Chair annually to discuss their own contribution to the board with a record of these meetings being retained.

#### How the Board operates

A number of committees and panels advise the Board on issues relevant to the aims, objectives and good governance of the Association:

- Governance Committee
- Finance Committee
- Organisational Development Committee
- Remuneration Committee
- Care Committee (established January 2012)
- Biomedical Research Advisory Panel
- Healthcare Research Advisory Panel.

The Board itself meets at least four times a year.

#### Branches and groups

At time of writing, the Association has 65 branches, 27 groups and three affiliates. Our branches and groups are run by local volunteers and operate in accordance with a charter or code of conduct drawn up by the Association.

Staff support branches and groups, providing advice and

guidance on structure, organisation and management of branch and group activities. The unique support provided by branches and groups to people with MND at a local level cannot be replicated or replaced.

Our most recent survey of branches and groups showed that two thirds of our volunteers had served for more than five years – a statistic that would be envied by many charities. The value of volunteers to people with MND and the Association is significant. During 2011/12 we estimate volunteers provided the equivalent of  $\pounds 2.7$  million worth of services, in addition to the  $\pounds 2.2$  million of income they raised.

#### Management

The Board takes responsibility for governance and strategy, and under a scheme of delegation, mandates the Chief Executive and senior managers to conduct operational management within clearly defined policies. A robust and formal reporting structure, together with the attendance of senior managers at Board and committee meetings, helps ensure appropriate checks and balances are maintained.

Senior managers 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 objectives. The Board use a range of information and indicators to measure the degree of success achieved by the Association in meetings its aims and objectives.

Performance objectives and measures are enshrined in our Strategic Framework 2009-15.

The Association is organised into eight teams:

- Chief executive's office
- External affairs
- Care (two teams one each for North and South)
- Research development
- Fundraising
- · People and organisation development
- Finance.

The Board is committed to excellence in leadership and governance. Senior managers translate this into activities which benefit people with MND, by progressing towards the achievement of long-term strategy, as set out in the Strategic Framework 2009-15.

Much of the work to develop good governance is informed by the principles contained in the Charity Commission publication CC10 – Hallmarks of an Effective Charity, and we believe our approach enables us to meet CC10's six identified hallmarks of a well run charity. Even so, we continually seek to improve and refine our governance activities and processes.

#### Grant making

We award grants in two areas:

- Research project and programme grants, PhD studentships and Clinical Research Fellowships. Our application and decision-making processes are published on our website
- Care to establish specialist MND Care Centres and enhance our Care Centre Network. The MND Association has encouraged identified centres of excellence to apply for Care Centre/Network status over the last 10 to 15 years. There are now 19 centres/networks in the programme covering England Wales and Northern Ireland. Typically, a care centre is directed by a consultant neurologist working with a care centre coordinator and a multi disciplinary team. Once a centre has been identified, a formal application is made to the MND Association. The Association employ a vigorous process of a full audit against our Standards of Care at application, and if a new application, this is followed by a site visit. The grant application is considered first by the appropriate director of care who has relationship management responsibility with the care centre. Following a satisfactory application, this is then referred through the Association's governance procedures - with the application first being considered by the Care Committee, which includes external experts in the field. If the application is approved by the Care Committee, then it is presented to the next full board of trustees meeting for formal approval (or otherwise).

#### **Risk management**

A comprehensive register of potential risks to the Association is reviewed at committee meetings and Board meetings, and reports relating to Board decisions and discussions include details of risks and where appropriate mitigation. We believe all identifiable strategic and major operational risks have been reviewed and systems established to manage and mitigate those risks.

#### **Environmental impact**

Minimising our impact on the environment reduces our carbon footprint, while ensuring money saved from improved resources management can be diverted into direct support for people with MND. We initiate and monitor changes to processes and practices that reduce our environmental impact.

#### Public benefit

We believe our 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.

# Reference and administrative details

#### President

Prof Colin Blakemore FMedSci Hon FRCP FRS

#### Trustees

Mark Todd – Chair Dr Jean Waters - Vice Chair David Gray – Honorary Treasurer, until 10 September 2011 Anne Bulford OBE - Honorary Treasurer, from 10 September 2011 Dr Christina Lloyd Peter Bickley Richard Coleman – elected 10 September 2011 Dr Juliet Draper Cynthia Hopkins Barbara Howe Alan Newton – until 10 September 2011 Sandra Osborne – appointed October 2011 Alun Owen Prof Victor Patterson Michael Ranson – appointed October 2011 Nalin Shukla – until 10 September 2011 Sandra Smith – elected 10 September 2011 Dr Hilary Walklett Prof Brian Wilson

**Chief Executive** Dr Kirstine Knox – *until April 2012* Alasdair McLeish (Acting Chief Executive)

#### Secretary

Jo Darby

#### **Registered offices**

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

#### **Professional advisers**

STATUTORY AUDITORS Sayer Vincent 8 Angel Gate City Road London EC1V 2SJ

#### INTERNAL AUDITORS RSM Tenon Limited St Matthew's House

6 Sherwood Rise Nottingham NG7 6JF

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

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

HSBC Bank plc St Clair House 5 Old Bedford Road Northampton NN4 7AA

## Finances

#### **Review of finance activities**

The charity is a company limited by guarantee and owns a trading company, Motor Neurone Disease (Sales) Ltd, which is registered in England and Wales. These financial statements are of the Group, which comprises both the charity and the trading company. 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).

#### **Neurological Commissioning Support Limited**

We are an equal partner with the Multiple Sclerosis Society and Parkinson's UK in Neurological Commissioning Support Limited (NCS). NCS provides practical support to commissioners in order to plan and deliver improved neurology services. Financial results of the NCS have not been consolidated into the Association's financial statements as the one-third share is not material, but further details, including unaudited profit and loss account and balance sheet, are included at Note 22 to the Financial Statements.

#### Branches

Our branches, whose financial results are included in these statements, are governed by the Board of Trustees. Each branch's management committee signs a branch charter each year.

There are also three offshore island organisations (Isle of Man, Jersey and Guernsey), which are affiliated, but not part of the Association and therefore their accounts are excluded from the consolidation.

#### **Fixed Assets**

Significant improvements to the Association's Fixed Assets register were made during the year, including a thorough review of those assets which had been fully depreciated but for which a balance remained in the previous year's balance sheet. As a result, fully depreciated assets originally costing £1.3 million were removed from the register and are shown as disposals in Note 11 to the Financial Statements.

#### Investment policy

The Investment Policy encompasses the trustees' dual responsibilities to optimise returns on reserves while paying due regard to the control of risk.

Our investments are restricted to cash deposits, near cash and general recognised cash equivalents (including but not limited to Certificates of Deposit and other short term paper). The minimum acceptable credit rating is A, excepting any paper or issuer on Negative Watch with any rating agency.

#### **Cash flow**

Our cash outflow exceeded inflow by £128,000 in the year. Cash reserves sit at £6.9 million at year end

#### Reserves

In setting the reserves policy, the trustees are guided by the need to ensure continuity and consistency of finance for the work of the Association and balance this with the desire to maximise progress in its care and research programmes. The trustees are also mindful of the wishes of donors and the need for transparency in reporting the financial position of the Association, and recognise that cash as opposed to non-cash assets is the basis for operational security.

Our policy historically has been to hold 6 – 9 months general expenditure in cash on a combined National Office and Branch basis. With guidance from the Charity Finance Group, the Institute of Fundraising and the Association of Chief Executives of Voluntary Organisations (ACEVO), we have undertaken a thorough review of our income streams, expenditure commitments and cash flow forecasting. On the basis of the conclusions reached, the Trustees have decided to modify the Reserves Policy:

- To hold 4-6 months general expenditure in cash on a combined National Office and Branch basis; and
- For the purposes of this policy, cash balances are calculated after deducting restricted funds.

This provides greater flexibility in managing the monetary resources of the Association and will be monitored as part of our finance governance framework.

Cash and readily realisable investments at 31 January 2012 were  $\pounds$ 6.9 million in total and  $\pounds$ 5.9 million after deducting restricted balances. This represents slightly less than six months general expenditure.

Non-cash net current assets were negative at 31 January 2012 due to the amount of research grant commitments, which total over £4 million, but trustees do not believe this hampers the work of the Association or causes any significant financial risk.

The Association holds restricted funds for a number of purposes, including biomedical research and the support of care development activities. During the year to 31 January 2012, expenditure on several research projects utilised restricted funds which had been provided in the previous year, resulting in a reduction in the balance of restricted funds held at the year end. Details of restricted funds are contained in note 18 to the financial statements.

#### **Re-appointment of auditors**

A resolution to re-appoint Sayer Vincent as our auditors will be proposed at the Annual General Meeting.

Mark Todd Chair, Board of Trustees 21 July 2012

# Independent auditors' report to the members and trustees of Motor Neurone Disease Association

We have audited the financial statements of Motor Neurone Disease Association for the year ended 31 January 2012 which comprise the consolidated statement of financial activities, the group and charity balance sheets, the consolidated cashflow statement, accounting policies and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the company's members as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and section 144 of the Charities Act 2011 and regulations made under section 154 of that Act. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditors' 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 company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.

#### Respective responsibilities of trustees and auditors

As explained more fully in the statement of trustees' responsibilities set out in the trustees' report, 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.

We have been appointed auditor under the Companies Act 2006 and section 151 of the Charities Act 2011 and report in accordance with those Acts. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's Ethical Standards for Auditors.

#### Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the charitable company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the trustees' report to identify material inconsistencies with the audited financial statements. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

#### **Opinion on financial statements**

In our opinion the financial statements:

- give a true and fair view of the state of the group's and the parent charitable company's affairs as at 31 January 2012, and of the group's incoming resources and application of resources, including its 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 and the Charities Act 2011.

# Opinion on other matters prescribed by the Companies Act 2006

In our opinion the information given in the trustees' report for the financial year for which the financial statements are prepared is consistent with the financial statements.

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

We have nothing to report in respect of the following matters where the Companies Act 2006 and the Charities Act 2011 requires us to report to you if, in our opinion:

- the parent charitable company has not kept adequate and sufficient accounting records, 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.

Helen Stat

Helen Elliott (Senior statutory auditor) 24 July 2012 for and on behalf of Sayer Vincent, Statutory Auditors, 8 Angel Gate, City Road, LONDON EC1V 2SJ

Sayer Vincent is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

## Consolidated Statement of Financial Activities

(incorporating an income and expenditure account)

For the year ended 31 January 2012

				Tota	l Funds
		Unrestricted	Restricted		
	Notes	Funds	Funds	2012	2011
		£	£	£	ł
Incoming resources					
Incoming resources from generated funds:					
Voluntary income:					
Donations & gifts	1a	5,413,802	2,414,905	7,828,707	8,427,989
Legacies		3,125,938	336,313	3,462,251	3,252,288
Sub total: Voluntary income		8,539,740	2,751,218	11,290,958	11,680,277
Activities for generating funds:					
Merchandising income		121,814	-	121,814	137,224
Fundraising		920,587	49,105	969,692	835,280
Investment income:					
Interest receivable		35,828	-	35,828	27,568
Incoming resources from charitable activities:					
Conference income		279,947	-	279,947	340,773
Information leaflets		1,849	-	1,849	8,194
Net gain on disposal of fixed assets		500	-	500	
Other income	1b	14,677	-	14,677	14,670
Total incoming resources		9,914,942	2,800,323	12,715,265	13,043,986
December of the					
Resources expended					
Costs of generating funds:		2 405 01 4		2 405 04 4	2 0 2 4 2 0
Fundraising costs		2,485,814	-	2,485,814	2,824,200
Merchandising and fundraising events		318,332	-	318,332	396,788
Sub total: Cost of generating funds		2,804,146	-	2,804,146	3,220,988
Charitable activities:					
Care and Research grants		1,443,549	2,692,021	4,135,570	4,402,086
Care development		4,508,013	953,779	5,461,792	5,168,963
Research development		788,080	284,400	1,072,480	860,702
Volunteer development		1,134,371	-	1,134,371	1,322,689
Governance costs		127,730	-	127,730	107,309
Sub total: Direct charitable expenditure		8,001,743	3,930,200	11,931,943	11,861,749
Total resources expended	5	10,805,889	3,930,200	14,736,089	15,082,73
Net outgoing resources before other					
recognised gains and losses		(890,947)	(1,129,877)	(2,020,824)	(2,038,751
Realised gains on investment assets	15	100,188	-	100,188	
Net expenditure for the year	3	(790,759)	(1,129,877)	(1,920,636)	(2,038,751
Unrealised gains/(losses) on investment assets	15	(2,132)	-	(2,132)	72,278
Net movement in funds		(792,891)	(1,129,877)	(1,922,768)	(1,966,473
Reconciliation of funds					
Fund balances brought forward at 1 February 2011		5,094,508	2,119,067	7,213,575	9,180,04
Fund balances carried forward at 31 January 2012		4,301,617	989,190	5,290,807	7,213,575

All movement on reserves and recognised gains and losses are shown above, and all activities are continuing. The movement on restricted funds is shown in note 18.

# FINANCIAL STATEMENTS

### **Balance Sheets**

As at 31 January 2012

			Group	(	Charity
	Notes	2012	2011	2012	2011
		£	£	£	£
Fixed assets					
Tangible fixed assets	11	326,332	523,802	326,332	523,802
Investments	12	-	-	2	2
		326,332	523,802	326,334	523,804
Current assets					
Stocks	13	16,542	10,298	-	-
Debtors and prepayments	13	3,347,776	3,291,346	3,338,927	3,375,660
Investments	15	23,560	1,592,183	23,560	1,592,183
Short term deposits	10	3,012,075	2,622,675	3,012,075	2,622,675
Bank deposits		3,878,986	4,394,504	3,811,962	4,240,778
Cash in hand		734	2,860	734	2,860
		10,279,673	11,913,866	10,187,258	11,834,156
Creditors:					
amounts falling due within one year	16	5,229,574	5,054,937	5,180,566	5,018,634
Net current assets		5,050,099	6,858,929	5,006,692	6,815,522
Total assets less current liabilities		5,376,431	7,382,731	5,333,026	7,339,326
Creditors:					
amounts falling due after more than one year	17	85,624	169,156	85,624	169,156
Net assets	19	5,290,807	7,213,575	5,247,402	7,170,170
Accumulated funds					
Restricted funds	18	989,190	2,119,067	989,190	2,119,067
Unrestricted funds:					
Unrestricted funds		4,258,212	5,051,103	4,258,212	5,051,103
Funds retained in subsidiary		43,405	43,405	-	-
		5,290,807	7,213,575	5,247,402	7,170,170

The financial statements on pages 19 to 35 were approved by the Board of Trustees on 21 July 2012, and were signed on its behalf by:

Derfulfad

Anne Bulford OBE Honorary Treasurer 21 July 2012

## Consolidated Cashflow Statement

For the year ended 31 January 2012

2012	2011
£	£

Reconciliation of changes in resources to net cash inflow from operating activities

Group:		
Net (expenditure)	(2,020,824)	(2,038,751)
Depreciation charged	321,088	339,776
Gain on sale of fixed assets	(500)	-
Income from bank interest	(35,828)	(27,568)
(Increase) in stock	(6,244)	(5,096)
(Increase)/Decrease in debtors	(56,430)	482,388
Increase in creditors	91,105	735,578
Net cash outflow from operating activities	(1,707,633)	(513,673)
Returns on investments and servicing of finance		
Income from bank interest	35,828	27,568
Proceeds from sale of investments	1,666,679	-
Net cash inflow from returns on investments and		
servicing of finance	1,702,507	27,568
Capital expenditure and financial investment		
Purchase of tangible fixed assets	(123,618)	(308,859)
Proceeds from disposals	500	-
Net cash outflow from investing activities	(123,118)	(308,859)
(Decrease) in cash in the period (note 20)	(128,244)	(794,964)

# STATEMENT OF ACCOUNTING POLICIES

#### Principal accounting policy

The financial statements have been prepared in accordance with applicable Accounting Standards in the United Kingdom and in accordance with the Statement of Recommended Practice – Accounting and Reporting by Charities (revised March 2005), and the Companies Act 2006.

#### **Basis of accounting**

The financial statements are prepared in accordance with the historical cost convention, as modified by the revaluation of investments.

#### **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 Companies Act 2006, a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared.

The Association is one of three parties in the Neurological Commissioning Support (NCS) joint venture and as such, is able to include one third of NCS's assets and liabilities in its accounts. The financial information for NCS is disclosed in note 22 to the financial statements, but one third of the assets and liabilities is not material to the Association so it has not been consolidated.

#### **Branch operations**

The charity comprises the national office and an extensive network of Branches and Groups located in England, Wales and Northern Ireland. All Branch, Group and national office financial information is consolidated using conventional accounting standards.

The charity monitors Branch operations through the Branch Charter and the guidelines set by the Trustees.

#### Legacy Income

Income from legacies is accounted for on a receivable, rather than cash received, basis so long as entitlement, certainty of receipt and measurability conditions have been satisfied. In some cases, therefore, legacy income is recognised significantly ahead of cash receipt.

#### Recognition of income and expenditure

Income from all sources other than events and conferences is credited to the Consolidated Statement of Financial Activities when receivable. Expenditure is accounted for on an accruals basis.

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 receivable to which a specific purpose has been defined by the donor is included in restricted funds. Expenditure which meets the defined purpose of the donation is matched to the income and charged to that restricted fund.

General donations and income derived for the objectives of the Association, and on which there are no restrictions as to their disposition, are recorded as unrestricted funds.

#### **Capital grants**

Grants for the purchase of fixed assets are credited as income to the restricted fund when receivable.

When the fixed asset itself is subsequently purchased with these grants, it is capitalised and depreciated in accordance with the policy on page 23, and the depreciation is charged against the restricted fund.

#### Investments

Current asset investments at the year end comprise donated shares, which are 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. Shares held at the year end are carried in the balance sheet at market value at that date.

#### **Contributions to pension funds**

The charity operates a group personal pension plan scheme for its employees. Contributions are charged to the Consolidated Statement of Financial Activities in the period to which they relate.

#### Grants payable

Although the Board of Trustees approve the whole life cost of each grant, the Consolidated Statement of Financial Activities includes a grants payable figure for the year in hand, which represents the approved amount, following a review of progress on each project and agreement with the grant recipient.

# STATEMENT OF ACCOUNTING POLICIES

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

Support costs are allocated to activities on the basis of the number of staff involved in the activities. Support costs are the costs of general management, accounting and budgeting, payroll administration, information and communications technology, human resources and facilities provision. Allocations are made across the charitable activities of care and research grant making, care development, research development and volunteer development and also to costs of generating funds and governance.

Certain other costs are incurred in respect of more than one activity. Where the costs, primarily staff employment costs, travel and associated expenses, cannot be directly attributed to a single activity, they are allocated on the basis of the number of staff and time involved across the activities of care development, research development, care and research grant activity, volunteer development, costs of generating funds, and governance.

Costs of generating funds comprise the costs incurred in producing materials for promotional activities, public relations, raising funds for the Association, and the employment and establishment costs of the staff involved in these activities and allocated support costs.

Governance costs relate to the costs of running the Association and the Branches, such as the costs of audit and statutory compliance, meetings, Trustees' expenses, organisational development, the employment and establishment costs of the staff involved and allocated support costs.

#### **Operating leases**

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

#### 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 exempt from 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.

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.

#### Tangible fixed assets

Equipment costing less than £750 per individual item is 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
Care equipment	3 years
Computer and other equipment	2 years
Computer software	4 years

#### 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.

#### For the year ended 31 January 2012

#### 1a Donations and gifts

Ta Bonatons ana gitts		
	2012	2011
	£	£
Individuals	2,747,475	2,879,394
Charitable foundations and other grantors (see note 2)	881,944	1,050,299
Corporate donations	653,140	527,050
Appeals	882,968	891,241
Voluntary fundraising	2,116,838	2,386,012
Tax recovered	546,342	693,993
	7,828,707	8,427,989

#### 1b Other income

	2012	2011
	£	£
Costs recovered	10,209	8,000
Royalties	238	1,040
Advertising	4,230	5,630
	14,677	14,670

#### 2 Grants receivable

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

	2012 £		2012 £
The Wolfson Foundation	135,000	The Foster Wood Foundation	10,000
The Euro-Matic Foundation	110,000	The Royal Air Force Benevolent Fund	10,000
The Garfield Weston Foundation	100,000	The Sovereign Health Care Charitable Trust	10,000
The Thompson Family Charitable Trust	50,000	The Eveson Charitable Trust	8,000
The Department of Health	35,000	Thames Wharf Charity	6,087
The Bruce Wake Charitable Trust	25,000	The Michael Dewhirst Charitable Trust	6,000
The Greendale Charitable Foundation	25,000	East Sussex County Council	5,767
The John Ellerman Foundation	25,000	The Donald Forrester Charitable Trust	5,000
The Harebell Centenary Fund	20,000	Help for Health	5,000
The William Brake Charitable Trust	20,000	The Sir Samuel Scott of Yews Trust	5,000
The Benindi Fund	15,000	The 29th May 1961 Charity	5,000
The Friends of Windle Pilkington House	14,275	The Jordan Charitable Foundation	5,000
The Peacock Charitable Trust	12,000	The Kirby Laing Foundation	5,000
The Elizabeth & Prince Zaiger Trust	12,000	The Offenheim Charitable Trust	5,000
C H K Charities Limited	10,000	The R D Turner Charitable Trust	5,000
The Frank Brake Charitable Trust	10,000	The Rowan Charitable Trust	5,000
The G J W Turner Trust	10,000	The Wixamtree Trust	5,000
The Anton Jurgens Charitable Trust	10,000	Others (under £5,000)	127,815
The Enid Linder Foundation	10,000	TOTAL	881,944

The Association would like to thank each of the above for their generosity and support.

#### For the year ended 31 January 2012

#### 3 Net expenditure for the year

This arises after charging:		
	2012	2011
	£	£
Auditors' remuneration:		
Internal Audit (RSM Tenon)	4,500	7,125
External Audit (Sayer Vincent)	21,000	19,000
Other Services (Sayer Vincent)	750	1,430
Branch Auditors' remuneration	17,112	15,160
Operating lease rentals:		
- motor vehicles	177,212	173,308
- land and buildings	167,010	182,237
- other	7,762	-
Depreciation of owned assets	321,088	339,777

#### 4 Trustees' emoluments and expenses

The Trustees neither received nor waived any emoluments during the year (2011: £nil). Travel, subsistence, conference and meetings expenses were incurred during the period and totalled £34,859 (2011: £28,063). These expenses were all incurred in the course of their duties and were reimbursed, or paid on behalf of, a total of 19 Trustees (2011:17).

Resources expended on total activities represent the following direct and allocated costs:

	Fundraising Merchandising costs and fundraising event costs	iising Merchandising costs and fundraising event costs	Care and Research grants payable	Care development	Research development	Volunteer development	Governance costs	Total 2012	Total 2011
	4	£	£	£	£	£	Ł	ų	£
Staff employment & travel costs	1,699,760	1	20,221	3,256,012	546,172	738,209	53,289	6,313,663	6,197,447
Establishment costs	303,268	I	19,465	416,317	73,286	1 28,222	4,290	944,848	960,575
Volunteers' expenses	1,180	ı	10	77,544	682	106,973	49	186,438	162,359
Equipment loan service	ı	I	I	1,016,385		ı	I	1,016,385	944,701
Patient care & grants	ı	I	1,033,131	479,855	1	ı	I	1,512,986	1,631,008
Conferences & meetings	I	I	I	102,469	323,630	1 25,050	I	551,149	555,718
Care & Research Centre grants	ı	I	602,267	I	ı	I	I	602,267	568,930
Research & studentship grants	ı	I	2,460,476	I	1	ı	I	2,460,476	2,528,537
Other research costs	I	I	I	I	46,585**	I	I	46,585	328
Publications & information	ı	I	I	49,616	7,079	I	I	56,695	98,657
Membership services	I	I	I	I	I	35,917	I	35,917	39,796
International Alliance	I	I	I	I	10,000	I	I	10,000	10,000
Publicity, public relations & printing	1,520	I	I	40,118	44,546	I	I	86,184	88,276
Fundraising	498,411	100,142	I	19,124	19,124	I	I	636,801	885,312
Fundraising events	7,347	218,190	I	4,352	1,376	I	I	231,265	310,954
Legal & professional	(25,672)*	I	I	I	ı	I	30,423	4,751	66,324
Trustees' expenses and development	I	I	I	I	ı	I	34,859	34,859	28,063
Annual General Meeting	I	I	I	I	I	I	4,820	4,820	5,752
	2,485,814	318,332	4,135,570	5,461,792	1,072,480	1,134,371	127,730	14,736,089	15,082,737

Included within the resources expended is irrecoverable VAT that amounts to £347,686 (2011: £296,746).

\* includes a refund of £30,000 for expenditure included in the year ended 31 January 2011

\*\* costs include consultancy on research project and share of costs of campaigns, political consultancy and commissioning

For the year ended 31 January 2012

# NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS

Total resources expended are further analysed as follows:

	Activities	Grant	Support	Total	Total
	undertaken	funding of	costs	2012	2011
	directly	activities			
	£	£	£	£	£
Care and Research grants (note 7)	I	4,095,874	39,696	4,135,570	4,402,086
Care development	4,524,829	I	936,963	5,461,792	5,168,963
Research development	901,952	I	170,528	1,072,480	860,702
Volunteer development	850,736	I	283,635	1,134,371	1,322,689
Governance	70,101	I	57,629	127,730	107,309
Costs of charitable activity	6,347,618	4,095,874	1,488,451	11,931,943	11,861,749
Fundraising, merchandising & events	2,185,686	I	618,460	2,804,146	3,220,988
Total resources expended 2012	8,533,304	4,095,874	2,106,911	14,736,089	
Total resources expended 2011	8,723,351	4,364,183	1,995,203		15,082,737

# 6 Support costs

Support costs are allocated to activities as follows:

2011 2011	£	261,726	337,707	425,931	481,375	488,464	1,995,203
Total 2012	ų	253,909	355,915	446,466	523,943	526,678	2,106,911
Governance	£	23,863	27,221	1,848	2,547	2,150	57,629
Volunteering development	£	29,860	46,967	63,180	68,679	74,949	283,635
Research development	£	35,708	23,018	31,558	43,511	36,733	170,528
Care development	Ч	100,033	157,342	210,907	217,595	251,086	936,963
Care and Research	grants £	3,887	6,114	8,382	11,557	9,756	39,696
Fundraising	£	60,558	95,253	130,591	180,054	152,004	618,460
		Management	Finance	Information and Communications Technology	Facilities	Human Resources	

For the year ended 31 January 2012

# NOTES TO THE CONSOLIDATED FINANCIAL STATEMENTS

Annual Report and Financial Statements

#### For the year ended 31 January 2012

#### 7 Grants payable

Grants were payable during the year as follows:

	2012	2011
	£	£
Grants to institutions	2,961,560	3,019,420
Grants to individuals	1,134,314	1,344,763
	4,095,874	4,364,183

Grants made to, and for, individuals affected by Motor Neurone Disease are for expenses such as respite care, building adaptations and equipment rental and benefited a large number of individuals through the Association's network of regions and branches.

	2012 £	2011 £
Balance at start of year	4,263,440	3,578,700
Awarded in the year	4,095,874	4,364,183
Paid in year	(3,961,353)	(3,679,443)
Balance at end of year	4,397,961	4,263,440
Falling due within one year (note 16)	4,312,337	4,094,284
Falling due after more than one year (note 17)	85,624	169,156

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

	2012 £		2012 £
Institute of Psychiatry, London	<b>2</b> 421,388	University Hospital Birmingham	<b>ء</b> 49,016
University of Sheffield	318,876	Hope Hospital, Manchester	44,658
University of Edinburgh	268,692	Barts & Royal Queen Mary, London	41,460
SITraN, Sheffield	234,975	University of Wales, Cardiff	40,341
Nuffield Orthopaedic Centre, Oxford	152,352	Lab Molecular Neurobiology, Milan	38,499
University of Liverpool	138,230	Royal Preston Hospital	37,506
Institute of Neurology, London	130,799	The Walton Centre, Liverpool	32,069
University of Birmingham	110,569	Royal Holloway, University of London	28,704
University of Cambridge	87,689	University of Newcastle	20,091
University of Oxford	86,305	Royal Free & University College Hospital, Middlesex	17,565
Cardiff University	85,268	University College London (see note below)	14,500
Oxford Biomedica	85,000	ALS Association, USA	9,385
Plymouth NHS Trust	76,105	University of Reading	9,161
Medical Research Council, Edinburgh unit	73,161	Columbia University, New York	3,142
Imperial College, London	67,655	University of Leuven, Belgium	2,913
Southampton General Hospital	65,954	National Hospital, London	2,000
Queen's Medical Centre, Nottingham	57,322	Duke University, Wachovia, USA	1,625
King's College, London	55,286	Biomedical Science Institute, UK	1,500
John Radcliffe Hospital, Oxford	51,799	TOTAL 2,	961,560

Note: MND Association Trustee Anne Bulford OBE is also Treasurer of University College London

#### For the year ended 31 January 2012

#### 8 Staff costs and emoluments

The average number of persons (full time equivalent) employed by the charity during the year is shown below:

	2012	2011
*Care development	70	68
* Research development	10	9
* Volunteer development	20	21
* Fundraising	48	45
Governance	1	2
Total employees	149 **	145

\* Staff numbers for these areas of activity include an appropriate apportionment of support staff

\*\* As at 31 January 2012, staff numbers stood at 143. There has been a further reduction of 6 staff in the early part of the 2012/13 financial year

The employment costs of all these employees were:

	2012 £	2011 £
Gross wages and salaries	4,701,271	4,644,087
Social security costs	504,606	487,604
Other pension costs	260,709	257,728
	5,466,586	5,389,419

The total number of employees whose emoluments for the year (not including pension contributions) fell within the following bands, were:

	2012	2011
£100,000 - £109,999	1	1
£70,000 - £79,999	1	1
£60,000 - £69,999	4	4

The employer's contributions to personal pension plans for the above employees amounted to £30,345 (2011: £32,340).

#### 9 Pension costs

The Association operates defined contribution personal pension plans 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 amounted to £260,709 (2011: £257,728).

#### 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 2012 (2011: Nil).

### For the year ended 31 January 2012

#### 11 Tangible fixed assets

		Computers, software, fixtures,		
	Care	fittings &		
	equipment	equipment	Total	
Group and Charity:	£	£	£	
Cost:				
At 1 February 2011	1,857,924	1,061,926	2,919,850	
Additions	74,873	48,745	123,618	
*Disposals	(797,337)	(492,422)	(1,289,759)	
At 31 January 2012	1,135,460	618,249	1,753,709	
Depreciation:				
At 1 February 2011	1,432,396	963,652	2,396,048	
Charged in the year	258,254	62,834	321,088	
*Eliminated on disposal	(797,337)	(492,422)	(1,289,759)	
At 31 January 2012	893,313	534,064	1,427,377	
Net book value:				
At 31 January 2012	242,147	84,185	326,332	
At 31 January 2011	425,528	98,274	523,802	

\*The high disposals figure, relating to fully depreciated assets, arose through a review of retained assets during the year and consequent updating of the fixed assets register.

#### For the year ended 31 January 2012

#### 12 Fixed asset investments

The Association owns a wholly owned subsidiary company, Motor Neurone Disease (Sales) Limited, which is registered in England and Wales. This subsidiary operates mail order catalogues selling promotional clothing, gifts and cards, runs Challenge events and other fundraising events and gift aids a proportion of its taxable profits to the Association each year. Audited accounts are filed with the Registrar of Companies, and below is a summary of its trading results for the year ended 31 January 2012:

#### Motor Neurone Disease (Sales) Limited Profit and Loss Account

	2012	2011
	£	£
Turnover	333,423	528,322
Cost of sales	(253,449)	(378,494)
Gross profit	79,974	149,828
Administration costs	(9,812)	(7,460)
Profit before interest and tax	70,162	142,368
Net interest (payable)	(500)	(500)
Net profit	69,662	141,868
Amount gift aided to the charity	(69,662)	(141,868)
Result for the year	-	-
Corporation tax	-	-
Result retained in the subsidiary	-	-

The aggregate of the assets, liabilities and funds was:

	2012 £	2011 £
Assets	197,040	276,789
Liabilities	(153,633)	(233,382)
Funds (representing 2 ordinary shares of £1 each)	43,407	43,407

The investment held by the Charity of £2 (2011: £2) represents shares in the subsidiary company at cost.

#### 13 Stocks

		Group		Charity	
	2012	2011	2012	2011	
	£	£	£	£	
Purchased goods for resale	16,542	10,298	-	-	

#### For the year ended 31 January 2012

#### 14 Debtors

	Group		Charity	
	2012	2011	2012	2011
	£	£	£	£
Loan to subsidiary company	-	-	20,000	20,000
Amounts due from subsidiary company	-	-	84,625	177,080
Legacies	2,871,384	2,943,328	2,871,384	2,943,328
Other debtors	124,603	34,519	98,550	5,374
Income tax reclaimable	152,666	98,582	152,666	98,582
Prepayments	199,123	214,917	111,702	131,296
	3,347,776	3,291,346	3,338,927	3,375,660

#### 15 Current asset investments

	Group		Charity	
	2012	<b>2012</b> 2011 <b>2012</b>	2012	2011
	£	£	£	£
Market value at 1 February 2011	1,592,183	1,519,905	1,592,183	1,519,905
Funds realised during year	(1,666,679)	-	(1,666,679)	-
Net gain on revaluation	98,056	72,278	98,056	72,278
Market value at 31 January 2012	23,560	1,592,183	23,560	1,592,183

The investments held at 1 February 2011 comprised funds invested with CCLA Investment Management Ltd. in an account linked to Government securities and stocks, and shares listed on recognised UK stock exchanges with the exception of one de-listed investment of shares, for which an estimated valuation was included. The investment with CCLA was realised during the year and therefore investments at 31 January 2012 relate to the value of listed shares held. The Association did not dispose of any of its shareholdings during the year.

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

	Group		Charity	
	2012	2011	2012	2011
	£	£	£	£
Trade creditors	619,866	658,993	572,491	627,629
Accruals	127,478	95,333	126,478	94,333
Other creditors	4,351,952	4,162,043	4,351,319	4,158,104
Payroll taxation and social security	130,278	138,568	130,278	138,568
	5,229,574	5,054,937	5,180,566	5,018,634

Other creditors include liability for research grants of £4,312,337 (2011: £4,094,284), up to the end of the following financial year.

#### For the year ended 31 January 2012

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

	G	iroup	Charity	
	2012	2011	2012	2011
	£	£	£	£
Other Creditors	85,624	169,156	85,624	169,156

The amount of £85,624 represents the commitment, in addition to that provided in Note 16, for the completion of a research contract with the Medical Research Council, where the agreement does not protect the Association financially should the project terminate prematurely.

#### **18 Restricted funds**

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust to be applied for the specific purposes stated:

Group and Charity:	Balance at 1 February 2011 £	Incoming resources £	Resources expended £	Balance at 31 January 2012 £
Research and studentships	1,007,493	1,267,372	(1,828,058)	446,807
Research Foundation	645,972	350,000	(905,273)	90,699
Care Centres	8,011	65,486	(72,498)	999
Care development	221,557	923,940	(922,541)	222,956
Branches	236,034	193,525	(201,830)	227,729
	2,119,067	2,800,323	(3,930,200)	989,190

The balance on each fund represents the residual income of grants made for the specific purpose of the fund, and for which the relevant expenditure has not yet been incurred.

Restricted funds are utilised as follows:

Research and studentships - for grant payments to be made enabling various research projects to continue Research Foundation - as above, relating to specified Research Foundation projects Care Centres - for care centres at various UK hospitals, largely to pay for coordinator posts Care development - for wheelchairs and other care equipment, including funds from the Midlands Co-op, for whom the Association was Charity of the Year Branches - for care equipment for people with MND within Branch areas

#### 19 Analysis of net assets between funds

	Restricted funds	Unrestricted funds	Total funds
Group:	£	£	£
Fund balances at 31 January 2012 are represented by:			
Fixed assets	-	326,332	326,332
Net current assets	1,074,814	3,975,285	5,050,099
Creditors: amounts falling due after more than one year	(85,624)	-	(85,624)
Total net assets	989,190	4,301,617	5,290,807

#### For the year ended 31 January 2012

#### 20 Analysis of changes in cash and net funds

Group:	Balance 1 February 2010 £	Cash flow changes £	Balance 1 February 2011 £	Cash flow changes £	Balance 31 January 2012 £
Net cash					
Short term deposits	3,612,349	(989,674)	2,622,675	389,400	3,012,075
Bank deposits	4,201,524	192,980	4,394,504	(515,518)	3,878,986
Cash in hand	1,130	1,730	2,860	(2,126)	734
Net funds	7,815,003	(794,964)	7,020,039	(128,244)	6,891,795

#### **21 Financial commitments**

At 31 January the charity and the group had the following annual commitments in respect of operating leases:

	2012 Land and	2012	2011 Land and	2011
	buildings	Other	buildings	Other
Group and Charity	£	£	£	£
Expires within one year	52,810	-	63,541	54,896
Expires between one and two years inclusive	5,400	97,784	-	1,064
Expires between two and five years inclusive	118,000	67,065	136,960	133,293
	176,210	164,849	200,501	189,253

At 31 January the charity and group had the following commitments in respect of grants payable for research projects, postgraduate studentships and Care Centres:

Group and Charity	2012 £	2011 £
Payable within one year	1,682,802	2,032,843
Payable in years two to five	1,374,406	1,600,355
	3,057,208	3,633,198

#### For the year ended 31 January 2012

#### 22 Joint Venture - Neurological Commissioning Support (NCS)

The Association is involved with the MS Society and Parkinson's UK in a Joint Venture to ensure that people affected by these neurological conditions have access to the right services, in the right place and at the right time. The three organisations, plus the affiliated Epilepsy Society, have formed the Neurological Commissioning Support (NCS) service in order to give practical support to commissioners in order to plan and deliver more cost-effective and better quality neurology services. The NCS is a non-profit organisation, which is accountable separately from the three charities, with a financial year end of 31 December. Unaudited results for the 13 months to 31 January 2012 are shown below.

#### NCS Profit and Loss Account (unaudited)

MNDA	share	Period to
to 31 Ja	nuary	31 January
	2012	2012
Income:	£	£
Grants & Fees 7	71,143	213,431
Events 2	20,300	60,900
Commissioning 1	1,560	34,679
Other 1	0,088	30,263
Total Income 11	3,091	339,273
Expenditure:		
	33,381	250,143
Commissioning Costs	9,027	27,080
Consultancy	2,605	7,816
All Other Costs 3	38,662	115,987
Total Expenditure 13	3,675	401,026
Net Deficit (2	0,584)	(61,753)

#### NCS Balance Sheet (unaudited)

	MNDA share	As at
	to 31 January	31 January
	2012	2012
	£	£
Current Assets	47,010	141,031
Current Liabilities	13,032	(39,096)
Net Assets	60,042	101,935
Represented by:	(20.584)	(61 752)

P&L Net Deficit	(20,584)	(61,753)
Prior year b/f	4,562	13,688
Shareholder Loans	50,000	150,000
Total Funds	33,978	101,935

Note: The £50,000 loan from the MND Association has been included as expenditure in the Association's Statement of Financial Activities for the year ended 31 January 2012.

#### Motor Neurone Disease Association

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