

MOTOR NEURONE DISEASE ASSOCIATION

England & Wales · Charity number 294354

Details

Other names MND ASSOCIATION, MNDA

Status Registered

Legal form Charitable company

Company number [02007023](#)

Registered 1986-05-14

Register [View on the Charity Commission register](#)

Contact

Address Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park Industrial Estate
Northampton
NN3 6BJ

Phone 01604 250505

Email enquiries@mndassociation.org

Website www.mndassociation.org

Activities

Objects: (A) THE RELIEF OF PERSONS WHO ARE, OR WHO ARE SUSPECTED OF BEING, AFFECTED BY MOTOR NEURONE DISEASE AND ITS 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.(B) 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.

Activities: The MND Association is the only national charity in England, Wales and Northern Ireland dedicated to improving care and support for people affected by MND, funding and improving research, and campaigning and raising awareness so that the needs of people with MND are addressed by society. Visit www.mndassociation.org

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Human Resources, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Disability
- **Who:** People With Disabilities

Geography

- Northern Ireland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£40,786,703	£33,944,213	£51,176,830	238
2023-12-31	£37,922,000	£26,785,000	£44,333,000	215
2022-12-31	£30,045,000	£22,796,000	£33,214,000	204
2021-12-31	£28,943,000	£18,063,000	£25,974,000	180
2020-12-31	£19,911,000	£15,583,000	£15,132,000	178

Trustees

Name	Role	Appointed
Alan Philip Graham MBE		2024-06-26
Craig Jones		2025-08-08
Dr John Ealing		2023-02-25
Dr Usman Khan		2021-03-16
Eleanor Dalley		2025-07-09
Elizabeth Ellis		2021-07-01
Hazel Carter		2023-07-01
Ian Lev		2022-06-27
James MARSHALL		2021-03-16
James Marc Barlow		2025-07-09
Kirrie Todd		2022-05-28
Shaun Gerard Mc Gee		2020-05-16
Susan Plummer		2025-07-09

MOTOR NEURONE DISEASE ASSOCIATION

England & Wales - Charity number 294354

Accounts



Annual Report

and Consolidated Financial Statements

For the year ended 31 December 2024





BUCKINGHAM PALACE

There are so many creative ways people choose to support the work of the Motor Neurone Disease Association. During my 16th year as Royal Patron it was interesting to hear about some of them during an afternoon tea at Headingley to thank Leeds Rhinos and all those inspired by our patrons, the late Rob Burrow CBE and his team-mate Kevin Sinfield CBE.

At the Northern Ireland Conference in April, I heard from enthusiastic volunteers about the many types of support they offer and about the positive impact their support has on people affected by the disease.

The Association has been funding research for more than four decades and I was pleased to learn of its work and meet supporters at the Countdown to a Cure Reception at the Royal College of Nursing in the autumn.

The work of the MND Association is a truly collaborative effort. Many thanks for your commitment and dedication to the MND community and I wish you every success for the year ahead.

A handwritten signature in black ink, appearing to read 'Anne', with a long horizontal flourish extending from the end.

Message

from the Chair

2024 was a year book-ended by the type of events that showcase the MND community at its very best. Early in the year we hosted our Royal Patron HRH The Princess Royal at a special reception at the Leeds Rhinos to say thank you to the rugby community for their incredible support inspired by legendary player Rob Burrow CBE, who very sadly died in June. And in December, we welcomed more than 1,400 delegates to our 35th International Symposium to share knowledge, convene meetings and kick off collaborations which we hope will lead to the kind of life-changing breakthroughs we all want to see.

At these events, and so many more throughout the year, we see the dedication and commitment of our members, volunteers and staff as they work together to deliver the five promises we have made to the MND community.

In 2024, we extended our reach further than ever, forming new partnerships to deliver services to support people with MND, raising awareness with new audiences and encouraging new supporters to work alongside us.

We led successful campaigns, opened new support services and continued our run of record fundraising years with our income topping an incredible £40 million. Thank you to all of you, our loyal fundraisers, supporters and donors for your incredible and generous support of our vital work.

I hope you enjoy reading about these achievements and more.



Dr Usman Khan
Chair, Board of Trustees



Contents

Trustees' Report (including the Strategic Report)	6
i. Objectives and activities	6
ii. Achievements and performance in 2024	7
iii. Future plans and priorities	20
iv. Fundraising governance priorities	22
v. Financial review	22
vi. Principal risks and uncertainties	23
Structure, Governance and Management	25
Statement of Trustees' Responsibilities and Corporate Governance	32
Organisational Information and Financial Statements	34
Independent Auditor's Report	36
Consolidated Statement of Financial Activities	39
Balance Sheet	40
Statement of Cash Flows	41
Statement of Accounting Policies	42
Notes to the Consolidated Financial Statements	45



Trustees' Report

The trustees are pleased to submit their Report on the Charity's activities together with the Financial Statements for the year ended 31 December 2024, which have been prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102), the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) – (2nd Edition, effective 1 January 2019) and the Companies Act 2006.

About MND

Motor neurone disease (MND) is a rapidly progressing neurological disease that affects the brain and spinal cord. More than 5,000 people in the UK are living with MND at any one time and the lifetime risk of being diagnosed with MND is around one in 300.

As symptoms progress, MND can leave people locked inside a failing body, unable to move, talk, swallow or even breathe.

Every day, six people are diagnosed with MND. Another six people die.

There are currently no effective treatments for the vast majority of people with MND. There is no cure.

i) Objectives and activities

About us

The MND Association (the Association) was founded in 1979 by a group of volunteers, all with their own personal experience of MND.

Over the years, the Association has grown into the vibrant community we know today, made up of members, volunteers, campaigners, supporters and staff from across England, Wales and Northern Ireland.

As well as being the biggest charitable funder of MND research in the UK, the Association focuses on improving access to care, providing support, and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland.

Our community is united behind one clear vision –
a world free from MND.

Our charitable objects as stated in our Articles of Association

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

The Association commissions, undertakes, promotes, monitors and manages research into all aspects of motor neurone disease and its associated conditions and causes, and works towards

their prevention and cure and to publish and disseminate the useful results for the benefit of the public.

Public benefit

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

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

ii) Achievements and performance in 2024

This year, with the help of our generous donors and the tireless determination of the MND community, we have had a direct impact on the quality of care of people with MND. We have launched and supported initiatives to widen the accessibility to MND clinical research and trials and continued to fund and support the brightest research minds and most

promising studies. We've worked closely with people affected by MND to achieve important successes in our influencing and campaigning work and capitalised on opportunities to generate even greater awareness of the realities of MND and our need for donations.

Our Promise:

1. We won't rest until MND is treatable and ultimately curable

The MND Association has been a leading authority in MND research for 45 years. We are at the forefront of the global fight against MND, funding and facilitating the research that is taking us ever closer to uncovering the causes of MND, effective treatments and ultimately a cure.

During 2024 we invested £8.8 million in new research, across 55 grants. We also provided £0.5 million of continuation funding to 14 ongoing grants. At the end of December 2024, the value of the MND Association's research portfolio had grown to a record commitment of £24.2 million, funding 133 grants. We award these grants through a competitive process, selecting only those

During 2024 we invested

£8.8 million

in new research, across 55 grants.



Researchers at King's College London laboratories



We know people with MND often spend hours researching and applying to take part in trials. MND Association Research Nurses will do that for them, providing all the guidance and support each person needs.

Sally Hughes, Director of Services and Partnerships, MND Association



Ewa Delmaczynska, MND Specialist Nurse at the MND Care Centre in Birmingham

of the highest scientific merit, greatest relevance and greatest potential for achieving our vision of a world free from MND.

As well as funding research, we're working to make it easier for more people with MND to take part in clinical trials of promising new treatments, accelerating discovery for everyone. This year we laid the foundations for the MND Association Research Nurse Network – a £7.2 million, five-year initiative to build a first-of-its-kind co-ordinated network of Research Nurses who will work alongside MND care teams in England, Wales and Northern Ireland. They will identify suitable trials, and help people with MND navigate the trial process, making research - and the potential to be taking drugs that could prove to be a treatment-part of holistic care for more individuals. Access to clinical trials was further boosted this year by the launch of TiM-R. Part-funded by us, TiM-R is a digital platform that allows people with MND to self-refer and participate in trials from their own home.

This year we have paved the way for new research partnerships to harness the power of artificial intelligence (AI) in our quest for a cure. AI will be a powerful tool to accelerate the identification of subtypes of MND, which will help to match individuals to experimental treatments that they are most likely to respond to in clinical trials. It will also accelerate our understanding of the genetic contribution to MND and identify new biological targets for MND drug design.

Gene therapies – drugs that correct the underlying genetic causes of disease – are a potential route to a cure for MND and, with Association funding, researchers are getting ever closer to making them a reality. In November, Professor Pietro Fratta launched Trace Neuroscience Inc. alongside US co-founders, to fund development of a gene therapy to restore production of an essential component of neuronal communication in the brain and spinal cord. The decline in this component – called UNC13A – occurs in 97% of people with MND and restoring it may slow down progression of the disease. The importance of UNC13A in MND was discovered in Association-funded research by Professor Fratta in 2022, paving the way for Trace Neuroscience to attract over \$100 million in venture capital funding to develop an MND gene therapy that can be trialled in humans.

Another member of Professor Fratta's team from University College London has made an important breakthrough towards functional MND gene therapies with our support. Dr Oscar Wilkins – to whom we awarded The Lady Edith Wolfson Rosetrees Fellowship – has developed a way to add precision targeting to gene therapies so they are activated only in motor neurones being damaged by MND, leaving healthy neurones unaffected. This approach could reduce the risk of the side effects that can come with ubiquitous treatments, which have been a major barrier to developing tolerable MND drugs.

Another approach to finding effective treatments for MND is to repurpose drugs already licenced for other illnesses. This strategy offers the hope of bringing new medicines to patients



The Rosetrees Foundation has a longstanding record of supporting the progress of innovative science from the lab to the clinic. We're delighted to partner with them on supporting this exciting research, led by an outstanding young researcher.

Dr Brian Dickie, Chief Scientist, MND Association



Dr Oscar Wilkins, University College London, who was awarded The Lady Edith Wolfson Rosetrees Fellowship

“

This pre-fellowship represents a crucial step forward in my research journey, as it will allow me to expand my previous work by incorporating biological data from different sources within the MND community.

Dr Heather Marriot,
King's College London

”



Dr Heather Marriot King's College London, who was awarded a pre-fellowship in 2024

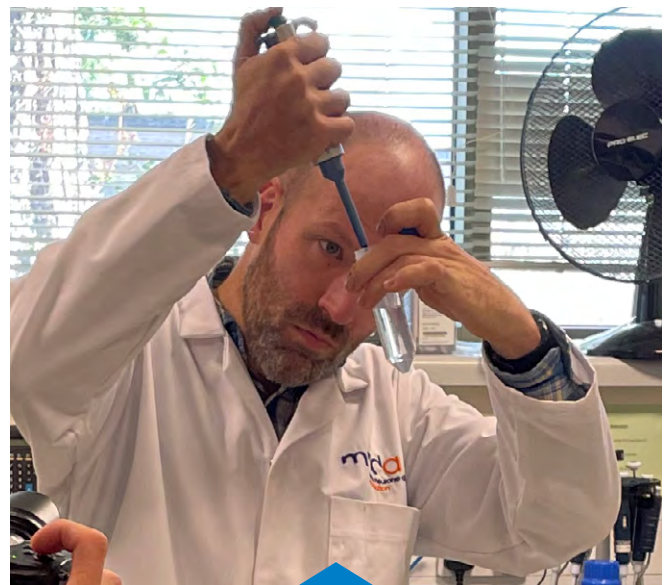
more rapidly, as they have already passed the lab tests and early trial phases that normally take years. The UK's first MND platform trial, MND-SMART, is testing several repurposed drugs in parallel, thanks in part to our £0.5 million investment. Nearly 900 participants have been recruited to this ground-breaking platform and this year it was confirmed that one of the first wave of drugs – amantadine – has passed its safety checks in people with MND. If found to be effective through future trials, it could enter the regulatory process as potential new treatment options for MND. One challenge of repurposing is to identify the treatments with the best chance of success in MND. This year we funded a project that will use a robotic system to screen thousands of current medicines, alone and in combination, for their potential to enhance motor neurone survival. The researchers originally applied for backing through the government's MND Translational Accelerator, but there wasn't enough funding available. We decided the research was too important to delay, so injected a further £400,000 to start the project immediately.

Collaboration is central to speeding up progress towards new treatments and a cure, and we drive opportunities for researchers, clinicians and people affected by MND to share ideas, knowledge and expertise. Since its launch last year, the UK MND Research Institute has begun to provide a virtual

hub for collaborative research, borne out of a shared vision of people with MND, researchers and MND charities. One initiative from the MND Research Institute is the pre-fellowship scheme to attract and retain early career researchers wanting to establish a career in MND translational research. Funded by us in partnership with MND Scotland, one pre-fellowship was awarded in 2024. Heather Marriot will conduct an 18-month project aiming to find early indicators of MND progression, which could help to match people with the most suitable clinical trials.

Supporting early career researchers like Heather is an investment to secure ongoing progress in the understanding and treatment of MND. In July, our annual EnCouRage UK two-day event brought together some of the UK's most talented MND researchers in the early stages of their careers, to share and learn with each other, senior researchers and people affected by MND. Many of the attendees will be approaching a career crossroads at the end of their PhD, and we hope to inspire them to make MND their chosen focus.

At the end of the year, we welcomed more than 1,200 people to our 35th International Symposium in Montreal, Canada, with 300 more attending online. With over 1,000 presentations and posters by researchers from 31 countries, this is the world's largest scientific and medical meeting focused on the disease. It enables researchers at every stage of their careers to share the latest ideas and discoveries, and ignite partnerships and collaborations.



“

I've identified new potential collaborations and new ways of verifying some of our findings using different cohorts from all around the world. It's absolutely essential we bring the community together somewhere like this to accelerate things forward.

Symposium delegate,
Dr Johnathan Cooper-Knock,
University of Sheffield

”

Our Promise:

2. We won't rest until everyone gets the care they need when they need it

By building knowledge and skills across health and social care, finding ways to improve services and providing direct support to families, we're raising standards and enhancing quality of life for people with MND.

Association-supported Care Centres and Networks connect NHS services, Association volunteers and staff, and community support services so that people with MND get the right care at the right time in the most convenient place. These centres and networks help ease the strain on families trying to navigate the complex mix of services needed by people with MND. This year, we launched the latest MND Care and Research Network, our 24th, based at St George's Hospital, Tooting, to improve support and co-ordination of services for around 180 people living with MND in South West London and Surrey.

We know that there are still some places where people living with MND cannot access the care and support they need. This year we funded five new Care Co-ordinator roles, including our first in Northern Ireland and Wales, extending support beyond our established Care Centres and Networks. Additional posts will



Different disciplines each play such a crucial role in addressing the multiple complex issues that can be experienced by people with MND. I'm a huge believer that the whole becomes more than the sum of its parts when the Multidisciplinary Team (MDT) works well.

**Keri Vickery MND
Care Co-ordinator,
Bristol MND Care Centre**



be recruited in 2025, to plug known gaps in joined-up MND care.

Our Community of Practice is a group of health and social care professionals working together with us to improve MND care. We support the community by providing resources and learning opportunities to educate and skill-up the wide range of professionals involved in caring for people with MND. Our learning events – from webinars to workshops – attracted over 1,400 professionals in 2024. For instance, 135 leaders and co-ordinators from Association-supported services attended our Care Centre and Network Day in June, to explore priority areas of care through discussion and learning. MND is a complex disease, and our programmes reflect this, covering topics from managing saliva and posture management, to MND genetics and anticipatory grief.

Psychological support is a vital element of holistic care for MND. In 2024, a clinical trial we co-funded showed that an intervention called Acceptance and commitment therapy (ACT) can help to improve quality of life in people with the disease. ACT emphasises acceptance of difficult feelings and thoughts rather than trying to control or avoid them which can sometimes lead to more distress. We're now funding specialist ACT training for psychologists who work with people with MND.

In 2023, we reviewed the guideline on MND produced by the National Institute for Care Excellence (NICE) and laid out recommendations for amendments that would empower health and social care professionals to provide the very best care possible. In 2024, we prioritised these areas, and met with NICE to agree how to work together to develop updated guidance.

In July, we funded a day of making memories at Peppa Pig World in Hampshire. Association volunteers helped to support scores of people with MND and their families during the day, which included craft sessions, lunch and opportunities to speak to other families affected by MND. The special day was just one of the ways in which we supported 458 families with children and young people facing a loved one's MND diagnosis. This included 688 counselling sessions and 142 memory boxes.

We also continue to work alongside our partners at national children's charity Barnardo's to cut the time it takes for children



There was so much sharing of experience and support, but also laughter and fun. Never underestimate the power of just being with others who are in the same situation as you.

**Laura Willix, Children and Young
People's Service Development
Manager, MND Association**



The Baker family who attended the memory making day at Peppa Pig World

to access professional support when a family member is diagnosed with MND. Referrals used to take 12 to 18 months, now they take five to seven days.

Our Promise:

3. We won't rest until every day with MND counts

Every year, thanks to the generosity of our supporters, we help thousands of people and families affected by MND by giving non-means-tested grants for a range of needs. We streamlined the application process and awarded a record total of £3.1 million in support grants to 3,151 people affected by MND in 2024, for items including equipment, services and adaptations. This included more than £114,000 enabling 149 people to access wheelchair accessories such as powerpacks, risers and attendant controls, which can make a life-changing difference for people with MND and their carers. The demand for our support grants is rising year-on-year and – thanks to our generous supporters – we were able to award funding to 534 more people compared to 2023.

In November, we increased the value of our cost-of-living grants from £350 to £500 for anyone struggling with household bills and everyday costs. It was part of the response to our research revealing that over 80% of unpaid carers have used savings to cover day-to-day items. As well as helping to plug the financial gaps caused by a diagnosis of MND, we support people to understand and apply for the state benefits they're entitled to, totaling £3.7 million in 2024.



Without this help, we would be further in debt to the energy company. I am happy with the financial support you have given me and can't thank you enough for that.

Steve Williams who is living with MND



“

Calls to Connect range from five minutes with someone wanting help applying for one of our grants to a much longer call speaking to a carer who has been recently bereaved. There's no time limit."

”

Victoria Maynell, Connect Helpline Manager, MND Association

Jay Sanchania, Senior Connect Adviser



Financial advice is just one of the areas we're contacted about through MND Connect, our dedicated helpline providing information, practical and emotional support, and signposting to other specialist services. This year we answered calls for help from 7,896 people by expanding MND Connect to six advisers with a range of experience and expertise, and adjusting the opening hours to match demand.

In communities across England, Wales and Northern Ireland our amazing volunteers continue to offer a network of one-to-one support to people living with MND when it is needed most. Through regular phone calls, emails, personal visits and texts, our 368 Association visitors and co-ordinators were on hand to offer advice and guidance, while our 87 branches and groups provided a safe space and local point of contact for anyone in need of friendship and support.

Association volunteers are also key to making our MND support groups a place for people affected by the disease to take time out, relax and chat. In 2024, support group volunteer Sam Tooze, who has MND, set up a new group in her area – bringing the total to 135. With our help, in partnership with local charity The Myton Hospices, this new support group is now available for people affected by MND in and around Rugby and Coventry.



“

I was excited to start the group as I felt people had too far to travel to get to other support groups in the area. Support groups are great places for people to take time out and chat.

**Sam Tooze,
support group founder, Rugby**

”



Members of the Coronation Street cast on final filming day

Our Promise:

4. We won't rest until you are heard

MND has a higher profile than ever before. We're building on that to drive change with and for the MND community and engage a new generation of supporters to power vital research and support.

This year we continued to support and advise ITV **Coronation Street's** writers as their award-winning MND storyline came to a climax with the death of character Paul in September.

The fictionalised version of MND had put the disease in the spotlight among the soap's fans, and we used that opportunity to raise awareness by sharing real MND stories in a powerful campaign.

The Love Inside contrasted the brutality of the disease with the one thing it cannot destroy. It featured Mike Sumner and his wife Zoe, Mike Small, and Louise Jordan and her husband Rob, who allowed us to capture intimate and moving moments in their daily lives. The TV ads became the first ever **Coronation Street Presents...** campaign and this attention-grabbing exclusive format helped to drive our highest ever position in a sector-leading recognition index. Very sadly, Mike Small and Louise have since died, a timely reminder of the urgency of our work. Part of their legacy is the awareness the adverts have created - with more people than ever being aware of us, we're able to engage new audiences to support our work.



Coronation Street Presents marking the Association's collaboration with the TV production team



It wasn't just about tofersen. It was about fighting to ensure our community has access to medicines now and in the future.

Tofersen just happens to be the first one. There will be more, I'm sure of it.

Eleanor Dalley, who is living with MND



Tofersen is exceptional.
Make the exception.



Prescribe Life

In October, we launched **Prescribe Life**, an influencing campaign to create a route for the two per cent of people with a rare type of MND to access the ground-breaking drug tofersen. Clinical trials have shown that the drug can give years more life to people who have SOD1 MND. It's the first effective treatment for MND identified in decades and patients are desperate for the drug to be approved for use on the NHS. However, the regulatory body NICE had announced they would evaluate the drug for use in the NHS through the standard route, which was bound to make it economically unviable. Tofersen's owner, Biogen, halted the approval application and the process was in deadlock.

We had to try to convince NICE to reconsider their decision. We were confident we had a strong argument for them to assess tofersen as a rare disease drug, but we were just one voice. So, with Eleanor Dalley – who has SOD1 MND – we launched a petition to show the strength of feeling in the MND community.

The response was amazing. Within a month, more than 15,000 people had signed, and our persistent pressure led NICE to change their mind. In November, they announced they would use its Highly Specialised Technology route to evaluate tofersen, giving it a much greater chance of approval. While there's more

work to do to get tofersen over the finish line and into the NHS, the whole MND community can be proud of what we achieved together through **Prescribe Life**. It's a campaign victory that could literally save lives.

The 2024 change of government presents an opportunity to make change for people with MND. During the general election, our community of campaigners urged candidates to sign our MND Guarantee and commit to supporting people affected by the disease if elected. Eighty-five of our signatories were elected and we're now building closer links with those MPs as MND advocates.

Following the election, the All-Party Parliamentary Group (APPG) on MND for which we provide the secretariat, was re-established, and Ian Byrne, MP for Liverpool West Derby was elected Chair of the group. The APPG meets regularly to discuss issues affecting people living with MND, raises awareness at the very highest level and is a lever for change. We formally thanked all outgoing members of the previous team. In particular, the former Chair Andrew Lewer MP, who has been a passionate and effective advocate for people affected by MND.

In November, we met with Sir Stephen Timms, Minister for Social Security and Disability, to make him aware that carers in



“ As Chair of the MND APPG I’ve seen first-hand the impacts of this awful disease. It is vital that we support research to deliver new MND treatments and ultimately, a cure.

APPG Chair Ian Byrne, MP for Liverpool West Derby



the MND community are being impacted by Carer’s Allowance overpayments. These often occur due to a carer unwittingly breaching earnings rules, and some are now being forced to pay back thousands. We will be advocating for MND carers and pressing for reform of the system during the Government’s review of the issue.

Ensuring the voices of people with MND are heard is vital to ensure future legislation works for the community, so we attended party conferences including those in Northern Ireland and Wales, meeting with MPs and raising challenges faced by people affected by MND. We also continued to submit detailed and considered responses to parliamentary committees and ministerial consultations on all policy areas that could impact people living with and affected by MND, such as the NHS 10-year plan.



The support we receive from the MND community is crucial, allowing us to amplify the voices of people affected by the condition and make a compelling case to key decision-makers.

Alex Massey, Head of Campaigning, Policy and Public Affairs, MND Association



Members of the Campaigns Team campaigning for the rights of people with MND and their carers

Our patrons and ambassadors



Rob Burrow CBE

In June 2024, our patron Rob Burrow CBE died of MND. His death generated a huge public response with national and international media coverage. We were privileged to be invited to take part in his memorial service held in Leeds, a chance for us to pay tribute, on behalf of the MND community, to the rugby league legend who did so much to inspire support in the cause. In December, Rob's friend and fellow Association patron Kevin Sinfield CBE completed his challenge to run seven ultra marathons in seven days. Kevin raised more than a million pounds for MND charities in memory of Rob. We are incredibly grateful to Kevin – the funds and the awareness he has raised will continue to make a huge difference to the MND community.

We are honoured to have the continuing support of our Royal Patron, HRH The Princess Royal, and of all our patrons and ambassadors who do so much to support the Association and raise awareness of MND.

Our patrons



Chris Broad



Benedict Cumberbatch CBE



Taron Egerton



The Baroness Finlay of Llandaff



Charlotte Hawkins



Eddie Redmayne OBE



Kevin Sinfield CBE



Jeremy Vine

Our ambassadors



JJ Anisiobi



Gina Bellman



Daniel Brocklebank



Misha Grimes



Olivia Lee

Our Promise:

5. We won't rest until no one faces MND alone

Regardless of background, gender, faith or sexual orientation, MND is unrelenting and the MND Association strives to offer help and support to all. This means making sure principles of equity, diversity and inclusion (EDI) are firmly embedded in everything we do, breaking down barriers that may stop people accessing what we can provide, and understanding the unique needs of different groups within the MND community.

We commissioned an EDI Audit in collaboration with Diverse Matters. It identified both our achievements and the areas where we must address weaknesses in order to ensure that all staff and volunteers feel valued, heard, and supported. We have launched a Task and Finish group with external expertise to act upon the findings of the audit, which we have refined into a set of seven priorities.



While we have taken important steps forward, we understand there is still much more to do. The Association has already started a review around the accessibility and inclusivity of all our public facing products and services and we were delighted to move to the next level of the Confident-Employer scheme, in recognition of our practical and awareness raising work around disability.

We thank

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

We acknowledge

Our former Chief Executive Sally Light was awarded an OBE in the King's Birthday Honours for her services to people with motor neurone disease.

We remember

All those members of the MND community who died from MND this year including our trustees Ed Cooke who died in February 2025 and Dr Michael Hope who died in June 2025.

*Taking part in
Manchester Pride parade*



iii) Future plans and priorities

Our Strategy 2025-2030

In 2025, we will launch an ambitious new strategy to guide our work to support the needs of people affected by MND and drive towards effective treatments and a cure.

The next five years offer real potential for change. Public awareness has grown - driven by the bravery of those who have shared their stories. This visibility has fuelled fundraising, enabling us to support more people and increase our investment in research.

Our new strategy is built around three interlinked Impact Goals, designed to maximise our impact and sustainability to improve the lives of people with MND today, while building hope for tomorrow.

Our Impact Goals

1. Tomorrow's Treatment: Over the past four decades, the MND Association and our partners have significantly advanced understanding of the biology behind MND. Yet MND is still a devastating, terminal illness, and most people living with it still have no access to effective treatment.

Our goal is to turn understanding into breakthroughs – and breakthroughs into treatments. To do this, we will focus on four key priorities:

- Deepening our understanding of MND: We will identify new ways to combat the disease by advancing our knowledge of its causes and progression – paving the way for future breakthroughs.
- Driving faster, more accurate diagnosis: We will ensure everyone with MND receives a prompt diagnosis and genetic profile, unlocking access to timely, tailored treatments.

- Pioneering new treatments and care: We will play a vital role in translating cutting-edge science into the development of new treatments. We'll support clinical trials and healthcare research to get them to people with MND.
- Backing the brightest minds in research: We will attract and support the best scientific minds with training, funding and world-class research infrastructure – ensuring MND research remains a vibrant, ambitious field.

2. My Support, My Way: A third of people with MND feel lonely or isolated. Many struggle to access the right support to help them maintain the friendships, connections, and interests they valued before diagnosis. Others face barriers to securing assistive technology or making vital home adaptations, limiting their independence and quality of life.

We will offer tailored, timely support that reflects individual needs and experiences.

We will focus on four priorities:

- Providing information and support tailored to each person's needs, ensuring people can access the right services from diagnosis through to end of life.
- Ensuring everyone has access to the emotional wellbeing and psychological support they need, from the moment of diagnosis.
- Providing practical and financial help to help people access the services and assistance they need.
- Offering a joined-up support experience to ensure everyone has access to our services in an integrated way.

3. Influence High Quality Care: While some people with MND receive excellent care, far too many do not. Even where services exist, they are not always joined up or of the standard people with MND have a right to expect.

We will push for consistently high-quality, personalised care for everyone with MND.

We will focus on three priorities:

Our strategy is built around three interlinked Impact Goals, which will create a lasting change



- Raising standards of care for everyone living with MND. This includes working in partnership, funding dedicated care coordinator roles and influencing Care Centres and Networks
- Shaping policy and practice by influencing decision-makers and system leaders at national and regional levels to close the gaps in care and support.
- Leading bold, evidence-based campaigns on issues that matter most to the MND community.

Being the charity the MND community needs

To deliver the scale of ambition we have set out in our Impact Goals, we need to evolve how we work as an organisation. We will:

- Grow our annual income to £50 million by 2030.
- Involve an inclusive range of people from across our community in shaping our decisions.
- Invest in awareness to deepen public understanding of MND and support our campaigning and fundraising.
- Harness data and technology to improve efficiency, increase impact and expand our digital engagement.
- Improve our visual identity and public presence to increase impact and reach.
- Develop our people and culture to work more effectively and deliver the greatest possible benefit for our community.

To learn more about our commitment to the MND community and our priorities, or to get involved, visit

www.mndassociation.org/MNDPromises



Strategy is about choices. We need to ensure we are purpose driven and making conscious decisions about how we develop our work to maximum benefit to the MND community.

**Tanya Curry, Chief Executive,
MND Association**



Laboratories at Sheffield Institute for Translational Neuroscience (SITraN)

iv) Fundraising governance priorities

We have a diverse portfolio of fundraising activities including raising funds from individuals, trusts and foundations, companies, events, local communities and legacies. We approach our supporters via direct mail, email, telephone, online and directly at events, and manage this fundraising both centrally and locally through our branches and groups.

We comply with current regulations and best practice set out by regulatory and professional membership bodies including the Fundraising Regulator, the Institute of Fundraising, the Gambling Commission and the Advertising Standards Authority.



Cheerpoint, Brighton Marathon

We are registered with the Fundraising Regulator and are committed to the Fundraising Preference Service, honouring any requests from the public to end contact with us. We fundraise in line with the Code of Fundraising Practice and adhere to data protection law. We are committed to ensuring that we are completely open and transparent about our fundraising and spending. As members of the Fundraising Regulator's self-regulatory scheme, we comply with its principles in all our fundraising:

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

Due to the nature of delivering fundraising across multiple sites, we are aware that the potential for breaches of fundraising code of practice and data protection compliance exist. We manage and minimise these risks through training and inductions for new starters and for our branches and groups; through quality checks and audits, and through our compliance policies.

As the MND Association, we acknowledge that the engagement of third parties can help us raise funds, as well as improve efficiency and reduce costs. We require that any third party we work with complies with data protection legislation as set out in the Code of Fundraising Practice including the requirements of the telephone, mailing, e-mailing and fundraising preference services.

We follow a robust procurement process when recruiting third parties to work on our behalf, making sure we apply appropriate due diligence and contracts for this activity. We work closely with these third parties, regularly reviewing their activity against performance targets and the Fundraising Code of Practice to ensure delivery of the best value for money for the charity and its supporters.

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

We received 18 complaints about our fundraising activity in 2024. All were promptly resolved without the need for escalation to the Fundraising Regulator. Complaints are taken very seriously and reviewed quarterly by the Board of Trustees. However, they represent a tiny fraction of our outgoing fundraising communications. There is a complaints policy, which is available on our website, which forms the basis for the training of all fundraising staff.

All fundraisers at the MND Association are guided in how to protect vulnerable people including how to recognise a person in vulnerable circumstances. All our direct mail, emails and thank you letters contain clear instructions as to how a supporter can easily opt out of receiving further communications from the charity should they choose to do so.

v) Financial review

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

Financial performance

2024 was an incredibly successful year for fundraising at the Association, with total income exceeding £40 million for the first time ever. Since 2020, income has grown from £19.9m to the 2024 level of £40.8 million.

The continuing focus on MND in the media and the high profile fundraising events that took place contributed to a record year. All areas of fundraising had a strong year, most notably legacy donations which accounted for 26% of the income received.

Sources of income

Income	£m	%
Fundraising	21.5	53%
Legacies	10.6	26%
Branches and Groups	3.5	9%
Earned Income	5.2	12%
Total Income	40.8	100%

£21.5 million was raised and donated by our incredible supporters and a record £3.5 million was raised by our branches and groups. We are tremendously grateful for their commitment and continued support.

£10.6 million was donated in 2024 in the form of legacy gifts which continue to make such a huge difference to the work we do. We are enormously grateful to the people who choose to remember the work of the Association in their Wills.

For every pound spent directly generating fundraising and legacy income, £6.78 was received.

How we spent the money raised

Expenditure	£m	%
Services and Partnerships	9.5	28%
Research	10.4	31%
Campaigning	2.4	7%
Volunteer Development	1.0	3%
Fundraising	5.8	17%
Operational Support Costs	4.8	14%
Total Expenditure	33.9	100%

Our expenditure year-on-year increased by £7.2million. This increase reflected increased spend on our core activities (research, services, campaigning and volunteering) as the Association grew to meet the needs of our community. Since 2020 our expenditure on core activities has grown significantly, moving from £9.9m in 2020 to £23.3m in 2024.

The biggest uplift year on year was in research expenditure which was almost £3.6 million higher as we increased our Biomedical and Healthcare grants spend, bringing our total research portfolio to £24.2 million.

Our services and partnerships expenditure also grew by £1.5m in the year mainly through increased grant support, most notably through our Cost of Living Support Fund. We exceeded all our planned commitments to our care grants programme to ensure that people affected by MND continued to receive critical financial support during the ongoing period of economic uncertainty. Campaigning costs also rose as we built on the Association’s heightened awareness through an integrated campaign aligned with the MND storyline in Coronation Street. A record year for income also saw fundraising costs rise proportionately as event costs, transaction fees and merchandise costs all increased.

Even with the increase in costs, the incredibly strong income performance led the Association to a net surplus of £6.8 million. Despite our extremely positive fundraising success over the last three years, we need to maintain the momentum to support our growing care, research and campaigning work which will cost at least £35 million a year, and allow us to continue to strive towards our mission of a world free from MND.

vi) Principal risks and uncertainties

Risk management

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

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

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

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

Reputational risk

Retaining the Association's reputation is paramount. Due to the diverse nature of our activities this risk relates to several areas including our extensive research programme (for example, our policies on the use of animals and embryonic stem cells in research), the provision of care through our MND Care Centres and Networks, the support provided by our Association visitor network, and the extensive activities of more than 13,000 volunteers – which includes those in our campaigns network – across England, Wales and Northern Ireland. Controls and policies relating to all our activities focus on reputational impacts and these are monitored regularly for compliance.

Financial risk

The Association is in a robust financial position having had another very strong year for income in 2024. However, the ongoing cost of living crisis has the potential to impact us on two fronts by making fundraising very challenging, while the need for financial support from the MND community continues to rise. The added risk in relation to the threats of tariffs in the global economy and the potential for this to drive upward inflationary pressures is also a significant concern. To mitigate this, the Association undertakes weekly income and core expenditure reporting so that we can identify and react to any financial pressures which we will manage tightly using our reserves.

While we remain cautious about the financial position in 2025, our strong financial performance and position in 2024 has enabled the auditors to confirm that the Association remains a going concern.

External environment risk

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

Compliance risk

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



Founding members of the MND Association

Structure, Governance and Management

The Association was originally formed on 6 October 1979 and was incorporated as a company limited by membership guarantee in 1986. The Association is governed by its Articles of Association and in the event of it being wound up, every member is liable for an amount not exceeding £1 to facilitate the payment of the debts and liabilities of the Association. At 31 December 2024, there were 12,926 members.

Governance

Our governance structure is designed to ensure that:

- there is strong representation from people living with and affected by MND
- there are strong connections to research teams and health and social care professionals
- the Association is advised by a breadth of specialist organisations and people

- the Association receives comprehensive information and advice to support decision-making
- the Association has flexible mechanisms for engagement with people affected by MND and our supporters.



Board meeting in session



The Board of Trustees

The Board (members of which are directors under company law) is the governing body of the Motor Neurone Disease Association and ordinarily meets in formal session four times a year.

The Articles of Association provide a degree of flexibility for changes to be made to the composition of the Board, subject to there always being a majority of elected trustees over co-opted trustees and there being no more than ten elected trustees, and the Board reviews its composition against these requirements on an annual basis.

All elected and co-opted trustees are provided with a comprehensive induction to the Association, which includes an overview of the organisational strategy and current priorities, together with briefings on the roles and duties of trustees. They receive subsequent development and training through internal coaching and external providers. The Board maintains an updated skills audit against a defined set of skills and this enables it to identify gaps and plan for future recruitment. The Board seeks to maintain and improve its governance arrangements and uses the Charity Governance Code to benchmark its structure and processes against the code's recommended practices.

Committees of the Board

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

Care Services and Research Committee

This committee reviews all aspects of the Association's work relating to improving care and providing support for people with MND, their carers and families. It oversees the strategy, planning and monitoring of the Association's research work with external partners, commitments to UK MND Research Institute and in a clinical research capacity it reviews risk and approves grant funding to support the work of MND Care Centres and Networks, up to an agreed limit, with grants above that limit being approved by the Board.

Engagement and Income Committee

This committee reviews strategic activities, policy, and effectiveness relating to the Association's engagement and fundraising activity work. This includes all aspects of fundraising development and strategy, campaigns and policy and public affairs activity, the marketing and communication work and Access to Treatment plans.



Catherine Knights, trustee

Finance and Audit Committee

This committee provides stewardship of all financial aspects of the charity's work, including the money raised from activities of the Association. The Committee oversees the digital and technology work of the Association, looking at how data and digital can drive innovation.

The committee scrutinises and evaluates the annual budget prior to Board approval. It ensures that the appropriate financial controls and regulatory requirements are adhered to and advises the Board accordingly. The committee also recommends the annual pay award for all employees (excluding the Executive Leadership Team and CEO), to the Board for approval.

Governance Committee

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

People, Culture and Inclusion Committee

This committee reviews all aspect of the charity's work in relation to employees and volunteers looking at their recruitment and retention and their experience of engaging with the Association. The committee also oversees safeguarding responsibilities of the charity and ensures monitoring of the associated risks. It also oversees the diversity and inclusion of the charity, making sure that all employees and volunteers operate in a safe and welcoming place.

Honorary Officer Group

Consisting of the Chairs of Committees, the Honorary Officer Group support the Chair of the Board of Trustees and the CEO in the governance of the Association. The group can also make urgent, essential decisions on behalf of the Board of Trustees when matters arise that require quick decisions.

Remuneration Committee

This committee is responsible for the annual review of the salary and other benefits of the Chief Executive and oversees the remuneration packages of members of the senior management team.

Biomedical and Healthcare Research Advisory Panels

These panels assess applications for funding for biomedical and healthcare research in accordance with guidelines from the Association of Medical Research Charities (AMRC) and in line with the Association's research strategy. They also monitor the progress of our research grants to ensure the research being conducted is in agreement with the terms of the funding. Those

proposals meeting the criteria are then scored, prioritised and recommended to the Board for approval.

Branches, groups and affiliates

At 31 December 2024, the Association had 87 branches and groups and two affiliates (based in Jersey and the Isle of Man). Each branch and group has agreed to abide by our branch and group charter which sets out the parameters of the powers delegated to them by the Board.

Branches and groups, whose financial results are included in these statements, are governed by the Board. The two affiliates are excluded from the consolidation as they are not part of the Association.

Branches and groups provide unique support to people affected by MND at a local level and also fundraise and campaign on their behalf. They raise and spend money locally on support grants, in line with guidelines which are reviewed annually by a support grant group in which volunteers are in the majority. Association staff support them by providing advice and guidance on recruitment and support of volunteers and local structure, organisation and management of their activities.



For over four decades, our amazing branches and groups have been providing local support and companionship for people living with and affected by MND. I've seen first-hand the difference volunteers can make and can't thank them enough.

**Jo Mountney, Director of
People Culture and Inclusion,
MND Association**



A 'Get Connected' networking event in the North West to share good practice between local branches and groups

Environmental impact

We continually strive to monitor and reduce our environmental impact and see sustainability as one of its key priorities. Money saved through environmental efficiencies is diverted into achieving the charity’s strategic objectives.

In 2024 we partnered with sustainability company, Auditel, to begin work to accurately calculate our baseline carbon emissions. With this robust benchmark in place, we will be able to meaningfully identify, implement and track changes to lessen our environmental impact.

In summary scope 1 used 53 units which accounts for 82.78% of our carbon footprint while scope 2 accounted for 11 units, accounting for 17.22%.

We have fully switched our fleet vehicles to hybrid cars and continue to encourage hybrid working, which has reduced the environmental impact of commuting to the office in cars. In 2025, we will be surveying staff to better understand work patterns and travel into the office to determine how we can support the further reduction of our carbon footprint.

For our online shop, we now actively source sustainable products wherever possible, and we are moving to a fully-digital ordering process, removing the need for a printed catalogue.

Over the coming 12 months, as part of our scope 3 emissions we will be analysing our supply chains to record where products we use as an Association, and sell in our online shop, are manufactured and how far they travel. From this we will consider changes to our buying practices to reduce any negative impact on the environment.

We are engaging with staff on this area of our work to embed best practice into decision-making, planning and execution. Our Green Group involves staff from across the Association working with their teams to improve sustainable behaviours in our offices.

Our baseline figures are provided below

2024	Scope	Energy consumed / miles travelled	Govt emissions conversion	Emmissions	Tonnes of carbon dioxide equivalent	% of impact on our carbon footprint	Emissions ratio
Fuel for business mileage	1	197,314.61 miles	0.2686	52,998.7 kg of CO2e	53	82.785	53
Electricity (our buildings)	2	53,265.16 kWh	0.20705	11,028.55211 kg of CO2e	11.03	17.22	11



One of our fleet provided in partnership with Toyota



Sustainable products from our online shop



Executive Leadership Team presenting at one of the Regional Roadshows

Management

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

Safeguarding

The Association provides services to a wide range of people and is committed to meeting the needs of people living with MND, their families and carers. We recognise that some of the people we are in contact with are adults and children or young people who may be at risk of harm. Our safeguarding policies are designed to inform and offer guidance to our staff and volunteers in the management of issues relating to protecting and promoting the welfare of adults and children at risk, and ensures we act appropriately when we become aware of an adult or child who may be at risk of harm. The policies also provide a framework which ensures that our staff and volunteers have the appropriate information and support to enable them to recognise abuse and neglect and to take the necessary steps to prevent it happening. The Association's Safeguarding Board and Board of Trustees regularly review our risk in relation to safeguarding issues and ensure implementation of any actions.

In 2024 we introduced new a safeguarding system and rolled it out to all staff across the Association. Staff are trained to raise concerns to Designated Safeguarding Managers, seek advice and guidance and then record information on the system. This process allows us to have a comprehensive approach to recognising concerns, make appropriate signposting and referrals as necessary and accurate recording and analysis of any lessons learned.

Whistleblowing

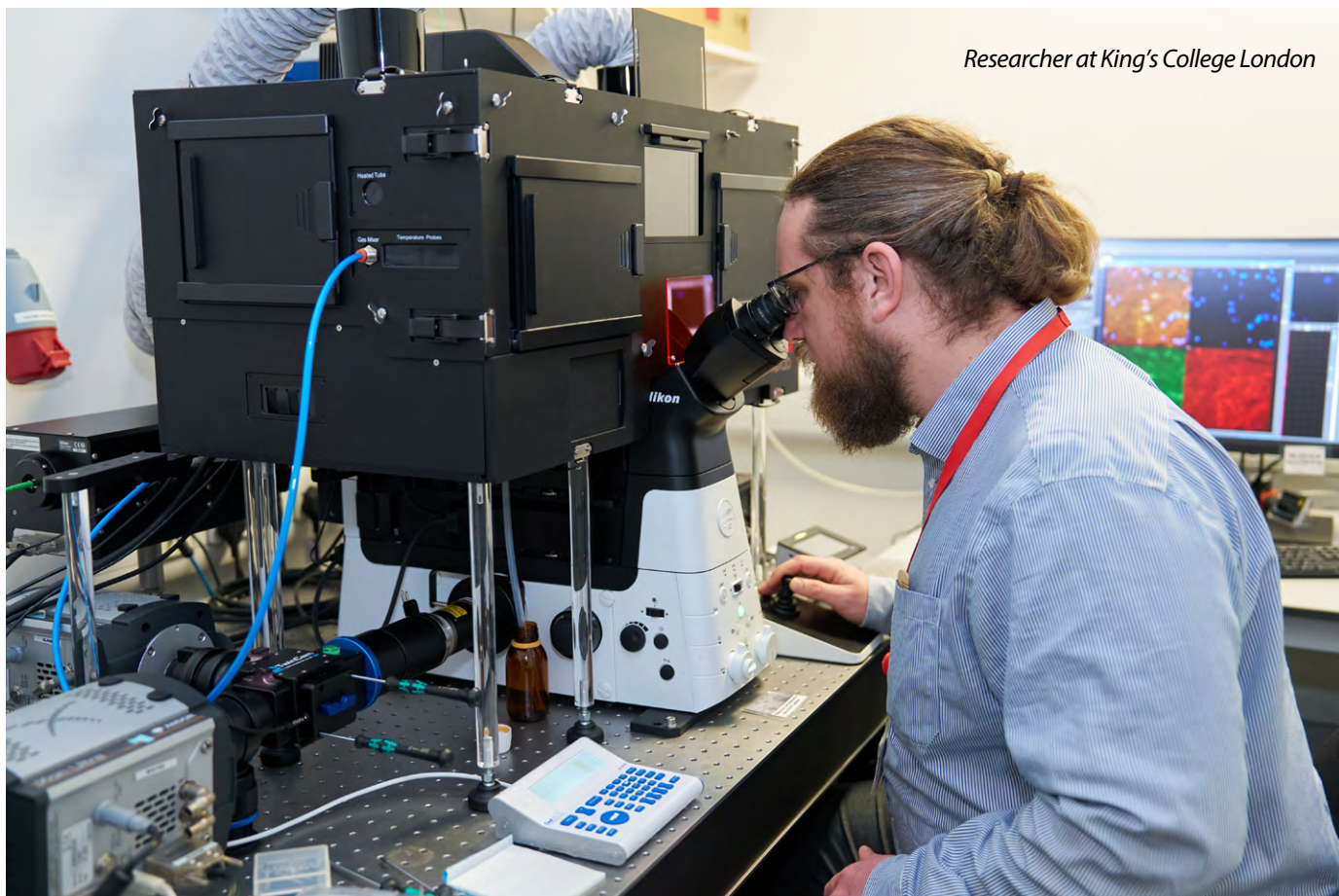
We take any evidence of malpractice very seriously and support anyone who is raising genuinely held concerns. Our up-to-date policies are backed up by mandatory staff and volunteer training.

Grants

Grants are awarded for both research projects and care services:

Research – we award project and programme grants, PhD studentships and Lady Edith Wolfson clinical and non-clinical fellowships. Application and decision-making processes, including comprehensive peer review, are published on the Association's website. These processes conclude with formal approval or rejection of applications by the Board.

Care – We provide grants to existing specialist MND Care Centres and Networks. At 31 December 2024 the Association was providing financial support to 24 such centres and networks.



Performance is monitored annually for existing Care Centres, with a full grant renewal process every four years.

We also offer grants for people who are living with, or affected by MND, including Cost of Living Support Grants, MND Support (Care) Grants and Quality of Life Grants as well as grants for children and young people.



Madeline Kingston attending a voice banking session in Kent

Investment policy

Investments are held to cover reserves for the management of risk and for future investment opportunities. The investment objective is to provide resources to cover short term demands arising from sudden or unexpected events that could influence fundraising income. The trustees take a prudent approach to risk, holding the majority of the Association's investments in cash deposits, near cash and generally recognised cash equivalents (including but not limited to Certificates of Deposit and other short-term investments). Counterparty limits and acceptable credit ratings are set by the Finance and Audit Committee. During the year, the higher than anticipated base interest rate levels and greater investment balances meant that returns on deposit investments improved, earning £1,802,000 in 2024 compared with £1,062,000 in 2023.

In 2022, the Finance and Audit Committee approved an amendment to the Investment Policy that enabled the Association to invest funds in a managed investment portfolio to try and counter the high inflationary impact on our cash reserves. The initial funds (held with Trinity Bridge – formerly Close Brothers Asset Management) totalled £5 million and are in a managed portfolio with strict investment objectives, including the prohibition of investment in organisations whose products may be harmful to people with MND or which contribute to the causes of MND. This portfolio is intended to be retained for the long term and so the financial statements will show these as fixed asset investments and all other cash deposits as current asset investments. This portfolio grew in value by £243,000 in 2024 (£208,000 in 2023).

During 2024, we increased the Association's holding in gilts with Trinity Bridge to a total of £8,000,000 to further diversify the Association's investment portfolio.

Group reserves policy

The trustees have adopted a robust and flexible reserves policy to meet the changing needs of the charity. This states that the unrestricted reserve should be no greater than six months expenditure represented in cash and readily realisable investments, held centrally and within branches. This level of reserves is consistent with the approach taken by many similar sized charities. Based on our 2025 budgets, this is a maximum of £22.8 million.

As at the year end, the unrestricted reserves balance sat at £42.1 million, following successive years of both high income growth and higher than budgeted income. This is significantly higher than is needed to ensure the short-term smooth running of the charity in the event of a sudden decline in income. But Trustees believe that the Association's strategy represents a prudent approach to reducing the level of reserves in a way that enables the Association to have the biggest positive impact towards its mission. As such, we have allocated funds to initiatives that mean the current designated funds will not be fully utilised until the end of 2028.

Details of the allocation of our designated funds can be found in the financial statements.

Statement of Trustees' Responsibilities and Corporate Governance



Jim Marshall, Honorary Treasurer with Dr Usman Khan, Chair of the Board of Trustees

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group and of the incoming resources and application of resources, including the income and expenditure, of the charitable group for that period. In preparing these financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Charities SORP
- Make judgements and accounting estimates that are reasonable and prudent
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in operation.

The trustees are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company and the group's transactions and disclose with reasonable accuracy at any time the financial position of the charitable group and enable them to ensure that the financial statements comply with the Companies Act 2006, the Charity

(Accounts and Reports) Regulations 2008 and the provisions of the charitable company's constitution. They are also responsible for safeguarding the assets of the charitable company and the group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

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

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

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

This **Trustees' Report**, prepared in accordance with the Charities Act 2011 and the Companies Act 2006 was approved by the Board of Trustees on 16 May 2025 including in their capacity as company directors, the strategic report contained therein, and signed on its behalf by:



Dr Usman Khan

Chair, Board of Trustees

16 May 2025

Organisational Information and Financial Statements

Board of Trustees



Chair: Dr Usman Khan



*Honorary Treasurer:
James Marshall*



Dr John Ealing



Hazel Carter



Simon Croxford



Elizabeth Ellis



Catherine Knights



Ian Lev



Dr Shaun McGee



Kirrie Todd



*Ed Cooke (from June 2024
until Feb 2025)*



Alan Graham (from June 2024)



*Michael Hope (from June 2024
until June 2025)*

Executive leadership team



Tanya Curry, Chief Executive



*Mark Chapman,
Director of Finance,
Strategy and Operations*



*Dr Brian Dickie, Director
of Research Development
(until January 2025)*



*Alan Gosschalk, Interim
Director of Fundraising
(until March 2024)*



*Sally Hughes, Director of
Services and Partnerships
(from February 2024)*



*Chris James, Director
of External Affairs
(until May 2024)*



*Jo Mountney, Director of
People, Culture and Inclusion
(from January 2024)*



*Richard Evans – Director of
Engagement (from April 2024)*



*Jo Coker – Director of Income
Generation (from May 2024)*



*Mike Rogers – Director of
Research and Innovation
(from January 2025)*

Company secretary

Mark Chapman

Registered office

Francis Crick House
6 Summerhouse Road
Northampton
NN3 6BJ

Professional advisers

Statutory auditors

HaysMac LLP
10 Queen Street Place
London
EC4R 1AG

Solicitors

Bates Wells
2-6 Cannon Street
London
EC4M 6YH

Bankers

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

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

Independent Auditor's Report to the Members of the Motor Neurone Disease Association

Opinion

We have audited the financial statements of Motor Neurone Disease Association for the year ended 31 December 2024, which comprise the Consolidated Statement of Financial Activities,

The Group and Charity Balance Sheets, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 ***The Financial Reporting Standard applicable in the UK and Republic of Ireland*** (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the groups and of the parent charitable company's affairs as at 31 December 2024 and of the groups and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial

statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

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

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so,

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

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

- adequate accounting records have not been kept by the parent charitable company, or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement set out on page 22, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to regulatory requirements of the Charity Commission, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006 and the Charities Act 2011, Charity SORP and payroll tax.

We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to the posting of inappropriate journal entries and management bias in certain accounting estimates. Audit procedures performed by the engagement team included:

- Inspecting correspondence with regulators and tax authorities;
- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud;
- Evaluating management's controls designed to prevent and detect irregularities;
- Identifying and testing journals, in particular journal entries posted with unusual account combinations, postings by unusual users or with unusual descriptions; and
- Challenging assumptions and judgements made by management in their critical accounting estimates]

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

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

Use of our report

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



Richard Weaver (Senior Statutory Auditor)

5 June 2025

For and on behalf of

HaysMac LLP
10 Queen Street Place
London
EC4R 1AG

Consolidated Statement of Financial Activities

(incorporating an income and expenditure account)

For the year ended 31 December 2024

Company Number (02007023) and Charity Number (294354)

	Notes	Unrestricted funds £000	Restricted funds £000	Total Funds 2024 £000	Total funds 2023 £000
Income and endowments from:					
Donations and legacies:	1a				
Donations		19,785	5,171	24,956	23,436
Legacies		10,593		10,593	10,366
Charitable activities					
Other trading activities	1b	1,773		1,773	1,478
Interest		1,802		1,802	1,062
Other	1c	1,663		1,663	1,580
Total income		35,616	5,171	40,787	37,922
Expenditure on:					
Raising funds		7,596	-	7,596	6,357
Charitable activities:					
Care		10,432	831	11,263	9,583
Research		7,445	3,292	10,737	7,119
Campaigning and raising awareness		2,661	528	3,189	2,792
Volunteer development		1,159	-	1,159	934
Total expenditure	4	29,293	4,651	33,944	26,785
Net income/ (expenditure)	3	6,323	520	6,843	11,137
Other recognised gains/ (losses):					
Other gains/ (losses)		1		1	(18)
Net movement in funds		6,324	520	6,844	11,119
Reconciliation of funds:					
Total funds brought forward		35,892	8,441	44,333	33,214
Total funds carried forward	18a, 19	42,216	8,961	51,177	44,333

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

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

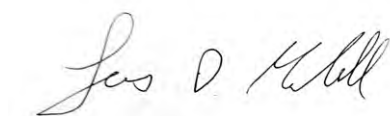
Balance Sheet

For the year ended 31 December 2024

Company Number (02007023) and Charity Number (294354)

		Group		Charity	
	Notes	2024 £000	2023 £000	2024 £000	2023 £000
Fixed assets					
Tangible assets	11a	167	304	167	304
Investments (Long Term)	11b	5,451	5,208	5,451	5,208
Total Tangible Assets		5,618	5,512	5,618	5,512
Current assets					
Stocks	13	29	23	-	-
Debtors	14	12,325	10,136	12,162	10,310
Investments (Short Term))	15	32,623	26,805	32,623	26,805
Cash at bank and in hand		27,162	22,625	26,812	22,242
		72,139	59,589	71,597	59,357
Creditors: amounts falling due within one year					
	16a	17,120	13,494	16,649	13,332
Net current assets		55,019	46,095	54,948	46,025
Total assets less current liabilities		60,637	51,607	60,566	51,537
Creditors: amounts falling due after more than one year					
	17	9,460	7,274	9,460	7,274
Net assets		51,177	44,333	51,106	44,263
Accumulated funds					
Restricted funds	18a	8,961	8,441	8,961	8,441
Designated funds	18a, 18b	19,384	20,222	19,384	20,222
Unrestricted funds:					
Unrestricted funds	18a	22,761	15,600	22,761	15,600
Funds retained in subsidiary	12a	71	70		
		51,177	44,333	51,106	44,263

The financial statements on pages 39 to 63 were approved and authorised for issue by the Board of Trustees on 16th May 2025 and were signed on its behalf by:



James Marshall
Treasurer



Dr Usman Khan
Chair

The net movement in funds for the Association for the year ending 31 December 2024 was £6,844,000 (2023 : £11,119,000).

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

Statement of Cash Flows

For the year ended 31 December 2024

	Notes	2024 £000	2023 £000
Cash flows from operating activities:			
Net income/ (expenditure) for the reporting year		6,844	11,119
Adjustments for:			
Depreciation and amortisation charges	11	231	266
Dividends and interest from investments		(2,132)	(1,206)
(Increase) / decrease in stock	13	(6)	(3)
(Increase) / decrease in debtors	14	(2,189)	(567)
Increase / (decrease) in creditors	16a,17	5,812	2,753
Other adjustment		-	1
Net cash generated from operating activities		8,560	12,363
Cash flows from investing activities:			
Movement in cash held as investment (Increase) / Decrease		(243)	(208)
Dividends and interest from investments		2,132	1,206
Reclassification of share portfolio from investment to Fixed Asset			(5,000)
Purchase of fixed assets	11	(94)	(127)
Net cash used in investing activities		1,795	(4,129)
Increase in cash and cash equivalents in the reporting year		10,355	8,234
Cash and cash equivalents at the start of the year		49,430	41,196
Cash and cash equivalents at the end of the year		59,785	49,430

Analysis of cash and cash equivalents

Group	Balance 1 January 2023 £000	Cash flow changes £000	Balance 1 January 2024 £000	Cash flow changes £000	Balance 31 December 2024 £000
Net cash					
Short term deposits - Transfer of Investment cash to Tangible Assets	24,326	2,479	26,805	5,818	32,623
Bank current accounts	16,867	5,754	22,621	4,537	27,158
Cash in hand	3	1	4	0	4
Net funds	41,196	8,234	49,430	10,355	59,785

Statement of Accounting Policies

Legal Status

The Association is a company limited by guarantee not having a share capital, incorporated in England and Wales (company number: 02007023) and a charity registered in England and Wales (charity number: 294354). The charity's registered office address is 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. The members undertake to contribute to the assets of the company in the event of it being wound up, either whilst members or within one year of the membership ceasing. The maximum contribution required from each member is £1. There were 12,926 members at 31 December 2024 (31 December 2023: 12,231).

Principal accounting policies

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

a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) second edition (effective 1 January 2019) – (Charities SORP FRS 102), and the Companies Act 2006.

The Motor Neurone Disease Association meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Critical accounting judgements and key sources of estimation uncertainty

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

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

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

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

c) Preparation of the accounts on a going concern basis

2024 proved to be another strong year for the charity with reserves increasing and the Association's financial position remaining strong. As such, the trustees consider there are no material uncertainties about the charity's ability to continue as a going concern. Trustees regularly review potential risks and make strategic changes as and when required. The review of the charity's financial position, reserves levels and future plans through to the end of December 2027 gives trustees confidence that the charity remains a going concern for the foreseeable future.

d) Consolidated financial statements

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

In accordance with the exemption afforded by section 408 of the Companies Act 2006 a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared. The surplus of the parent charity was £6,843,000 (2023: surplus £11,137,000).

e) Income

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

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

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

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the

Statement of Accounting Policies (continued)

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

f) Investment income

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

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

g) Fund accounting

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

h) Expenditure and irrecoverable VAT

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

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

- Volunteering costs are those incurred in supporting our large network of volunteers.

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

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

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

j) Operating leases

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

k) Intangible fixed assets

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

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

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

l) Tangible fixed assets

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

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

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

Statement of Accounting Policies (continued)

m) Investments

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

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

Fixed asset investments comprise an investment portfolio held with TrinityBridge (formerly Close Brothers Asset Management). Trustees agreed to invest some of our cash funds into long term investments in order to mitigate high inflationary pressure on cash reserves. These investments are not intended to be cashed in within the next 12 months and so are treated as fixed asset investments.

The investment with TrinityBridge held at the year end is carried in the balance sheet at fair value as at that date.

n) Financial instruments

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

o) Cash at bank and in hand

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

p) Debtors

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

q) Stocks

Stocks are stated at the lower of cost and net realisable value. In general, cost is determined on a first in first out basis and includes transport and handling costs. Net realisable value is the price at

which stocks can be sold in the normal course of business after allowing for the costs of realisation. Provision is made where necessary for obsolete, slow moving and defective stocks.

r) Creditors and provisions

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

s) Long term liabilities

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

t) Employee benefits

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

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

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

u) Taxation

As a registered charity, the Association benefits from being exempt from tax on surpluses generated by its charitable activities.

In 2019 the Association applied for Group VAT status on the basis that it had become financially beneficial for the whole group to be able to recover some elements of VAT, rather than just the Sales Company.

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.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

Income

1a Donations and legacies

	2024 £000	2023 £000
Individuals	5,904	5,986
Community and other fundraising	12,094	10,964
Appeals	1,516	1,890
Charitable foundations (see note 2)	1,399	1,219
Corporate donations	1,578	1,120
Tax recovered	2,465	2,257
	24,956	23,436
Legacies (see note 14)	10,593	10,366
	35,549	33,802

See Statement of Accounting Policies e) for treatment of legacy income

1b Other trading activities

	2024 £000	2023 £000
Charity-organised fundraising	721	377
Merchandise sales and advertising	276	197
Conferences and events	776	904
	1,773	1,478

1c Other

	2024 £000	2023 £000
Costs recovered from the International Alliance / MND Sales	32	31
Medical Research Council Early in career research grants	1,309	1,405
Other	322	144
	1,663	1,580

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

2 Grants receivable from Charitable foundations

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

	2024 £000		2024 £000
Alan Davidson Foundation	152	The Mayhew Charitable Trust	10
My Name's Doddie Foundation	150	The Steel Charitable Trust	10
The Heaton-Ellis Trust	120	The Morrisons Foundation	9
Stand Against MND	100	Assurant Foundation	8
The Folkington Trust	100	Oxygen House Foundation	7
Darby Rimmer MND Foundation	50	The Ofenheim Charitable Trust	7
The Constance Travis Charitable Trust	50	The Antony Hornby Charitable Trust	7
The Talbot Trusts	50	Graham & Mary Stacy Trust	6
Catherine Cirket Discretionary Trust	36	Hyde Park Place Estate Charity	6
Lloyds Bank Foundation for England & Wales	27	The G C Gibson Charitable Trust	6
The Eric Wright Charitable Trust	26	The Orr Mackintosh Foundation	6
David Barnett Charitable Trust	25	Z Zurich Foundation	6
Richard Mackay Charitable Trust	25	The Nora Milburn Charitable Trust	6
The William Brake Foundation	25	The Pamela Cordelia Smith Charitable Trust	5
The Freshfield Foundation	24	Celtic FC Foundation	5
The BNA Charitable Incorporated Organisation	22	Charles S French Charitable Trust	5
Edith Murphy Foundation	16	David Lister Charitable Trust	5
The Frank Brake Charitable Trust	15	John and Diana Kemp-Welch Charitable Trust	5
The Liz and Terry Bramall Foundation	15	M K Rose Charitable Trust	5
The Malcolm Gunter Foundation	15	Sir John Priestman Charity Trust	5
The Prowting Charitable Foundation	15	The 29th May 1961 Charitable Trust	5
The Annandale Charitable Trust	12	The Belstead Ganzoni Charitable Settlement	5
The Geoffrey & Pauline Martin Trust	12	The Billmeir Charitable Trust	5
NPT Transatlantic Ltd	12	The Cadogan Charity	5
Peacock Charitable Trust	11	The Chalk Cliff Trust	5
P F Charitable Trust	10	The Dyers' Company Charitable Trust	5
The 3 Ts Charitable Trust	10	The L & R Gilley Charitable Trust	5
The Elizabeth and Prince Zaiger Trust	10	The Leslie Mary Carter Charitable Trust	5
The Fieldrose Charitable Trust	10	The Light Fund Charity	5
The Forbes Charitable Trust	10	The Marlow Trust	5
The Goldcrest Charitable Trust	10	The Simon Gibson Charitable Trust	5
The Ian Fleming Charitable Trust	10	The Theodore Maxxy Charitable Trust	5
The Jones 1986 Charitable Trust	10	The Tula Trust Ltd	5
The Joron Charitable Trust	10		
The Louis Nicholas Residuary Charitable Trust	10	TOTAL	1,399

In 2023, grants receivable from Charitable foundations totalled £1,219,000

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

3 Net income for the year

This arises after charging:

	2024 £000	2023 £000
Auditors' remuneration:		
External audit	31	35
Internal audit	17	15
Operating lease rentals:		
Motor vehicles	249	298
Land and buildings	435	247
Other	68	10
Depreciation and amortisation of owned assets	231	266

4 Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Notes	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2024 £000	Total 2023 £000
Care and care centres		4,841	4,610	1,812	11,263	9,583
Research		1,286	9,143	308	10,737	7,119
Campaigning and raising awareness		2,442	-	747	3,189	2,792
Volunteering		964	-	195	1,159	934
Costs of charitable activity		9,533	13,753	3,062	26,348	20,428
Raising funds		5,852	-	1,744	7,596	6,357
Total resources expended 2024		15,385	13,753	4,806	33,944	26,785
Total resources expended 2023	23a	13,601	9,270	3,914		26,785

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

5 Support costs

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

	Care £000	Research £000	Campaigning and raising awareness £000	Volunteering £000	Raising funds £000	Total 2024 £000	Total 2023 £000
Management	296	49	121	31	283	780	626
Governance	48	9	20	4	45	126	128
Finance	188	31	76	20	182	497	481
Information, Technolgy & Digital	684	114	281	71	659	1,809	1,479
Facilities	334	56	137	35	322	884	674
Human resources	255	42	105	27	246	675	521
Conferences and events	7	7	7	7	7	35	5
	1,812	308	747	195	1,744	4,806	3,914

Full details of prior year support costs can be found in note 23b

6 Grants payable

Grants were awarded during the year as follows:

	2024 £000	2023 £000
Grants to institutions (note 6b)	10,412	6,690
Grants to individuals	3,341	2,580
	13,753	9,270

Grants made to, and for, individuals affected by motor neurone disease are for expenses such as respite care, building adaptations and equipment rental.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

6 Grants payable (continued)

	2024 £000	2023 £000
Balance at start of year	18,124	15,729
Awarded in year	13,753	9,270
Paid in year	(8,019)	(6,875)
Balance at end of year	23,858	18,124
Falling due within one year (note 16a)	14,398	10,850
Falling due after more than one year (note 17)	9,460	7,274
	23,858	18,124

Commitments

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

Group and Charity	2024 £000	2023 £000
Payable within one year	1,286	1,084
	1,286	1,084

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

6b Grants payable split by benefactor

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

	2024 £000			2024 £000	
King's College London	1,901	Research	Barts Care Centre	64	Care
University College London	1,273	Research	University Hospitals of North Midlands NHS Trust	61	Care
University of Sheffield	1,201	Research	Norfolk/Norwich Care Centre	61	Care
University of Edinburgh	939	Research	University Hospital, Birmingham	56	Care
Trinity College Dublin	437	Research	John Radcliffe Hospital, Oxford	54	Care
Cardiff University	432	Research	Cambridge	53	Care
University Of Manchester	404	Research	Sheffield Care Centre	52	Care
Great Western Hosp NHS Forndation Trust	268	Research	University of Queensland	49	Research
University of Oxford	267	Research	University of Liverpool	49	Research
University of Aberdeen	267	Research	LifeArc	41	Research
Norfolk and Norwich University Hospitals NHS Foundation Trust	257	Research	AMC	41	Care
Queen Mary University of London	254	Research	South West London Care Centre	34	Care
University of East Anglia	240	Research	Lancashire and South Cumbria / Preston	33	Care
University of Plymouth	151	Research	The Dipex Charity	26	Research
Istituto di Ricerche Farmacologiche Mario Negri	142	Research	Belfast	26	Care
University of St Andrews	136	Research	Universtiy of Sheffield	23	Research
University College Cork	133	Research	Manchester Care Centre	12	Care
University of Exeter	132	Research	Columbia University	10	Research
Nottingham University Hospital	120	Care	University of Sussex	10	Research
King's College London	86	Care	Manchester Metropolitan University	10	Research
University of Dundee	85	Research	Sussex MND Care and Research Network	9	Care
Plymouth Primary Care Trust (S. West)	77	Care	ISFTD (International Society for Frontotemporal Dementias)	7	Research
The James Cook Uni Hosp (M'Boro)	73	Care	Southampton	5	Care
Liverpool Care Centre	73	Care			
S Wales Care Network (Cardiff)	72	Care			
Leeds Care Centre	70	Care			
Bristol Care Centre	70	Care			
National Hospital, London	66	Care			
			TOTAL	10,412	

In 2023, grants payable totalling £6,690,000 were made

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

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

The employment costs of all employees were:

	2024 £000	2023 £000
Gross wages and salaries	9,048	7,858
Social security costs	950	801
Other pension costs	618	558
Medical insurance	20	12
	10,636	9,229

The total number of employees whose emoluments for the year (not including pension contributions) exceeded £70,000 relates to all of the seven members of the senior management team in position throughout 2024. These emoluments are identified as follows:

	2024	2023
£140,000 - £149,999	1	
£130,000 - £139,999		1
£100,000 - £109,999	1	1
£90,000 - £99,999	3	3
£80,000 - £89,999	1	2
£70,000 - £79,999	1	2
£60,000 - £69,999	17	8

Employers pension contributions for the seven higher paid employees above are £42,668 for the year ended 31 December 2024 (2023: £52,870).

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

	2024 £000	2023 £000
Gross wages and salaries	640	692
Benefits-in-kind	1	1
Pension costs	43	53
Social security costs	72	77
	756	823

Trustee remuneration and expenses	2024 £000	2023 £000
Reimbursement directly to trustees	2	3
Payment to third parties in respect of trustee expenses	6	2
	8	5

Number of trustees holding office during the year	14	16
---	----	----

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

The charity trustees neither received nor waived any emoluments during the year (2023: £nil). Trustee expenses in the year include travel and subsistence expenses totalling £8,500 (2023: £4,787). These expenses were all incurred in the course of their duties and were reimbursed, or paid directly to third parties on their behalf as shown above. Trustee indemnity insurance is held at a cost of £1,573 (2023: £1,573).

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

8 Staff numbers

	2024 Headcount	2023 Headcount
Care	90	86
Research	15	15
Campaigning and raising awareness	37	29
Volunteering	9	10
Raising funds	87	75
	238	215

Staff numbers above include an appropriate apportionment of support staff.

9 Pension costs

The Association operates defined contribution personal pension schemes for employees. The assets of the schemes are held separately from those of the Association in funds independently administered by Royal London. The amounts paid to the funds represent contributions from both the employer and employees. The employer's contributions in the year were £618,885 (2023: £558,486). There are no other ongoing obligations arising. Amounts outstanding at year end were £0 (2023: £0).

10 Taxation

The 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 2023.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

11a Fixed assets

Group and Charity	Motor vehicles £000	Computers, fixtures, fittings and equipment £000	Total tangible fixed assets £000	Total intangible fixed assets* £000
Cost				
At 1 January 2024		1,854	1,854	46
Additions	-	94	94	-
Disposals	-	-	-	-
At 31 December 2024	-	1,948	1,948	46
Depreciation and amortisation				
At 1 January 2024		1,550	1,550	46
Charged in the year	-	231	231	-
Eliminated on disposal	-	-	-	-
At 31 December 2024	-	1,781	1,781	46
Net book value				
At 31 December 2024	-	167	167	-
At 31 December 2023	-	304	304	-

* Intangible fixed assets comprises purchased software licences.

11b Fixed Assets - Investments (Long Term)

Group and Charity	2024 £000	2023 £000
Market value at 1 January	5,208	5,000
Acquisitions at cost		
Sale proceeds from disposals	-	-
Gain / (Loss) in year	243	208
Market value at 31 December	5,451	5,208
TrinityBridge - Asset Portfolio	5,451	5,208
	5,451	5,208

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

12 Fixed asset investments

Motor Neurone Disease (Sales) Limited

The Association owns a wholly owned subsidiary company, Motor Neurone Disease (Sales) Limited, which is registered in England and Wales (Company number: 01989172) at Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. This subsidiary operates mail order catalogues selling promotional clothing, gifts and cards and runs Challenge and other fundraising events. All taxable profits are donated to the Association each year under Gift Aid. Audited accounts are filed with the Registrar of Companies, and below is a summary of its trading results for the year ended 31 December 2024:

Motor Neurone Disease (Sales) Limited Income Statement	2024 £000	2023 £000
Turnover	587	492
Cost of sales	(549)	(481)
Gross profit	38	11
Administration costs	(34)	(26)
Profit / (Loss) before interest and tax	4	(15)
Net interest payable	(3)	(3)
Profit / (Loss) on ordinary activities before tax	1	(18)
Corporation tax	-	-
Profit / (Loss) for the financial year	1	(18)

The aggregate of the assets, liabilities and funds was:

	2024 £000	2023 £000
Assets	664	635
Liabilities	(593)	(565)
Funds (representing 2 ordinary shares of £1 each)	71	70
Profit gifted to charity in following year		
Net funds after transfer of profit	71	70

The investment held by the Charity of £2 (2023: £2) represents shares in the subsidiary company at cost.

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

	2024 £000	2023 £000
Gross income	40,787	37,922
Surplus for the year	6,843	11,137

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

13 Stock

	Group		Charity	
	2024 £000	2023 £000	2024 £000	2023 £000
Purchased goods for resale	29	23	-	-

14 Debtors

	Group		Charity	
	2024 £000	2023 £000	2024 £000	2023 £000
Loan to subsidiary company	-	-	50	50
Amounts due from subsidiary company	-	-	73	353
Legacies	11,274	8,767	11,100	8,903
Other debtors	270	507	131	132
Income tax reclaimable	449	592	449	592
Prepayments	332	270	359	280
	12,325	10,136	12,162	10,310

15 Current asset investments

The total of current asset investments £32,623,181 (2023: £26,805,389) is constituted by fixed term and other bank and building society deposits with maturity dates within 12 months.

16a Creditors: amounts falling due within one year

	Group		Charity	
	2024 £000	2023 £000	2024 £000	2023 £000
Accruals for grants payable	14,398	10,850	14,398	10,850
Trade creditors	1,543	1,359	1,527	1,346
Accruals and deferred income (note 16b)	878	819	507	753
Payroll taxation and social security	103	223	103	223
Provisions and other creditors (note 21)	198	243	114	160
	17,120	13,494	16,649	13,332

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

16b Analysis of deferred income

	Group		Charity	
	2024 £000	2023 £000	2024 £000	2023 £000
Deferred income at 1 January	8	195	8	195
Released during the year	(263)	(195)	(178)	(195)
Deferred during the year	435	8	435	8
Deferred income at 31 December	180	8	265	8

17 Creditors: amounts falling due after one year

	Group		Charity	
	2024 £000	2023 £000	2024 £000	2023 £000
Research & Care Centre Creditors	9,460	7,274	9,460	7,274
	9,460	7,274	9,460	7,274

18a Statement of funds

	Group			Charity			Balance at 31 December 2024 £000
	Balance at 1 January 2023 £000	Income £000	Expenditure £000	Balance at 1 January 2024 £000	Income £000	Expenditure £000	
Group and Charity							
Unrestricted funds:							
General funds	11,488	23,251	(19,069)	15,670	7,456	(294)	22,832
Designated funds:							
Care Centre grants	881	1,084	(881)	1,084	1,286	(1,084)	1,286
Research & Strategic Investment	15,266	6,475	(2,603)	19,138		(1,040)	18,098
note 18b	16,147	7,559	(3,484)	20,222	1,286	(2,124)	19,384
Total unrestricted funds	27,635	30,810	(22,553)	35,892	8,742	(2,418)	42,216

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

18a Statement of funds (continued)

Group and Charity	Balance at 1 January 2023 £000	Income £000	Expenditure £000	Balance at 1 January 2024 £000	Income £000	Expenditure £000	Balance at 31 December 2024 £000
Restricted funds:							
Research	2,906	5,249	(1,983)	6,172	3,517	(3,292)	6,397
Care	861	1,399	(1,810)	450	955	(831)	574
Volunteering	-			-			-
Branches and Groups	1,812	430	(423)	1,819	685	(514)	1,990
Campaigning	-	34	(34)	-	14	(14)	-
Total restricted funds	5,579	7,112	(4,250)	8,441	5,171	(4,651)	8,961
Total funds	33,214	37,922	(26,803)	44,333	13,913	(7,069)	51,177

Charity		Balance at 1 January 2023 £000	Income £000	Expenditure £000	Balance at 1 January 2024 £000	Income £000	Expenditure £000	Balance at 31 December 2024 £000
Unrestricted funds:								
General funds		11,400	23,477	(19,277)	15,600	7,455	(294)	22,761
Designated funds	note 18b	16,147	7,351	(3,276)	20,222	1,286	(2,124)	19,384
		27,547	30,828	(22,553)	35,822	8,741	(2,418)	42,145
Restricted funds		5,579	7,112	(4,250)	8,441	5,171	(4,651)	8,961
Total funds		33,126	37,940	(26,803)	44,263	13,912	(7,069)	51,106

Restricted Funds

Restricted funds are utilised as follows:

Research	for grant payments to be made enabling various research projects to continue
Care	for equipment and care / support provided to people living with MND
Branches and Groups	for care for people with MND within local areas
Campaigning	for raising awareness of MND across England, Wales and Northern Ireland

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

18b Designated funds

Designated funds represent:

	2024 £000	2023 £000
i) the amounts committed by the Association in respect of grants payable for the MND Care Centre Network not reflected in the Consolidated Statement of Financial Activities. Care Centre commitments run for up to 4 years and so the funds designated for these are required to meet future commitments on agreed contracts extending to 2025.	1,286	1,084
ii) In recent years the Board has designated significant funds to Research activities. The specific activities for which these funds will be used are details below: a) £5m to support a high-profile international research prize to encourage new researchers to join the search for a cure. b) £2m to support the activities of the UK MND Research Institute over the next 3-4 years. c) £1.5m to support the Acorn Plus Biobank initiative. This is a plan to extend the existing biobank initiative at Oxford University which created a national register for plwMND and family members carrying the C9orf72 gene. d) £0.8m supporting additional Healthcare innovation grants to help with evidence to influence NICE guidelines nationally as well as some strategic local influencing opportunities.	9,263	9,386
iii) In 2023, the Board approved a scheme to provide a network of Research Nurses across the Association's Care Centres & Networks. £5m was set aside for this initiative. The ultimate aims of the Research Nurse role and programme are to: • Promote clinical trials and recruitment of people with MND - ensuring equitable access across England, Wales and Northern Ireland. • Enhance clinical research capacity as part of the core delivery model. By developing research active MND care teams we aim to ultimately improve the outcomes for people with MND. • Ensure patients have timely access to relevant clinical trials - promoting choice, control and hope for people living with this terminal disease.	4,963	5,000
iv) Trustees agreed to designate £5m of the surplus income from 2021/22 to support the delivery of our promises. These funds have been allocated to the following initiatives: • £1.4m modernising our outdated systems so that they are fit for purpose. Significant investment need to bring our Fundraising, Grants, HR, Recruitment and Learning & Development systems up to date and drive efficiency. • £1.0m for technology & innovation grants as the Association moves forward with its technology & innovation plans to find solutions to bring greater choice to plwMND. £250k will be awarded in each of the next 4 years to institutions. • £0.7m for various Services & Partnerships initiatives through 2025. This includes development of a NICE audit tool, support for the MND Views website initiative, continuing support for the Think Tank, a community specialist programme and a community of practice programme (DeMaNDs). • £0.3m to provide on-going support for our integrated campaign activity building towards greater awareness of MND. This commitment will be spent through 2025. • the balance of these funds will be used to provide further investment in grants to support the needs of people living with MND and DEI initiatives to bring inclusive service provision.	3,796	4,577
v) Provision of access to multi-disciplinary care	76	175
	19,384	20,222

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

19 Analysis of net assets between funds

2024

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Group:				
Fund balances at 31 December 2024 are represented by:				
Fixed assets	-	-	167	167
Net current assets less long-term liabilities	8,961	19,384	22,665	51,010
Total net assets	8,961	19,384	22,832	51,177

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2024 are represented by:				
Fixed assets	-	-	167	167
Net current assets less long-term liabilities	8,961	19,384	22,594	50,939
Total net assets	8,961	19,384	22,761	51,106

2023

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Group:				
Fund balances at 31 December 2023 are represented by:				
Fixed assets	-	-	304	304
Net current assets less long-term liabilities	8,441	20,222	15,366	44,029
Total net assets	8,441	20,222	15,670	44,333

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2023 are represented by:				
Fixed assets	-	-	304	304
Net current assets less long-term liabilities	8,441	20,222	15,296	43,959
Total net assets	8,441	20,222	15,600	44,263

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

20 Leasing commitments

Operating leases

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

	2024 £000	2023 £000
Within one year	334	278
Between two to five years	657	601
Over five years	-	108
	991	987

The charge to the Statement of Financial Activities is £434,605 (2022: £323,147).

21 Provisions for liabilities and charges

Charity	Leasehold dilapidations £000	Bad debts (incl Legacy) £000	Obsolete stock £000	Total £000
At 1 January 2024	99	86	-	185
Additions	-	18	-	18
Utilised	-	-	-	-
Balance at 31 December 2024	99	104	-	203

Group	Leasehold dilapidations £000	Bad debts £000	Obsolete stock £000	Total £000
At 1 January 2024	99	86	-	185
Additions	-	18	-	18
Utilised	-	-	-	-
Balance at 31 December 2024	99	104	-	203

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

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

22. PRIOR Year - Consolidated Statement of Financial Activities (incorporating an income and expenditure account)

For the year ending 31 December 2023

	Unrestricted Funds £000	Restricted Funds £000	Total Funds 2023 £000
Income and endowments from:			
Donations and legacies:			
Donations	16,324	7,112	23,436
Legacies	10,366	-	10,366
Charitable activities	-	-	-
Other trading activities	1,478	-	1,478
Investments	1,062	-	1,062
Other	1,580	-	1,580
Total income	30,810	7,112	37,922
Expenditure on:			
Raising funds	6,357	-	6,357
Charitable activities:			
Care	7,773	1,810	9,583
Research	5,136	1,983	7,119
Campaigning and raising awareness	2,335	457	2,792
Volunteer development	934	-	934
Total expenditure	22,535	4,250	26,785
Net gain / (loss) on investments	-	-	-
Net income for the year	8,275	2,862	11,137
Other recognised gains/ (losses) :			
Gains/ (losses) on revaluation of fixed assets	-	-	-
Other gains/ (losses)	(18)	-	(18)
Net movement in funds	8,257	2,862	11,119
Reconciliation of funds:			
Total funds brought forward	27,635	5,579	33,214
Total funds carried forward	35,892	8,441	44,333

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

23 Prior year figures

23a Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2023 12 months £000
Care and care centres	3,976	4,042	1,565	9,583
Research	1,613	5,228	278	7,119
Campaigning and raising awareness	2,261	-	531	2,792
Volunteering	757	-	177	934
Costs of charitable activity	8,607	9,270	2,551	20,428
Raising funds	4,994	-	1,363	6,357
Total resources expended 2023 (12 months)	13,601	9,270	3,914	26,785

23b Support costs

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

	Care £000	Research £000	Campaigning awareness £000	Volunteering £000	Raising funds £000	Total 2023 12 months £000
Management	251	44	85	28	218	626
Governance	51	9	18	5	45	128
Finance	192	34	65	22	168	481
Digital	166	29	56	19	144	414
Information and communications technology	426	76	144	48	371	1,065
Facilities	270	48	91	30	235	674
Human resources	208	37	71	24	181	521
Conferences and events	1	1	1	1	1	5
	1,565	278	531	177	1,363	3,914

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

23 Prior year figures (continued)

23c Analysis of net assets between funds

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Group:				
Fund balances at 31 December 2023 are represented by:				
Fixed assets	-	-	304	304
Net current assets less long-term liabilities	8,441	20,222	15,366	44,029
Total net assets	8,441	20,222	15,670	44,333
Charity:	£000	£000	£000	£000
Fund balances at 31 December 2023 are represented by:				
Fixed assets	-	-	304	304
Net current assets less long-term liabilities	8,441	20,222	15,296	43,959
Total net assets	8,441	20,222	15,600	44,263



Motor Neurone Disease Association
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton, NN3 6BJ

Tel: 01604 250505

Email: enquiries@mndassociation.org

www.mndassociation.org

Royal Patron: HRH The Princess Royal

Registered Charity No 294354, Company Limited by Guarantee No 2007023

©MND Association 2025 AnnReport/24

Front Cover: Ken Blackburn who is living with MND and his wife Kay at the York Regional Roadshow

MOTOR NEURONE DISEASE ASSOCIATION

England & Wales - Charity number 294354

Accounts

Annual Report

and Consolidated Financial Statements

For the year ended 31 December 2023

**20
23**

Message from the Chair

2023 has been a busy year for the Association. We welcomed our new Chief Executive, Tanya Curry who has led the organisation with purpose and gusto. This year has been one of more – more investment in research, more care and support given to people living with or affected by MND, more financial grants given, more fundraising activity and another astonishing Kevin Sinfield CBE challenge.

I am continuously inspired by the dedication and commitment of our staff, volunteers and members working together to deliver the five Promises we made to the MND community. And, in recognition of the importance of collaboration, we have strengthened our relationships with other charities, partners and institutions to increase our reach and continue to raise awareness of MND.

None of this would have been possible without another record-breaking fundraising year with our income nearing £38 million. I want to thank all of our loyal fundraisers, supporters and donors for their incredible and generous support.

At the end of 2023, our rich and diverse community has been one voice behind one vision – a world free from MND.

I hope you enjoy reading about our achievements in 2023 as much as I have.



Dr Usman Khan

Chair, Board of Trustees



BUCKINGHAM PALACE

In my 15th year as Royal Patron of the MND Association, I was pleased to attend three very different but equally interesting events, thanking supporters and highlighting the charity's work. The first engagement was an evening reception with supporters which focused on women who have excelled in sport, hosted by the British Olympic Association.

In the summer, I attended the first MND Association Care Showcase, hosted by the Duke of Buccleuch at Boughton House. This focused on the improvement and development of support for people with MND and I heard more about the work of the Association's National Care Team and the difference it is making.

Significant developments in technology are also having a positive impact in supporting people in their daily lives, which was highlighted at the Summit of Technology event I attended in July. It will be interesting to see how future collaboration with partners and businesses with complementary skills and expertise continues to drive this work.

I am also encouraged to see collaboration between charities with similar goals. As in so many walks of life, working together brings many benefits. In our case, of course, these benefits will be felt by people with, and affected by, MND.

I congratulate you all on your commitment and dedication to the MND community and wish you all every success for the year ahead.

A handwritten signature in black ink, appearing to read 'Anne', with a long horizontal flourish extending to the right.

Contents

Trustees' Report (including the Strategic Report)	5
i. Objectives and activities	5
ii. Achievements and performance in 2023	5
iii. Future plans and priorities	8
iv. Fundraising governance priorities	8
v. Financial review	9
vi. Principal risks and uncertainties	10
Structure, Governance and Management	12
Statement of Trustees' Responsibilities and Corporate Governance	15
Organisational Information	16
Independent Auditor's Report	17
Statement of Financial Activities	19
Consolidated Balance Sheet	20
Consolidated Cash Flow Statement	21
Statement of Accounting Policies	22
Notes to Financial Statements	25

Trustees' Report

The trustees are pleased to submit their Report on the Charity's activities together with the Financial Statements for the year ended 31 December 2023, which have been prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102), the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) – (2nd Edition, effective 1 January 2019) and the Companies Act 2006.

About MND

Motor neurone disease (MND) is a rapidly progressing neurological disease that affects the brain and spinal cord. More than 5,000 people in the UK are living with MND at any one time and the lifetime risk of being diagnosed with MND is around one in 300.

As symptoms progress, MND can leave people locked inside a failing body, unable to move, talk, swallow or even breathe.

Every day, six people are diagnosed with MND. Another six people die.

There are currently no effective treatments. There is no cure.

i) Objectives and activities

About us

The MND Association (the Association) was founded in 1979 by a group of volunteers, all with their own personal experience of MND.

Over the years, the Association has grown into the vibrant community we know today, made up of members, volunteers, campaigners, supporters and staff from across England, Wales and Northern Ireland.

As well as being the biggest charitable funder of MND research in the UK, the Association focuses on improving access to care, providing support, and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland.

Our community is united behind one clear vision – **a world free from MND.**

Our charitable objects as stated in our Articles of Association

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

The Association commissions, undertakes, promotes, monitors and manages research into all aspects of motor neurone disease

and its associated conditions and causes, and works towards their prevention and cure and to publish and disseminate the useful results for the benefit of the public.

Public benefit

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

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

ii) Achievements and performance in 2023

This year, the incredible support we receive from our supporters and donors has enabled us to take advantage of many new opportunities, particularly when it comes to campaigning for better provision and raising awareness of MND and the funding of new research which we believe will pave the way for new treatments and the promise of a cure.

We have also taken the opportunity to look closely at the services we offer, working collaboratively with people living with MND, their families and carers to ensure the work we do delivers the right support at the right time.

Our Promise: We won't rest until MND is treatable and ultimately curable

The MND Association is at the forefront of the global fight against MND, as a visionary, a trusted partner and a leading authority on MND research for more than 40 years.

At the end of December 2023, the value of the MND Association's research portfolio had grown to a record commitment of £20.7 million, funding 109 grants. These grants are awarded through a competitive process. Only those of the highest scientific merit and greatest relevance, with the greatest potential for achieving our vision of a world free from MND are selected.

Continued, targeted investment in MND research over many decades – alongside the enduring dedication of our supporters – has paved the way for significant progress in facilitating new partnerships this year, with a focus on emerging precision medicine and the pioneering use of Artificial Intelligence (AI) which is being used to accelerate the mining of genetic material to help identify new drug targets.

The progression of research means new opportunities in the field of emerging treatments. We continue to work collaboratively with MND Scotland and My Name's Doddie Foundation and other experts from the wider MND community, with a focus on people with MND gaining equitable and timely access to effective, proven treatments. Throughout the year, together, we have continually monitored the national and international research landscape of potential treatments that are currently involved in clinical trials while engaging with regulators, healthcare providers and Government agencies to ensure an efficient response. People living with MND have remained central to the approach we have taken to the regulatory and approval process challenges, sharing their views and opinions to ensure the Association's work remains fully informed.

The extraordinary support of the Association's loyal supporters, fundraisers and donors has ignited revolutionary new research projects which aim to accelerate the search for effective treatments for MND.

Alongside our partners at LifeArc and My Name's Doddie Foundation, the MND Association jointly awarded £1 million to researchers at University College London (UCL) and £0.5 million to researchers at the University of Newcastle, to progress research into potential cutting-edge therapies for MND, through the £1.5 million MND Translational Research Fund.

The Association also committed £0.5 million to MND-SMART, the UK's largest MND clinical drug trial which is testing a series of drugs that have already been approved as treatments for other diseases. More than 500 participants have been recruited to this ground-breaking trial.

A project, led by Professor Guillaume Hautbergue at the University of Sheffield, supported by joint funding from the MND Association and LifeArc, received a further £5 million investment from the business community to take the research through the next drug development stages. The researchers have uncovered a potential new method of preventing nerve cell death in the most common genetic form of MND. It is hoped these findings will lead to the development of a therapy for those with the C9orf72 gene, which currently affects around 5-10% of people with MND.

With collaboration very much at its heart, the Association was at the launch of the UK MND Research Institute at King's College London in November. The Institute has been borne out of a shared vision of people with MND, researchers and MND charities to provide a virtual hub for researchers and clinicians to share ideas, knowledge and expertise in order to create a springboard towards new treatments and the promise of a cure.

Elsewhere, the Association has been a conduit for conversation and change. In July, our second EnCouRage UK two-day event focused on showcasing, supporting and developing early career researchers who represent the future of MND research.

While at the end of the year, we welcomed 1,300 people from 48 countries to our 34th International Symposium on ALS / MND. Hosted in Basel, Switzerland, our first in-person, overseas event since 2019 gave delegates the chance to share the latest ideas and discoveries, and develop partnerships and collaborations.

Further investment in the future has been made available through a pre-fellowship programme, funded in partnership with MND

Scotland, with the aim of training future leaders. In 2023, three pre-fellowships were offered to researchers who will investigate a wide range of topics, from developing potential drugs to clarifying possible sub-groups of MND.

Our Promise: We won't rest until everyone gets the care they need when they need it

Empowering people with MND to live as independently as possible for as long as possible has been a key focus of our work throughout 2023.

We recognise there are still some places across England, Wales and Northern Ireland where people living with MND cannot access the care and support they need. We have listened and taken prompt action to identify those areas with the greatest need, developing and nurturing partnerships with the NHS to improve the range of services available to people living with MND, their carers, and their families.

In the West Midlands, the Association funded a new MND Care Co-ordinator post at the Birmingham MND Care Centre to improve its capacity to deliver and improve care for people with MND living across the region. We awarded extra funding to six services in Northern Ireland, Newcastle, Middlesbrough, Nottingham, Derby and Oxford to provide targeted additional resources and we are also funding a number of new Community Specialist posts taking us into the heart of communities.

In addition, we have reviewed the guideline on MND produced by the National Institute for Care Excellence (NICE) and laid out our recommendations for amendments to the current guidance, which will empower health and social care professionals to provide the very best care possible.

In June, the Association held its annual Care Centre and Network Day, the first in-person event to be held since 2019, with the theme **Partnerships for Success – The Way Forward for MND Care**. The event provided a unique opportunity for directors and co-ordinators from 22 Association-funded Care Centres and Networks to come together to learn, share experiences and focus on improving care for people living with MND.

The MND Association's Wheelchair Support Service provided more than £102,000 in support grants, enabling 136 people with MND to access wheelchair accessories such as powerpacks, risers, attendant controls and powered elevated leg rests. We are grateful to The Wolfson Foundation which generously donated £75,000 to the MND Association to enable us to continue this life-changing work.

Working alongside our partners at national children's charity Barnardo's, we have cut the time it takes for children to access professional support, when a family member is diagnosed with MND, from 12 to 18 months to no more than seven days.

As well as providing 289 counselling sessions during the year, in January, the Children and Young People's team, together with the North Lancashire and South Cumbria support group, organised a family fun day at Bendrigg Lodge in Kendal, providing an opportunity for families affected by MND to meet, share quality time together and create powerful, lasting memories.

Our Promise: We won't rest until every day with MND counts

People living with MND remain firmly at the heart of everything we do and through the collective power of our community and our partnerships, we are developing new ways to provide support.

Our work with technology giants including Rolls-Royce and Google took centre stage at a showcase summit of technology in July attended by the Association's Royal Patron, HRH The Princess Royal. The Next Gen Think Tank's revolutionary projects include the award-winning, voice-banking e-book ***I Will Always Be Me, Project Relate, Quips*** and ***Mind's Eye***, an art app which unlocks the potential of AI to enable people living with MND to embrace their creativity.

As well as developing access to emerging technology and high quality, multidisciplinary care, the MND Association has offered practical support in the form of grants to individuals which totalled in excess of £2.2 million this year. Thanks to the incredible generosity of our supporters, the Association has been able to ease the burden MND places on those affected, particularly with the challenges faced by many through the cost of living crisis. Throughout the year our dedicated Welfare Benefits Service has provided information and support to people living with MND who may be eligible for additional state benefits and support. The service identified £3.6 million worth of benefits which could be claimed by 1,037 people living with MND.

Working alongside 600 people from across our community, we have taken the opportunity to evaluate our support grants programme. Overall, the response suggested it is working well, with many people saying grants have helped them to feel supported and allowed them to make special memories. In the year ahead, we will raise awareness of the programme, improve guidance about the application process and maximise partnership opportunities to ensure people living with MND are able to benefit from as much support as possible.

In communities across England, Wales and Northern Ireland our amazing volunteers continue to offer a network of one-to-one support to people living with MND when it is needed most.

Through regular phone calls, emails, personal visits and texts, our 357 Association visitors (AVs) and co-ordinators were on hand to offer advice and guidance, while our 87 branches and groups provided a safe space and local point of contact for anyone in need of friendship and support.

Our Promise: We won't rest until you are heard

We maximise every opportunity to raise awareness of MND and amplify the voices of people affected by MND to bring the reality of the disease to life for millions of people, inspiring many to support us in their own unique way.

In 2023, we were privileged to work alongside the creative teams of two iconic British television programmes – BBC's ***Casualty*** and ITV's ***Coronation Street*** – to develop prominent storylines about characters living with MND. ***Casualty*** sensitively told the story of someone who was living with MND and the challenges they faced while viewers of ***Coronation Street*** watched character

Paul Foreman, played by Peter Ash, come to terms with his diagnosis in June.

With the eyes of the nation firmly upon MND, the Association seized the opportunity to create and develop an integrated campaign to raise further awareness of MND. This campaign will be delivered throughout 2024.

The enduring power of the friendship between former Leeds Rhinos rugby players Rob Burrow CBE and Kevin Sinfield CBE continues to inspire people. Some 15,000 runners – including more than 2,300 running on behalf of the MND Association – took part in the inaugural Rob Burrow Leeds Marathon and Half Marathon in May, collectively raising £1.76 million. In December, Kevin undertook his fourth challenge, ***7 in 7 in 7*** which saw him run seven ultra marathons in seven cities in just seven days, an extraordinary accomplishment which raised £460,000 for the Association, secured significant coverage on BBC's ***Breakfast*** and inspired new people to support the Association, for which we are extremely grateful.

This heightened awareness has given the Association a springboard on which to launch campaigns and open robust conversations with those in authority to help bring about meaningful change.

In January, our report, ***The provision of care for people living with motor neurone disease in Northern Ireland***, shone the spotlight on the lack of services available. The Association called for the development of a Northern Ireland MND Regional Care Network to provide multidisciplinary care, support for unpaid family carers and improved access to housing adaptations.

The Association's first ***Act to Adapt*** Action Week took place in April, raising awareness of the importance of home adaptations. Alex Herd, KT Wong and Sam Hayden-Harler all shared their very personal experiences on our social media channels amplifying this crucial message and driving forward our campaign.

Ensuring carers have the support they need has been the focus of a new phase in our ***Support MND Carers*** campaign. We engaged with delegates at the Local Government Association Conference in July, raising awareness among councillors and local authority staff.

Nationally, Parliamentarians, researchers, campaigners and people affected by MND gathered in the House of Lords to mark 20 years of the All-Party Parliamentary Group (APPG) on MND, which meets regularly to discuss issues affecting people living with MND and raise awareness at the very highest level.

Parliament buildings across England, Wales and Northern Ireland were the backdrop for events coinciding with Global MND Awareness Day in June. Over three consecutive days, our teams raised awareness of MND among Parliamentarians and decision-makers and empowered them to make a difference.

Throughout the year we have been incredibly grateful to the many people living with MND who have willingly shared their stories to inform much of the Association's work. We are honoured to have the continued support of our Royal Patron, HRH The Princess Royal, our patrons – including Rob Burrow CBE and Kevin Sinfield CBE – our ambassadors and supporters, who do so much.

Our Promise: We won't rest until no one faces MND alone

Regardless of background, gender, faith or sexual orientation, MND is unrelenting and the MND Association offers help and support to all.

Breaking down any barriers which may stop people from accessing that vital support is crucial, and this year our focus has centred around additional help for anyone for whom English is not their first language, while building strong relationships within all communities.

At a recent event, non-English speakers were matched with staff or volunteers with compatible language skills. They were invited to join a telephone call where staff and volunteers could gain an understanding of their individual needs, and explain what support is available from the Association including care information leaflets in their own language. Through our Diversity Equity Ethnic Minority (DEEM) Network group, we trialled language specific support groups, providing peer support to people in their preferred language. The first of these was aimed at Hindi speaking people living with MND and their families.

In North West Wales, widely considered the heartland of the Welsh-speaking nation, our North West Wales Group funded two bilingual support meetings, offering a place where people affected by MND could come together in a relaxed, informal environment and chat in both Welsh and English. Being able to speak freely in a chosen language provides both reassurance and comfort, and boosts an important emotional connection.

In July, West London and Middlesex Branch members approached the West London Queer Project, to raise awareness of MND. This inspired an event to mark the start of Pride Month with a sponsored 10km Thames Park Walk in aid of the West London and Middlesex Branch, raising £2,158. People living with and affected by MND, branch members, volunteers and staff also joined tens of thousands of LGBTQ+ people and allies to support Manchester Pride.

Meanwhile, a Veterans Support Group was launched specifically for service personnel affected by MND to help reduce loneliness. The forum gives them space to relive their former active lives with like-minded people. Two further network groups – EMBRACE for members of the Black Asian and Minority Ethnic community and PRIDE for the LGBTQIA+ community have been created for staff, volunteers and people living with MND.

While we have taken important steps forward, we understand there is still much more to do. The Association has already started a review around the accessibility and inclusivity of all our public facing products and services and we were delighted to move to the next level of the Confident-Employer scheme, in recognition of our practical and awareness raising work around disability.

We would like to thank

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

Remembering

All those members of the MND community who died from MND this year. As we remember their courage and their contribution to the work of the Association, they will continue to inspire our fight against MND and remind us of the need to do everything we can to support those living with the disease and those closest to them.

iii) Future plans and priorities

The strength in our financial position will ensure we can continue with the work needed to progress our fight against MND. As we enter a period in which we will review our future strategy to ensure it best supports the needs of people with and affected by MND, we do so knowing we have resources available to make a real difference to our community.

The recent advancements in research, leading to real hope for people with MND, must continue. We now have £9.4 million allocated in our designated reserves to support future activity with the UK MND Research Institute; progress more translational research; support the MND Smart programme; and to help with genetic testing and counselling. Partnership funding with Government and other charities, including LifeArc, will continue to help the development of the UK MND Research Institute. This is in addition to the Association's existing portfolio of research grants which exceeded £20 million in value at the end of 2023.

Our success in 2023 has also given trustees the opportunity to allocate £5 million of our surplus to an exciting new five year initiative which will see more than 20 research nurses introduced into our Care Centres and Networks. These specialist roles will form the cornerstone of ambitious plans to ensure that, in the future, everyone diagnosed with MND will have the support and opportunity to take part in research and clinical trials as part of their holistic care.

Our vital work in the area of access to emerging treatments will continue, both through our own channels and in collaboration with others, most importantly people with MND, who are helping inform our direction while also sharing their compelling stories to make the strongest case.

Our My MND My Needs survey was our most comprehensive survey of people with MND. Already the results are informing our thinking as we work to develop future services and partnerships. We look forward to sharing more about this work and the drive for improvement over the coming year.

To learn more about our commitment to the MND community and our priorities, or to get involved, visit www.mndassociation.org/MNDPromises

iv) Fundraising governance priorities

We have a diverse portfolio of fundraising activities including raising funds from individuals, trusts and foundations, companies, events, local communities and legacies. We approach our supporters via direct mail, email, telephone, online and directly at events, and manage this fundraising both centrally and locally through our branches and groups.

We comply with current regulations and best practice set out by regulatory and professional membership bodies including the Fundraising Regulator, the Institute of Fundraising, the Gambling Commission and the Advertising Standards Authority.

We are registered with the Fundraising Regulator and are committed to the Fundraising Preference Service, honouring any requests from the public to end contact with us. We fundraise in line with the Code of Fundraising Practice and adhere to data protection law. We are committed to ensuring that we are completely open and transparent about our fundraising and spending. As members of the Fundraising Regulator’s self-regulatory scheme, we comply with its principles in all our fundraising:

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

Due to the nature of delivering fundraising across multiple sites, we are aware that the potential for breaches of fundraising code of practice and data protection compliance exist. We manage and minimise these risks through training and inductions for new starters and for our branches and groups; through quality checks and audits, and through our compliance policies.

As the MND Association, we acknowledge that the engagement of third parties can help us raise funds, as well as improve efficiency and reduce costs. We require that any third party we work with complies with data protection legislation as set out in the Code of Fundraising Practice including the requirements of the telephone, mailing, e-mailing and fundraising preference services.

We follow a robust procurement process when recruiting third parties to work on our behalf, making sure we apply appropriate due diligence and contracts for this activity. We work closely with these third parties, regularly reviewing their activity against performance targets and the Fundraising Code of Practice to ensure delivery of the best value for money for the charity and its supporters.

When we benefit from commercial companies raising funds on our behalf through the sale of products, we operate within a

written agreement to ensure their activities are not harmful to the Association. Trustees regularly review the fundraising strategy and are made aware of any significant new activities and/or contracts where values need to be carefully aligned.

We received 18 complaints about our fundraising activity in 2023. All were promptly resolved without the need for escalation to the Fundraising Regulator. Complaints are taken very seriously and reviewed quarterly by the Board of Trustees. There is a complaints policy, available on our website, which forms the basis for the training of all fundraising staff.

All fundraisers at the MND Association are guided in how to protect vulnerable people including how to recognise a person in vulnerable circumstances. All our direct mail, emails and thank you letters contain clear instructions as to how a supporter can easily opt out of receiving further communications from the charity should they choose to do so.

v) Financial review

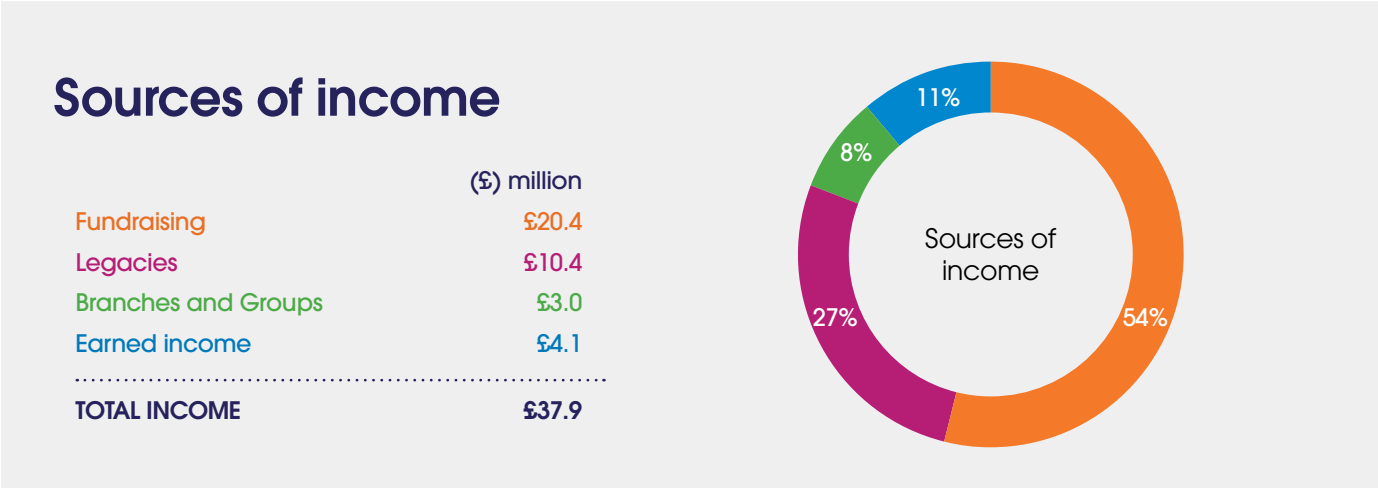
The MND Association is a company limited by guarantee and is registered in England and Wales. These financial statements are for the group which comprises both the Association and its wholly owned trading company Motor Neurone Disease (Sales) Ltd. The results for the year are set out in the Consolidated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

Financial performance

2023 was an incredibly successful year for fundraising at the Association, with total income reaching almost £38 million in the 12 month period for the first time ever. This compares with £30 million in 2022.

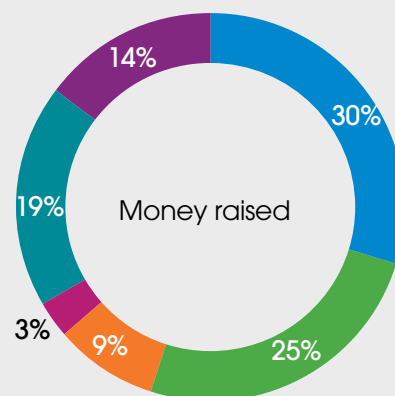
The increased focus on MND in the media and the high profile fundraising events that took place contributed to a record year. All areas of fundraising had a strong year, most notably legacy donations which accounted for 27% of the income received.

£20.4 million was raised and donated by our incredible supporters and a record £3 million was raised by our branches and groups.



How we spent the money raised

	(£) million
Care	£8.0
Research	£6.8
Campaigning	£2.3
Volunteer development	£0.8
Fundraising	£5.0
Operational Support Costs	£3.9
TOTAL COSTS	£26.8



We are tremendously grateful for their commitment and continued support.

£10.4 million was donated in 2023 in the form of legacy gifts which continue to make such a huge difference to the work we do. We are enormously grateful to the people who choose to remember the work of the Association in their Wills.

For every pound spent directly generating fundraising and legacy income, £6.80 was received.

Our expenditure year-on-year increased by £4million. This increase reflected increased spend on our core activities as the Association grew to meet the needs of our community. The biggest uplift was in care expenditure which was almost £1.2 million higher as we offered increased grant support, most notably through our emergency grant. We exceeded all our planned commitments to our care grants programme to ensure that people affected by MND continued to receive critical financial support during the cost of living crisis.

Campaigning costs also rose £0.8m as we built on the Association's heightened awareness through an integrated campaign and focussed on developing research outcomes through the creation of an access to treatments working group.

A record year for income also saw fundraising costs rise proportionately in line with income as event costs, transaction fees and merchandise costs all increased.

Despite the increase in costs, the incredibly strong income performance led the Association to a net surplus of £11.1 million. The Board of Trustees has agreed to designate £5 million of this surplus to support our research nurse initiative which will bring much needed support to our MND Care Centres and Networks. More details of this initiative can be found in the **Future Plans and Priorities** section.

Despite our extremely positive fundraising success over the last two years, we need to maintain the momentum to support our growing care, research and campaigning work which will cost at least £30 million a year, and allow us to continue to strive towards our mission of a world free from MND.

vi) Principal risks and uncertainties

Risk management

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

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

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

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

Reputational risk

Retaining the Association's reputation is paramount. Due to the diverse nature of our activities this risk relates to several areas including our extensive research programme (for example, our policies on the use of animals and embryonic stem cells in research), the provision of care through our MND Care Centres and Networks, the support provided by our Association visitor network, and the extensive activities of more than 13,000 volunteers – which includes those in our campaigns network –

across England, Wales and Northern Ireland. Controls and policies relating to all our activities focus on reputational impacts and these are monitored regularly for compliance.

Financial risk

While the Association had an incredibly strong year for income in 2023, we remain very aware of the risk to future income as household incomes are impacted by significant costs of utilities, inflation and stubbornly high interest rates. The impact on the Association could lead to reduced income generation at the same time as the need for further financial support grows from our community. To mitigate this risk, the Association undertakes weekly income and core expenditure reporting so that we can identify and react to any financial pressures which we will manage tightly using our reserves.

While we remain cautious about the financial position in 2024, the robust performance in 2023 has significantly reduced our financial risk and means that the Association will begin the year in a much stronger position than anticipated. The strong financial position has enabled the auditors to confirm that the Association remains a going concern.

External environment risk

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

Compliance risk

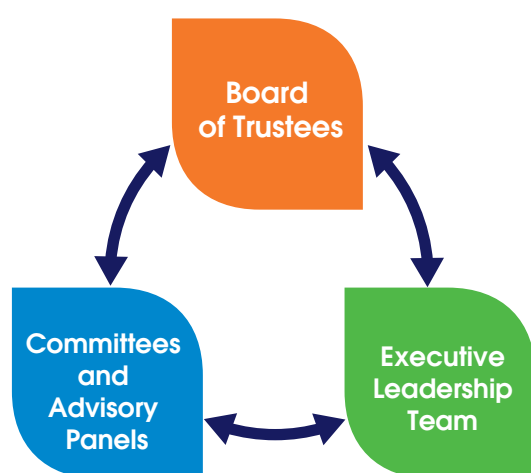
The Association must comply with a range of legal and regulatory requirements including charity law, data protection, fundraising standards, health and safety and safeguarding. To mitigate these risks the Association has robust and embedded processes and policies, which are complemented by regular and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

Structure, Governance and Management

Structure

The Association was originally formed on 6 October 1979 and was incorporated as a company limited by membership guarantee in 1986. The Association is governed by its **Articles of Association** and in the event of it being wound up, every member is liable for an amount not exceeding £1 to facilitate the payment of the debts and liabilities of the Association. At 31 December 2023, there were 12,231 members.

Governance



Our governance structure is designed to ensure that:

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

The Board of Trustees

The Board (members of which are directors under company law) is the governing body of the Motor Neurone Disease Association and ordinarily meets in formal session four times a year.

The Articles of Association provide a degree of flexibility for changes to be made to the composition of the Board, subject to there always being a majority of elected trustees over co-opted trustees and there being no more than ten elected trustees, and the Board reviews its composition against these requirements on an annual basis.

All elected and co-opted trustees are provided with a comprehensive induction to the Association, which includes an overview of the organisational strategy and current priorities, together with briefings on the roles and duties of trustees. They receive subsequent development and training through internal coaching and external providers. The Board maintains an updated skills audit against a defined set of skills and this enables it to identify gaps and plan for future recruitment. The Board seeks to maintain and improve its governance arrangements and uses the Charity Governance Code to benchmark its structure and processes against the code's recommended practices.

Committees of the Board

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

Care Services and Research Committee

This committee reviews all aspects of the Association's work relating to improving care and providing support for people with MND, their carers and families. It oversees the strategy, planning and monitoring of the Association's research work with external partners, commitments to UK MND Research Institute and in a clinical research capacity. It reviews risk and approves grant funding to support the work of MND Care Centres and Networks, up to an agreed limit, with grants above that limit being approved by the Board.

Engagement and Fundraising Committee

This committee reviews strategic activities, policy, and effectiveness relating to the Association's engagement and fundraising activity work. This includes all aspects of fundraising development and strategy, campaigns and policy and public affairs work, the marketing and communication work and Access to Treatment work.

Finance and Audit Committee

This committee provides stewardship of all financial aspects of the charity's work, including the money raised from activities of the Association. The Committee oversees the digital and technology work of the Association, looking at how data and digital can drive innovation.

The committee scrutinises and evaluates the annual budget prior to Board approval. It ensures that the appropriate financial controls and regulatory requirements are adhered to and advises the

Board accordingly. The committee also recommends the annual pay award for all employees (excluding the Executive Leadership Team and CEO), to the Board for approval.

Governance Committee

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

People, Culture and Inclusion Committee

This committee reviews all aspect of the charity's work in relation to employees and volunteers looking at their recruitment and retention and their experience of engaging with the Association. The committee also oversees safeguarding responsibilities of the charity and ensures monitoring of the associated risks. It also oversees the diversity and inclusion of the charity, making sure that all employees and volunteers operate in a safe and welcoming place.

Honorary Officer Group

Consisting of the Chairs of Committees, the Honorary Officer Group support of the Chair of the Board of Trustees and the CEO in the governance of the Association. The group can also make urgent, essential decisions on behalf of the Board of Trustees when matters arise that require quick decisions.

Remuneration Committee

This committee is responsible for the annual review of the salary and other benefits of the Chief Executive and oversees the remuneration packages of members of the Executive Leadership Team.

Biomedical and Healthcare Research Advisory Panels

These panels assess applications for funding for biomedical and healthcare research in accordance with guidelines from the Association of Medical Research Charities (AMRC) and in line with the Association's research strategy. They also monitor the progress of our research grants to ensure the research being conducted is in agreement with the terms of the funding. Those proposals meeting the criteria are then scored, prioritised and recommended to the Board for approval.

Branches, groups and affiliates

At 31 December 2023, the Association had 87 branches and groups and two affiliates (based in Jersey and the Isle of Man). Each branch and group has agreed to abide by our branch and group charter which sets out the parameters of the powers delegated to them by the Board.

Branches and groups, whose financial results are included in these statements, are governed by the Board. The two affiliates are excluded from the consolidation as they are not part of the Association.

Branches and groups provide unique support to people affected by MND at a local level and also fundraise and campaign on their behalf. They raise and spend money locally on support grants, in line with guidelines which are reviewed annually by a support grant group in which volunteers are in the majority. Association staff support them by providing advice and guidance on recruitment and support of volunteers and local structure, organisation and management of their activities.

Environmental impact

The Association initiates and monitors changes to process and practice that reduce its environmental impact and sees sustainability as one of its key priorities.

Since moving to our new national office at Francis Crick House in January 2020 we have encouraged hybrid working leading to significant reduction in travel and meeting costs as staff work from home more regularly. Our online shop offering was relaunched in 2022 to introduce a sustainable products range and we now actively source sustainable products wherever possible. We also continue to replace our car fleet with new hybrid vehicles.

In 2024 we have targeted a full baseline assessment which will be followed by review of key processes around sourcing of equipment, merchandise used in fundraising, and day-to-day consumables. We will also be reviewing the channels by which we communicate with our community.

Money saved through environmental efficiencies is diverted into achieving the charity's strategic objectives.

Management

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

Safeguarding

The Association provides services to a wide range of people and is committed to meeting the needs of people living with MND, their families and carers. We recognise that some of the people we are in contact with are adults and children or young people who may be at risk of harm. Our safeguarding policy is designed to inform and offer guidance to our staff and volunteers in the management of issues relating to protecting and promoting the welfare of adults and children at risk, and ensures we act appropriately when we become aware of an adult or child who may be at risk of harm. The policy also provides a framework

which ensures that our staff and volunteers have the appropriate information and support to enable them to recognise abuse and neglect and to take the necessary steps to prevent it happening. The Association's Safeguarding Board and Board of Trustees regularly review our risk in relation to safeguarding issues and ensure implementation of any actions.

Whistleblowing

We take any evidence of malpractice very seriously and support anyone who is raising genuinely held concerns. We reviewed these policies in detail in 2023 and they are backed up by mandatory staff and volunteer training.

Grants

Grants are awarded for both research projects and care services:

Research – we award project and programme grants, PhD studentships and Lady Edith Wolfson clinical and non-clinical fellowships. Application and decision-making processes, including comprehensive peer review, are published on the Association's website. These processes conclude with formal approval or rejection of applications by the Board.

Care – We provide grants to existing specialist MND Care Centres and Networks. At 31 December 2023 the Association was providing financial support to 22 such centres and networks. Performance is monitored annually for existing Care Centres, with a full grant renewal process every four years.

We also offer grants for people who are living with, or affected by MND, including Cost of Living Support Grants, MND Support (Care) Grants and Quality of Life Grants as well as grants for children and young people.

Investment policy

Investments are held to cover reserves for the management of risk and for future investment opportunities. The investment objective is to provide resources to cover short term demands arising from sudden or unexpected events that could influence fundraising income. The trustees take a prudent approach to risk, holding the majority of the Association's investments in cash deposits, near cash and general recognised cash equivalents (including but not limited to Certificates of Deposit and other short-term investments). Counter party limits and acceptable credit ratings are set by the Finance and Audit Committee. Any investment donated to the Association will ordinarily be sold at the earliest opportunity unless there is a specific request from the donor for the shares to be held as fixed asset investments. During the year, the base interest rate increases meant that returns on deposit investments improved, earning £1,062,000 in 2023 compared with £276,000 in 2022.

In 2022, the Finance and Audit Committee approved an amendment to the Investment Policy that enabled the Association to invest funds in a managed investment portfolio to try and counter the high inflationary impact on our cash reserves. The initial funds (held with Close Brothers Asset Management)

totalled £5 million and are in a managed portfolio with strict investment objectives, including the prohibition of investment in organisations whose products may be harmful to people with MND or which contribute to the causes of MND. This portfolio is intended to be retained for the long term and so the financial statements will show these as fixed asset investments and all other cash deposits as current asset investments. This portfolio grew in value by £208,000 in 2023.

During 2023, an additional £3 million was invested with Close Brothers Asset Management in short term Gilts to further diversify the Association's investment portfolio.

Group reserves policy

The trustees have adopted a robust and flexible reserves policy to meet the changing needs of the charity. This states that the general reserve should be no greater than six months general expenditure represented in cash and readily realisable investments, held centrally and within branches. Based on our 2024 expenditure plans, this is a maximum of £15.6 million. As at the year end, the unrestricted/undesignated reserves balance sat at £15.6 million. Trustees believe that this remains a prudent level given the continuing uncertainty associated with the future economic outlook which could have a detrimental impact on our ability to raise funds.

Any general funds in excess of the target limit for general reserves are required to be allocated into designated funds with trustees agreeing how these funds will be utilised. In 2023, £5 million was designated by trustees to support our recently announced investment in research nurses. The holding of designated reserves allows the Association to commit to long-term initiatives in support of our Promises and the needs of people living with MND, their families and support networks and so are a key part of our future plans. The growth in these reserves over recent years means the Association will be able to accelerate our long-term plans, knowing we have the financial resources to deliver them. The initiatives to which they are allocated, especially research, take time to identify and will then be spread over a number of years and so it is anticipated that the current funds will not be fully utilised until the end of 2027. Details of the allocation of our designated funds can be found in the financial statements.

Statement of Trustees' Responsibilities and Corporate Governance

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group and of the incoming resources and application of resources, including the income and expenditure, of the charitable group for that period. In preparing these financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Charities SORP
- Make judgements and accounting estimates that are reasonable and prudent
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in operation.

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

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

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

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

This **Trustees' Report**, prepared in accordance with the Charities Act 2011 and the Companies Act 2006 was approved by the Board of Trustees on 20 May 2023 including in their capacity as company directors, the strategic report contained therein, and signed on its behalf by:



Dr Usman Khan

Chair, Board of Trustees

17 May 2024

Organisational information and financial statements

Board of Trustees

Chair: Dr Usman Khan

Vice Chair: Catherine Knights

Honorary Treasurer: James Marshall

Dr John Ealing (from February 2023)

Hazel Carter (from July 2023)

Simon Croxford

Elizabeth Ellis

Susan Fletcher-Watts (until November 2023)

Dr Katherine Jackson (until December 2023)

Dr Usman Khan

Catherine Knights

Ian Lev

James Marshall

Debra Martin

Dr Shaun McGee

Siobhán Rooney (until July 2023)

Katherine Styles (until July 2023)

Kirrie Todd

Senior management team

Tanya Curry, Chief Executive

Linda Allen, Director of Fundraising (until June 2023)

Mark Chapman, Director of Finance

Dr Brian Dickie, Director of Research Development

Nick Goldup, Director of Care Improvement
(until December 2023)

Alan Gosschalk, Interim Director of Fundraising
(from July 2023 to March 2024)

Sally Hughes, Director of Services and Partnerships
(from February 2024)

Chris James, Director of External Affairs

Jo Mountney, Director of People, Culture and Inclusion
(from January 2024)

Richard Trotter, Interim Director of HR
(from May 2023 to December 2023)

Chris Wade, Director of Engagement (until April 2023)

Company secretary

Mark Chapman

Registered office

Francis Crick House
6 Summerhouse Road
Northampton
NN3 6BJ

Professional advisers

Statutory auditors

haysmacintyre LLP
10 Queen Street Place
London
EC4R 1AG

Solicitors

Bates Wells
2-6 Cannon Street
London
EC4M 6YH

Bankers

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

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

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

Opinion

We have audited the financial statements of Motor Neurone Disease Association for the year ended 31 December 2023, which comprise the Consolidated Statement of Financial Activities, The Group and Charity Balance Sheets, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 ***The Financial Reporting Standard applicable in the UK and Republic of Ireland*** (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 December 2023 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

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

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

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

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

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

- adequate accounting records have not been kept by the parent charitable company, or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report.

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement set out on page 15, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to regulatory requirements of the Charity Commission, and we considered the

extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006 and the Charities Act 2011, Charity SORP and payroll tax.

We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to the posting of inappropriate journal entries and management bias in certain accounting estimates. Audit procedures performed by the engagement team included:

- Inspecting correspondence with regulators and tax authorities;
- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud;
- Evaluating management's controls designed to prevent and detect irregularities;
- Identifying and testing journals, in particular journal entries posted with unusual account combinations, postings by unusual users or with unusual descriptions; and
- Challenging assumptions and judgements made by management in their critical accounting estimates]

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

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

Use of our report

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



Richard Weaver (Senior Statutory Auditor)

10 June 2024

For and on behalf of Haysmacintyre LLP, Statutory Auditor, 10 Queen Street, London, EC4R 1AG

Consolidated Statement of Financial Activities

(incorporating an income and expenditure account)

For the year ended 31 December 2023

Company Number (02007023) and Charity Number (294354)

	Notes	Unrestricted funds £000	Restricted funds £000	Total Funds 2023 £000	Total funds 2023 £000
Income and endowments from:					
Donations and legacies:	1a				
Donations		16,324	7,112	23,436	19,519
Legacies		10,366		10,366	8,888
Charitable activities					
Other trading activities	1b	1,478		1,478	906
Investments		1,062		1,062	276
Other	1c	1,580		1,580	456
Total income		30,810	7,112	37,922	30,045
Expenditure on:					
Raising funds		6,357	-	6,357	4,910
Charitable activities:					
Care		7,773	1,810	9,583	7,802
Research		5,136	1,983	7,119	7,473
Campaigning and raising awareness		2,335	457	2,792	1,952
Volunteer development		934	-	934	659
Total expenditure	4	22,535	4,250	26,785	22,796
Net income/ (expenditure)	3	8,275	2,862	11,137	7,249
Other recognised gains/ (losses):					
Other gains/ (losses)		(18)		(18)	(9)
Net movement in funds		8,257	2,862	11,119	7,240
Reconciliation of funds:					
Total funds brought forward		27,635	5,579	33,214	25,974
Total funds carried forward	18a, 19	35,892	8,441	44,333	33,214

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

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

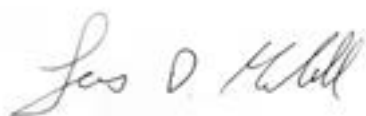
Balance Sheet

As at 31 December 2023

Company Number (02007023) and Charity Number (294354)

		Group		Charity	
	Notes	2023 £000	2022 £000	2023 £000	2022 £000
Fixed assets					
Tangible assets	11a	304	444	304	444
Investments (LT)	11b	5,208	5,000	5,208	5,000
Total Tangible Assets		5,512	5,444	5,512	5,444
Current assets					
Stocks	13	23	20	-	-
Debtors	14	10,136	9,569	10,310	10,335
Investments	15	26,805	19,326	26,805	19,326
Cash at bank and in hand		22,625	16,870	22,242	16,483
		59,589	45,785	59,357	46,144
Creditors: amounts falling due within one year	16a	13,494	12,551	13,332	12,998
Net current assets		46,095	33,234	46,025	33,146
Total assets less current liabilities		51,607	38,678	51,537	38,590
Creditors: amounts falling due after more than one year	17	7,274	5,464	7,274	5,464
Net assets		44,333	33,214	44,263	33,126
Accumulated funds					
Restricted funds	18a	8,441	5,579	8,441	5,579
Designated funds	18a, 18b	20,222	16,147	20,222	16,147
Unrestricted funds:					
Unrestricted funds	18a	15,600	11,400	15,600	11,400
Funds retained in subsidiary	12a	70	88		
		44,333	33,214	44,263	33,126

The financial statements on pages 19 to 43 were approved and authorised for issue by the Board of Trustees on 17 May 2024, and were signed on its behalf by:



James Marshall
Treasurer



Dr Usman Khan
Chair

The net movement in funds for the Association for the year ending 31 December 2023 was £11,119,000 (2022 : £7,240,000).

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

Statement of Cash Flows

For the year ended 31 December 2023

Company Number (02007023) and Charity Number (294354)

	Notes	2023 £000	2022 £000
Cash flows from operating activities:			
Net income/ (expenditure) for the reporting year		11,119	7,240
Adjustments for:			
Depreciation and amortisation charges	11	266	263
Gift Aid donation from subsidiary (reversal)		-	
Intercompany eliminated on consolidation			
Dividends and interest from investments		(1,206)	(276)
Gain on disposal of fixed assets	11	-	-
(Increase) / decrease in stock	13	(3)	2
(Increase) / decrease in debtors	14	(567)	(1,669)
Increase / (decrease) in creditors	16a,17	2,753	2,813
Other adjustment		1	
Net cash generated from operating activities		12,363	8,373
Cash flows from investing activities:			
Cost of additions to investments			-
Movement in cash held as investment (Increase) / Decrease		(208)	
Proceeds from sales of investments		-	-
Decrease in cash element of investment portfolio (Shares not realised)		-	-
Dividends and interest from investments		1,206	276
Reclassification of share portfolio from investment to Fixed Asset		(5,000)	
Purchase of fixed assets	11	(127)	(125)
Net cash used in investing activities		(4,129)	151
Increase in cash and cash equivalents in the reporting year		8,234	8,524
Cash and cash equivalents at the start of the year		41,196	32,672
Cash and cash equivalents at the end of the year		49,430	41,196

Analysis of cash and cash equivalents

Group	Balance 1 January 2022 £000	Cash flow changes £000	Balance 1 January 2023 £000	Cash flow changes £000	Balance 31 December 2023 £000
Net cash					
Short term deposits	17,238	7,088	24,326	2,479	26,805
Bank current accounts	15,431	1,436	16,867	5,754	22,621
Cash in hand	3	(0)	3	1	4
Net funds	32,672	8,524	41,196	8,234	49,430

Statement of Accounting Policies

Legal Status

The Association is a company limited by guarantee not having a share capital, incorporated in England and Wales (company number: 02007023) and a charity registered in England and Wales (charity number: 294354). The charity's registered office address is 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. The members undertake to contribute to the assets of the company in the event of it being wound up, either whilst members or within one year of the membership ceasing. The maximum contribution required from each member is £1. There were 12,231 members at 31 December 2023 (31 December 2022: 11,154).

Principal accounting policies

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

a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) second edition (effective 1 January 2019) – (Charities SORP FRS 102), and the Companies Act 2006.

The Motor Neurone Disease Association meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Critical accounting judgements and key sources of estimation uncertainty

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

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

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

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

c) Preparation of the accounts on a going concern basis

Despite the economic uncertainty post-pandemic, 2023 proved to be another strong year for the charity with reserves increasing and the Association's financial position remaining strong. As such, the trustees consider there are no material uncertainties about the charity's ability to continue as a going concern. Trustees regularly review potential risks and make strategic changes as and when required. The review of the charity's financial position, reserves levels and future plans through to the end of December 2026 gives trustees confidence that the charity remains a going concern for the foreseeable future.

d) Consolidated financial statements

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

In accordance with the exemption afforded by section 408 of the Companies Act 2006 a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared. The surplus of the parent charity was £11,137,000 (2022: surplus £7,249,000).

e) Income

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

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

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

Statement of Accounting Policies (continued)

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

f) Investment income

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

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

g) Fund accounting

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

h) Expenditure and irrecoverable VAT

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

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

- Volunteering costs are those incurred in supporting our large network of volunteers.

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

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

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

j) Operating leases

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

k) Intangible fixed assets

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

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

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

l) Tangible fixed assets

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

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

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

Statement of Accounting Policies (continued)

m) Investments

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

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

Fixed asset investments comprise an investment portfolio held with Close Brothers Asset Management (CBAM). Trustees agreed to invest some of our cash funds into long term investments in order to mitigate high inflationary pressure on cash reserves. These investments are not intended to be cashed in within the next 12 months and so are treated as fixed asset investments.

The investment with CBAM held at the year end is carried in the balance sheet at fair value as at that date.

n) Financial instruments

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

o) Cash at bank and in hand

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

p) Debtors

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

q) Stocks

Stocks are stated at the lower of cost and net realisable value. In general, cost is determined on a first in first out basis and includes transport and handling costs. Net realisable value is the price at which stocks can be sold in the normal course of business after

allowing for the costs of realisation. Provision is made where necessary for obsolete, slow moving and defective stocks.

r) Creditors and provisions

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

s) Long term liabilities

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

t) Employee benefits

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

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

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

u) Taxation

As a registered charity, the Association benefits from being exempt from tax on surpluses generated by its charitable activities.

In 2019 the Association applied for Group VAT status on the basis that it had become financially beneficial for the whole group to be able to recover some elements of VAT, rather than just the Sales Company.

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.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

Income

1a Donations and legacies

	2023 £000	2022 £000
Individuals	5,986	5,675
Community and other fundraising	10,964	6,268
Appeals	1,890	2,062
Charitable foundations (see note 2)	1,219	3,262
Corporate donations	1,120	711
Tax recovered	2,257	1,541
	23,436	19,519
Legacies (see note 14)	10,366	8,888
	33,802	28,407

See Statement of Accounting Policies e) for treatment of legacy income

1b Other trading activities

	2023 £000	2022 £000
Charity-organised fundraising	377	425
Merchandise sales and advertising	197	154
Conferences and events	904	327
	1,478	906

1c Other

	2023 £000	2022 £000
Costs recovered from the International Alliance and MND (Sales) Limited	31	(7)
MRC Early in career research grants	1,405	450
Other	144	13
	1,580	456

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

2 Grants receivable from Charitable foundations

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

	2023 £000		2023 £000
Alan Davidson Foundation	151	Ofenheim Charitable Trust	7
My Name's Doddie Foundation	100	Thomas and Rosemary Greenhalgh Charitable Trust	7
Wolfson Foundation	75	G C Gibson Charitable Trust	6
Heaton-Ellis Trust	66	Pamela Cordelia Smith Charitable Trust	5
The Constance Travis Charitable Trust	50	Billmeir Charitable Trust	5
Darby Rimmer MND Foundation	50	Brian Wilson Charitable Trust	5
Garfield Weston Foundation	50	Christopher H R Reeves Charitable Trust	5
BNA Charitable Incorporated Organisation	40	Dyers Company Charitable Trust	5
Netherby Trust	40	February Foundation	5
Richard Mackay Charitable Trust	31	George Cadbury Trust	5
Bruce Wake Charitable Trust	30	Henry C Hoare Charitable Trust	5
Barbara Naylor Trust	27	Hobson Charity Limited	5
Revere Charitable Trust	25	James Weir Foundation	5
William Brake Foundation	25	Jones 1986 Charitable Trust	5
Freshfield Foundation	24	Kirby Laing Foundation	5
Basil Samuel Charitable Trust	20	L & R Gilley Charitable Trust	5
Hollick Family Foundation	20	Light Fund Charity	5
Lloyds Bank Foundation for England & Wales	17	M K Rose Charitable Trust	5
Catherine Cirket Discretionary Trust	16	Margaret Giffen Charitable Trust	5
Edith Murphy Foundation	15	Michael Guest Charitable Foundation	5
Frank Brake Charitable Trust	15	Oldhurst Trust	5
J J Fenwick Charitable Trust	15	Pilkington Charities Fund	5
William Kessler Charitable Trust	13	Scarborough Group Foundation	5
Elizabeth and Prince Zaiger Trust	12	Screwfix Foundation	5
Peacock Charitable Trust	11	The Simon Gibson Charitable Trust	5
The Charles Wolfson Charitable Trust	10	Sir James Knott Trust	5
Duke of Newcastle's 1986 Charitable Trust	10	The Sir James Reckitt Charity	5
Fieldrose Charitable Trust	10	Sir John Priestman Charity Trust	5
Goldcrest Charitable Trust	10	Sylvia Aitken Charitable Trust	5
Lawson Trust CIO	10	Tula Trust Ltd	5
P F Charitable Trust	10	Wyfold Charitable Trust	5
Robert Barr's Charitable Trust	10		
Steel Charitable Trust	10	Anonymous or less than £5,000	17
Assurant Foundation	8		
Zochonis Charitable Trust	8	TOTAL	1,219
Gowling WLG (UK) Charitable Trust	8		

In 2022, grants receivable from Charitable foundations totalled £3,262,000

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

3 Net income for the year

This arises after charging:

	2023 £000	2022 £000
Auditors' remuneration:		
External audit	35	29
Internal audit	15	
Other services	-	-
Operating lease rentals:	-	-
Motor vehicles	298	290
Land and buildings	247	207
Other	10	10
Depreciation and amortisation of owned assets	266	263
Loss on disposal of fixed assets	-	-

4 Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

Notes	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2023 £000	Total 2022 £000
Care and care centres	3,976	4,042	1,565	9,583	7,802
Research	1,613	5,228	278	7,119	7,473
Campaigning and raising awareness	2,261	-	531	2,792	1,952
Volunteering	757	-	177	934	659
Costs of charitable activity	8,607	9,270	2,551	20,428	17,886
Raising funds	4,994	-	1,363	6,357	4,910
Total resources expended 2023	13,601	9,270	3,914	26,785	22,796
Total resources expended 2022	23a 10,262	9,496	3,038		22,796

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

5 Support costs

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

	Care £000	Research £000	Campaigning and raising awareness £000	Volunteering £000	Raising funds £000	Total 2023 £000	Total 2022 £000
Management	251	44	85	28	218	626	543
Governance	51	9	18	5	45	128	175
Finance	192	34	65	22	168	481	521
Digital	166	29	56	19	144	414	-
Information and communications technology	426	76	144	48	371	1,065	767
Facilities	270	48	91	30	235	674	664
Human resources	208	37	71	24	181	521	363
Conferences and events	1	1	1	1	1	5	5
	1,565	278	531	177	1,363	3,914	3,038

Full details of prior year support costs can be found in note 23b

6 Grants payable

Grants were awarded during the year as follows:

	2023 £000	2022 £000
Grants to institutions (note 6b)	6,690	7,570
Grants to individuals	2,579	1,926
	9,270	9,496

Grants made to, and for, individuals affected by motor neurone disease are for expenses such as respite care, building adaptations and equipment rental.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

6 Grants payable (continued)

	2023 £000	2022 £000
Balance at start of year	15,729	12,987
Awarded in year	9,270	9,496
Paid in year	(6,875)	(6,754)
Balance at end of year	18,124	15,729
Falling due within one year (note 16a)	10,850	10,265
Falling due after more than one year (note 17)	7,274	5,464
	18,124	15,729

Commitments

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

Group and Charity	2023 £000	2022 £000
Payable within one year	1,084	881
	1,084	881

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

6b Grants payable split by benefactor

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

	2023 £000			2023 £000	
University of Sheffield	2,083	Research	Southampton Care Centre	58	Care
University of Edinburgh	758	Research	University Hospital, Birmingham	56	Care
University College London	681	Research	Sussex MND Care & Research Network	52	Care
Kings College London	512	Research	Barts Care Centre	51	Care
Trinity College Dublin	462	Research	The Francis Crick Institute	50	Research
University of Liverpool	307	Research	Sheffield Care Centre	50	Care
Royal Papworth Hospital	210	Research	Lancashire and South Cumbria / Preston Care Centre	47	Care
Belfast Care Centre	132	Care	Nottingham University Hospital	35	Care
University of Sussex	109	Research	Manchester Care Centre	34	Care
Manchester Metropolitan University	104	Research	University of Oxford	26	Research
South Wales Care Network (Cardiff)	92	Care	Newcastle General Hospital	23	Care
The James Cook University Hospital (Middlesbrough)	80	Care	Newcastle University	20	Care
Kings College	74	Care	University of Exeter	20	Research
Plymouth Primary Care Trust (S.West)	74	Care	Belfast Health and Social Care Trust	14	Research
National Hospital, London	71	Care	Bereavement Project	14	Care
Leeds Care Centre	68	Care	Science Media Centre	6	Research
Liverpool Care Centre	67	Care	Royal Veterinary College	6	Research
Cambridge Care Centre	63	Care			
Bristol Care Centre	61	Care			
Norfolk/Norwich Care Centre	60	Care			
University Hospitals of North Midlands NHS Trust	60	Care			
			TOTAL	6,690	

In 2022, grants payable totalling £7,570,000 were made.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

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

The employment costs of all employees were:

	2023 £000	2022 £000
Gross wages and salaries	7,858	6,829
Social security costs	801	708
Other pension costs	558	488
Medical insurance	12	39
	9,229	8,064

The total number of employees whose emoluments for the year (not including pension contributions) exceeded £80,000 relates to all of the seven members of the Executive Leadership Team in position throughout 2023. These emoluments are identified as follows:

	2023	2022
£130,000 - £139,999	1	
£100,000 - £109,999	1	1
£90,000 - £99,999	3	2
£80,000 - £89,999	2	4
£70,000 - £79,999	2	-
£60,000 - £69,999	8	3

Employers pension contributions for the 7 higher paid employees above are £80,379 for the year ended 31 December 2023 (2022: £55,925).

The trustees devolved the day-to-day running of the Association to the 7 members of the senior management team, who served in the year, as identified on page 16 of these accounts. As such, this body is identified as the key management personnel of the Association and included below are the following payments specifically to this group:

	2023 £000	2022 £000
Gross wages and salaries	692	629
Benefits-in-kind	1	4
Pension costs	53	56
Social security costs	77	76
	823	765

	2023 £000	2022 £000
Trustee remuneration and expenses		
Reimbursement directly to trustees	3	5
Payment to third parties in respect of trustee expenses	2	6
	5	11

Number of trustees holding office during the year	16	19
--	-----------	-----------

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

The charity trustees neither received nor waived any emoluments during the year (2022: £nil). Trustee expenses in the year include travel and subsistence expenses totalling £4,787 (2022: £11,205). These expenses were all incurred in the course of their duties and were reimbursed, or paid directly to third parties on their behalf as shown above. Trustee indemnity insurance is held at a cost of £1,573 (2022: £1,573).

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

8 Staff numbers

The average headcount number of employees for the year is shown below:

	2023 Headcount	2022 Headcount
Care	86	82
Research	15	14
Campaigning and raising awareness	29	28
Volunteering	10	9
Raising funds	75	71
	215	204

Staff numbers above include an appropriate apportionment of support staff.

9 Pension costs

The Association operates defined contribution personal pension schemes for employees. The assets of the schemes are held separately from those of the Association in funds independently administered by Royal London. The amounts paid to the funds represent contributions from both the employer and employees. The employer's contributions in the year were £558,486 (2022: £487,836). There are no other ongoing obligations arising. Amounts outstanding at year end were £0 (2022: £0).

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 2023.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

11a Fixed assets

Group and Charity	Motor vehicles £000	Computers, fixtures, fittings and equipment £000	Total tangible fixed assets £000	Total intangible fixed assets* £000
Cost				
At 1 January 2023		1,727	1,727	46
Additions	-	127	127	-
Disposals	-	-	-	-
At 31 December 2023	-	1,854	1,854	46
Depreciation and amortisation				
At 1 January 2023		1,284	1,284	46
Charged in the year	-	266	266	-
Eliminated on disposal	-	-	-	-
At 31 December 2023	-	1,550	1,550	46
Net book value				
At 31 December 2023	-	304	304	-
At 31 December 2022	-	444	444	-

* Intangible fixed assets comprises purchased software licences.

11b Fixed Assets - Investments (Long Term)

Group and Charity	2023 £000	2022 £000
Market value at 1 January	5,000	-
Acquisitions at cost	-	5,000
Sale proceeds from disposals	-	-
Gain / (Loss) in year	208	-
Market value at 31 December	5,208	5,000
Close Brothers - Asset Portfolio	5,208	5,000
	5,208	5,000

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

12 Fixed asset investments

Motor Neurone Disease (Sales) Limited

The Association owns a wholly owned subsidiary company, Motor Neurone Disease (Sales) Limited, which is registered in England and Wales (Company number: 01989172) at Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. This subsidiary operates mail order catalogues selling promotional clothing, gifts and cards and runs Challenge and other fundraising events. All taxable profits are donated to the Association each year under Gift Aid. Audited accounts are filed with the Registrar of Companies, and below is a summary of its trading results for the year ended 31 December 2023:

Motor Neurone Disease (Sales) Limited Income Statement	2023 £000	2022 £000
Turnover	492	420
Cost of sales	(481)	(324)
Gross profit	11	96
Administration costs	(26)	(21)
Profit / (Loss) before interest and tax	(15)	75
Net interest payable	(3)	(3)
Profit / (Loss) on ordinary activities before tax	(18)	72
Corporation tax	-	-
Profit / (Loss) for the financial year	(18)	72

The aggregate of the assets, liabilities and funds was:

	2023 £000	2022 £000
Assets	635	417
Liabilities	(565)	(257)
Funds (representing 2 ordinary shares of £1 each)	70	160
Profit gifted to charity in following year		(72)
Net funds after transfer of profit	70	88

The investment held by the Charity of £2 (2020: £2) represents shares in the subsidiary company at cost.

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

	2023 £000	2022 £000
Gross income	37,922	30,045
Surplus for the year	11,137	7,249

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

13 Stocks

	Group		Charity	
	2023 £000	2022 £000	2023 £000	2022 £000
Purchased goods for resale	23	20	-	-

14 Debtors

	Group		Charity	
	2023 £000	2022 £000	2023 £000	2022 £000
Loan to subsidiary company	-	-	50	50
Amounts due from subsidiary company	-	-	353	64
Legacies	8,767	8,143	8,903	8,678
Other debtors	507	337	132	454
Income tax reclaimable	592	578	592	578
Prepayments	270	511	280	511
	10,136	9,569	10,310	10,335

15 Current asset investments

The total of current asset investments £26,805,389 (2022: £19,326,469) is constituted by fixed term and other bank and building society deposits with maturity dates within 12 months.

16a Creditors: amounts falling due within one year

	Group		Charity	
	2023 £000	2022 £000	2023 £000	2022 £000
Accruals for grants payable	10,850	10,265	10,850	10,265
Trade creditors	1,359	615	1,346	1,155
Accruals and deferred income (note 16b)	819	898	753	968
Payroll taxation and social security	223	280	223	280
Provisions and other creditors (note 21)	243	493	160	330
	13,494	12,551	13,332	12,998

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

16b Analysis of deferred income

	Group		Charity	
	2023 £000	2022 £000	2023 £000	2022 £000
Deferred income at 1 January	195	28	195	28
Released during the year	(195)	(28)	(195)	(28)
Deferred during the year	8	195	8	195
Deferred income at 31 December	8	195	8	195

17 Creditors: amounts falling due after one year

	Group		Charity	
	2023 £000	2022 £000	2023 £000	2022 £000
Research & Care Centre Creditors	7,274	5,464	7,274	5,464
	7,274	5,464	7,274	5,464

18a Statement of funds

Group and Charity	Balance at 1 January 2022 £000	Income £000	Expenditure £000	Balance at 1 January 2023 £000	Income £000	Expenditure £000	Balance at 31 December 2023 £000
Unrestricted funds:							
General funds	8,279	18,401	(15,192)	11,488	23,251	(19,069)	15,670
Designated funds:							
Care Centre grants	881			881	1,084	(881)	1,084
Ice Bucket Challenge funded projects:							
Research	1	66	(67)	-			-
Care	2	21	(23)	-			-
Campaigning and raising awareness	55	(55)	-	-			-
Volunteering and new opportunities	-		-	-			-
Research & Strategic Investment	11,717	6,297	(2,748)	15,266	6,475	(2,603)	19,138
note 18b	12,656	6,329	(2,838)	16,147	7,559	(3,484)	20,222
Total unrestricted funds	20,935	24,730	(18,030)	27,635	30,810	(22,553)	35,892

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

18a Statement of funds (continued)

Group and Charity	Balance at 1 January 2022 £000	Income £000	Expenditure £000	Balance at 1 January 2023 £000	Income £000	Expenditure £000	Balance at 31 December 2023 £000
Restricted funds:							
Research	1,428	3,913	(2,435)	2,906	5,249	(1,983)	6,172
Care	1,584	1,207	(1,930)	861	1,399	(1,810)	450
Volunteering	-	-	-	-	-	-	-
Branches and Groups	2,027	180	(395)	1,812	430	(423)	1,819
Campaigning	-	15	(15)	-	34	(34)	-
Total restricted funds	5,039	5,315	(4,775)	5,579	7,112	(4,250)	8,441
Total funds	25,974	30,045	(22,805)	33,214	37,922	(26,803)	44,333

Charity		Balance at 1 January 2022 £000	Income £000	Expenditure £000	Balance at 1 January 2023 £000	Income £000	Expenditure £000	Balance at 31 December 2023 £000
Unrestricted funds:								
General funds		8,191	18,329	(15,120)	11,400	23,477	(19,277)	15,600
Designated funds	note 18b	12,656	6,329	(2,838)	16,147	7,351	(3,276)	20,222
		20,847	24,658	(17,958)	27,547	30,828	(22,553)	35,822
Restricted funds		5,039	5,315	(4,775)	5,579	7,112	(4,250)	8,441
Total funds		25,886	29,973	(22,733)	33,126	37,940	(26,803)	44,263

Restricted Funds

Restricted funds are utilised as follows:

Research	for grant payments to be made enabling various research projects to continue
Care	for equipment and care / support provided to people living with MND
Branches and Groups	for care for people with MND within local areas
Campaigning	for raising awareness of MND across England, Wales and Northern Ireland

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

18b Designated funds

Designated funds represent:

	2023 £000	2022 £000
i) the amounts committed by the Association in respect of grants payable for the MND Care Centre Network not reflected in the Consolidated Statement of Financial Activities. Care Centre commitments run for up to 4 years and so the funds designated for these are required to meet future commitments on agreed contracts extending to 2025.	1,084	881
ii) £9m of the 2021 surplus was designated for the delivery of our new Promises. The remaining balances of these designations are detailed below:		
Research - supporting Promise 1; clinical trials, access to treatments and translational research	3,786	4,570
Promises 2,3,4,5; supporting equity in provision of care, initiatives to deliver personalised care, policy and campaign work and an inclusive service provision	4,577	4,577
Strategic investments, including provision of access to multi-disciplinary care	175	519
iii) In 2022, the Board approved the designation of a further £5.6m of the 2022 surplus to support increased Research opportunities (increasing access to treatments, genetic testing and counselling and support for new Research aligned with the #United2EndMND coalition)	5,600	5,600
iv) In 2023, the Board approved a scheme to provide a network of Research Nurses across the Association's Care Centres & Networks. £5m from the 2023 surplus was set aside for this initiative	5,000	-
	20,222	16,147

19 Analysis of net assets between funds

2023

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2023 are represented by:				
Fixed assets	-	-	304	304
Net current assets less long-term liabilities	8,441	20,222	15,366	44,029
Total net assets	8,441	20,222	15,670	44,333

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2023 are represented by:				
Fixed assets	-	-	304	304
Net current assets less long-term liabilities	8,441	20,222	15,296	43,959
Total net assets	8,441	20,222	15,600	44,263

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

19 Analysis of net assets between funds (continued)

2022

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2022 are represented by:				
Fixed assets	-	-	444	444
Net current assets less long-term liabilities	5,579	16,147	11,044	32,770
Total net assets	5,579	16,147	11,488	33,214

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2022 are represented by:				
Fixed assets	-	-	444	444
Net current assets less long-term liabilities	5,579	16,147	10,956	32,682
Total net assets	5,579	16,147	11,400	33,126

20 Leasing commitments

Operating leases

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

	2023 £000	2022 £000
Within one year	278	323
Between two to five years	601	840
Over five years	108	108
	987	1,271

The charge to the Statement of Financial Activities is £277,584 (2022: £323,147).

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

21 Provisions for liabilities and charges

Charity	Leasehold dilapidations £000	Bad debts (incl Legacy) £000	Obsolete stock £000	Total £000
At 1 January 2023	99	86	-	185
Additions	-	-	-	-
Utilised	-	-	-	-
Balance at 31 December 2023	99	86	-	185

Group	Leasehold dilapidations £000	Bad debts £000	Obsolete stock £000	Total £000
At 1 January 2023	99	86	-	185
Additions	-	-	-	-
Utilised	-	-	-	-
Balance at 31 December 2023	99	86	-	185

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

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

22. Consolidated Statement of Financial Activities (incorporating an income and expenditure account) For the year ending 31 December 2022

	Unrestricted Funds £000	Restricted Funds £000	Total Funds 2022 £000
Income and endowments from:			
Donations and legacies:			
Donations	14,204	5,315	19,519
Legacies	8,888		8,888
Charitable activities			
Other trading activities	906	-	906
Investments	276	-	276
Other	456		456
Total income	24,730	5,315	30,045
Expenditure on:			
Raising funds	4,910	-	4,910
Charitable activities:			
Care	5,872	1,930	7,802
Research	5,038	2,435	7,473
Campaigning and raising awareness	1,542	410	1,952
Volunteer development	659	-	659
Total expenditure	18,021	4,775	22,796
Net gain / (loss) on investments	-	-	-
Net income for the year	6,709	540	7,249
Other recognised gains/ (losses) :			
Gains/ (losses) on revaluation of fixed assets	-	-	-
Other gains/ (losses)	(9)	-	(9)
Net movement in funds	6,700	540	7,240
Reconciliation of funds:			
Total funds brought forward	20,935	5,039	25,974
Total funds carried forward	27,635	5,579	33,214

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

23 Prior year figures

23a Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2022 12 months £000
Care and care centres	3,754	2,833	1,215	7,802
Research	594	6,663	216	7,473
Campaigning and raising awareness	1,540	-	412	1,952
Volunteering	521	-	138	659
Costs of charitable activity	6,409	9,496	1,981	17,886
Raising funds	3,853	-	1,057	4,910
Total resources expended 2022 (12 months)	10,262	9,496	3,038	22,796

23b Support costs

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

	Care £000	Research £000	Campaigning awareness £000	Volunteering £000	Raising funds £000	Total 2022 12 months £000
Management	217	39	73	25	189	543
Governance	70	12	24	8	61	175
Finance	208	37	71	23	182	521
Information and communications technology	307	54	104	35	267	767
Facilities	266	47	90	29	232	664
Human resources	145	26	49	17	126	363
Conferences and events	2	1	1	1	-	5
	1,215	216	412	138	1,057	3,038

Notes to the Consolidated Financial Statements

For the year ended 31 December 2023

23 Prior year figures (continued)

23c Analysis of net assets between funds

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2022 are represented by:				
Fixed assets	-	-	444	444
Net current assets less long-term liabilities	5,579	16,147	11,044	32,770
Total net assets	5,579	16,147	11,488	33,214

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2022 are represented by:				
Fixed assets	-	-	444	444
Net current assets less long-term liabilities	5,579	16,147	10,956	32,682
Total net assets	5,579	16,147	11,400	33,126

 mndassociation

 mndassoc

 mndassoc

Motor Neurone Disease Association
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton, NN3 6BJ

Tel: 01604 250505

Email: enquiries@mndassociation.org

www.mndassociation.org

Royal Patron: HRH The Princess Royal

Registered Charity No 294354, Company Limited by Guarantee No 2007023

©MND Association 2024 AnnReport/23

Cover: Louise Jordan with her husband Rob in 2023, photographed during filming for the Associations 2024 TV advertising campaign.

MOTOR NEURONE DISEASE ASSOCIATION

England & Wales - Charity number 294354

Accounts



20
22

Annual Report

and Consolidated Financial Statements

For the year ended 31 December 2022

mnda
motor neurone disease
association

Message from the Chair

In 2022, the MND Association started the year by making five new Promises to the MND community – Promises which have guided our work and accelerated our progress towards our ultimate vision of a world free from MND ever since.

While our commitment to our long-term vision remains resolute and unchanged, the bold Promises we have made to the MND community have allowed us to sharpen our focus on the key areas which we know matter most to those whose lives have been affected by MND – in particular, the search for new treatments and improvements to care and support.

This year, thanks to the incredible support of our loyal fundraisers, supporters and donors, our fundraising topped £30 million for the very first time, fuelling the drive towards keeping those Promises.

This significant increase in donations has enabled us to use our position on the global stage to push forward ground-breaking research and nurture relationships with the next generation of research talent, use our influence to drive forward improvements to care and support, and harness the unique strength and spirit of our community to raise awareness of MND at every opportunity.

Our Promises have been made with people living with MND at the forefront of our minds – and we will not rest until all five Promises have been kept.



Dr Usman Khan

Chair, Board of Trustees



BUCKINGHAM PALACE

At the beginning of 2022, the Motor Neurone Disease Association launched five ambitious Promises and it has been heartening to see work on delivering those gather pace throughout the year.

One of those Promises – that the Association won't rest until MND is treatable and ultimately curable – relies on being able to attract the very best researchers into the field. So I was delighted to attend the first in person event, held by the Association, aimed at recognising, retaining and encouraging MND researchers who are in the early stages of their career. The event at the University of Northampton, EnCouRage UK, brought together new young researchers, those who have been in the field for many years, and people affected by MND. As always, it was an absolute pleasure to meet people from across the MND community and to hear their incredible stories.

The importance of collaboration is evident in many areas of the Association's work. I have been hearing about new care partnerships, technology developments and fundraising initiatives, and look forward to seeing how these progress.

I would like to acknowledge the commitment and dedicated work of the Association's supporters, volunteers and staff in supporting those affected by this devastating disease. I hope that the difference you have made through your actions and the improvements you are making to the lives of people living with MND and their families, will sustain and encourage your efforts in the coming year.

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

A handwritten signature in black ink, appearing to read 'Anne', with a long, sweeping underline.

Contents

TRUSTEES' REPORT (INCLUDING THE STRATEGIC REPORT)	5
i. Objectives and activities	5
ii. Achievements and performance in 2022	5
iii. Future plans and priorities	8
iv. Fundraising governance priorities	8
v. Financial review	9
vi. Principal risks and uncertainties	10
 STRUCTURE, GOVERNANCE AND MANAGEMENT	 12
STATEMENT OF TRUSTEES' RESPONSIBILITIES AND CORPORATE GOVERNANCE	15
ORGANISATIONAL INFORMATION	16
INDEPENDENT AUDITOR'S REPORT	17
STATEMENT OF FINANCIAL ACTIVITIES	19
CONSOLIDATED BALANCE SHEET	20
CONSOLIDATED CASH FLOW STATEMENT	21
STATEMENT OF ACCOUNTING POLICIES	22
NOTES TO FINANCIAL STATEMENTS	25

Trustees' Report

The Trustees are pleased to submit their Report on the Charity's activities together with the Financial Statements for the year ended 31 December 2022, which have been prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102), the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) – (2nd Edition, effective 1 January 2019) and the Companies Act 2006.

About MND

Motor neurone disease (MND) is a rapidly progressing neurological disease that affects the brain and spinal cord. More than 5,000 people in the UK are living with MND and the lifetime risk is up to one in 300 people.

As symptoms progress, MND can leave people locked inside a failing body, unable to move, talk, swallow or even breathe.

Every day, six people are diagnosed with MND. Another six people die.

There are currently no effective treatments. There is no cure.

i) Objectives and activities

About us

The MND Association (the Association) was founded in 1979 by a group of volunteers, all with their own personal experience of MND.

Over the years, the Association has grown into the vibrant community we know today, made up of members, volunteers, campaigners, supporters and staff from across England, Wales and Northern Ireland.

As well as being the biggest charitable funder of MND research in the UK, the Association focuses on improving access to care, providing support and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland.

Our community is united behind one clear vision –
a world free from MND.

Our charitable objects as stated in our Articles of Association

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

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

Public benefit

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

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

ii) Achievements and performance in 2022

This year our Association has pulled together as a community like never before, harnessing the momentum we saw in 2021 to make progress in the delivery of our five Promises, which have been made in collaboration with the wider MND community.

Together, we have continued to make a real difference to the lives of those who are living with and affected by MND in England, Wales and Northern Ireland.

Promise 1: We won't rest until MND is treatable and ultimately curable

For more than 40 years the MND Association has been a pioneer at the forefront of the global fight against MND, working with partners around the world on ground-breaking projects which have accelerated scientific understanding across the world.

As one of the world's leading authorities on MND research, we have used experience and expertise built up over decades to pin-point those projects we believe have the best chance of delivering innovative new therapies to ensure MND becomes a disease which is not only treatable, but ultimately curable.

At the end of December 2022, the value of the MND Association's research portfolio was just over £20 million – enabling us to fund 104 grants spanning discovering science in the laboratory through to clinical research and therapeutic trials.

In 2022, with support from the Jon Moulton Charitable Foundation and the Garfield Weston Foundation, we provided crucial funding for the MIROCALS clinical trial which is

investigating the use of the drug interleukin-2 (IL-2) as a possible treatment for MND.

The drug has shown a significant effect on survival rates with results announced at the MND Association's International Symposium on ALS/MND in December, revealing the risk of death at 21 months decreased by more than 40% for eight out of ten people who received the treatment.

Through our continued investment in Project AMBRoSIA, we are also getting closer to being able to measure the progression of the disease more accurately, opening up the possibility of personalised care for people affected by MND and improving the efficiency of clinical trials.

This important study, funded by the Association with the support of London City Swim Foundation and the Linbury Trust, has shown measurement of the neurofilament light chain in blood samples to be a reliable indicator of MND progression. Rolled out in clinics, these tests could give neurologists the information they need to monitor MND more effectively, improve standards of care, and research.

Meanwhile, collaboration with our partners across the UK and beyond has remained as important as ever.

The Association's International Symposium on ALS/MND is a cornerstone of the global fight against MND, in 2022 bringing together 1,292 of the world's leading MND researchers from 44 countries to showcase and discuss the latest developments.

In June, we committed a further £1 million to a grant worth £4.25 million which is supporting a UK-wide Collaborative Partnership across six universities. The money will be used to investigate the ways drug testing can be streamlined to ensure potential new treatments can be delivered to MND clinics even faster.

At the end of last year, the Government announced details about the distribution of around £30million of the £50million pledged to targeted MND research by the Government, following the successful United To End MND campaign, in which the MND Association played a leading role. As a result, the virtual UK MND Research Institute is now a reality with the Association supporting its formation and ongoing governance.

We're also laying further foundations for the future of MND research by connecting and building relationships with the next generation of research talent.

At our inaugural in person MND EnCouRage UK event in July, which was attended by our Royal Patron, HRH The Princess Royal, young researchers at the start of their careers met with people affected by MND to hear how the work of researchers across the UK is so critical to the global fight against MND, and to our wider community.

Promise 2: We won't rest until everyone gets the care they need when they need it

Ensuring everyone living with and affected by MND has access to the care and support they need, when they need it, has always been one of the Association's priorities, and this year has seen us develop and expand the services we provide.

Over the course of the year, 3,972 people with MND benefitted from the support available at one of the 22 Association-funded Care Centres and Networks across England, Wales and Northern Ireland.

Research has shown that the timely, co-ordinated multidisciplinary care available in Care Centres increases life expectancy in people who are living with MND, and we are determined to ensure the same level of care is available to all, regardless of where they live.

To date, 14 new community specialist roles are being prioritised in the areas where they are needed most through the Association's Access to Multidisciplinary Care project which aims to bring care much closer to home. Working in communities, the community specialists will provide an all-important link between people living with MND and their multidisciplinary care team, co-ordinating the care they receive.

We've established new partnerships with the NHS in four key areas – with a further six set to be created in 2023. These important partnerships will create dedicated posts which will extend the reach of co-ordinated, multidisciplinary care. At the same time, we are working with health and social care professionals to encourage and support the development of high quality care for all through the MND Professionals' Community of Practice.

Promise 3: We won't rest until every day with MND counts

Innovative partnerships with global technology giants including Rolls-Royce, Google and Microsoft are helping us make sure that every day with MND really does count.

For our community, that means giving people living with MND the chance to live the best lives possible, for as long as possible.

Through the work of our NextGen Think Tank, the Association has given many more people living with MND the opportunity to bank their voice – giving back some of what MND cruelly takes away.

Our ground-breaking e-book, ***I Will Always Be Me***, has proved hugely successful, with 1,200 people – 569 people living with MND – registering to bank their voice by reading the story out loud. Thanks to funding from the Association, and support from Dell Technologies and Intel, the book is now free to use for anyone living in England, Wales and Northern Ireland. In Scotland, the book is being made available through our partnership with MND Scotland.

The development of the book, together with the technology now available, has dramatically reduced the time it takes for someone to bank their voice from three months to just 30 minutes.

Improving the quality of life of people living with MND through speech continues to be an area of focus for the NextGen Think Tank, which announced the development of a new project at its summit in October.

Project Relate, an accessibility app being developed by Google in collaboration with people living with MND and the Association and people living with MND, will help people with the disease communicate better by transcribing speech. The

app can be taught to recognise unique speech patterns and rhythms ensuring people whose speech has been affected continue to be heard.

Through our partnership with leading children's charity Barnardo's, we have supported 174 families affected by MND, offering 549 one-to-one counselling sessions and cutting the time it takes to access support from 18 months to just five days.

We've awarded support grants worth £818,470 to 873 people living with MND and distributed 304 Emergency Support grants worth £75,525. Children and young people, whose lives have been affected by MND have also benefitted, with 218 grants worth £53,995 helping to pay for activities which make life just a little bit easier.

Out in the community, our amazing network of volunteers continues to offer one-to-one support when it is needed most.

Across England, Wales and Northern Ireland, 300 Association visitors (AVs) are in contact with more than 1,300 people through personal visits, regular phone calls and texts. During 2022, we trained 78 new AVs with support from The Netherby Trust, enabling us to develop our network even further, while our 90 branches and groups provided friendship and an important sense of community.

Promise 4: We won't rest until you are heard

Bringing the reality of MND to life for millions of viewers, listeners and readers gives us the power to bring about change and makes sure people living with MND continue to be heard at the very highest level.

Thanks to the overwhelming courage of people living with MND, we have shared real stories of what it's like to live with this devastating disease, adding their voices to our campaigns and using lived experience to influence decision-makers.

In 2022, more than four years after the launch of the **Scrap 6 Months** campaign run in partnership with Marie Curie, His Majesty The King granted Royal Assent to the Social Security (Special Rules for End of Life) Bill ending the need for people living with MND to prove they have less than six months to live before accessing the benefits fast-track process.

In October, the Association's campaigners secured support for our **Welsh Homes for MND** campaign from 20 members of the Senedd, which aims to make access to the housing adaptation process easier for people living with MND and their families. Our **Act to Adapt** campaign in England has proved equally successful, with one council in Merseyside introducing a fast-track for people with MND and removing the need for financial assessments for Disabilities Facilities Grants under £5,000.

The Association continues to champion the needs of carers, meeting with members of the Legislative Assembly in Northern Ireland and MPs in Westminster to highlight the significant impact MND has on people living with the disease and their loved ones.

The MND Association also plays a leading role in the All-Party Parliamentary Group on MND (APPG) and this year our campaigners helped to mark its 20th anniversary alongside

key figures in Westminster including the current chair, Andrew Lewer MP.

Having followed the progress of the **United To End MND** campaign throughout 2021, the media continued to work with us to put pressure on the Government to deliver the £50 million promised for targeted MND research. And the relentless commitment paid off when the Secretary of State announced details regarding the distribution of the majority of the funds.

Elsewhere, the Association's patrons Kevin Sinfield OBE and Rob Burrow MBE dominated the headlines, featuring on BBC **Breakfast** for no less than ten consecutive days in November and securing coverage in both the local and national press, on television, radio and online.

Inspired by his friend and former teammate, Kevin completed the Ultra 7 in 7 – seven ultra-marathons in seven days – raising more than £2.4 million for the MND community, including the Association, and inspiring many others to make donations and support us – some for the very first time.

Weeks earlier, a second documentary featuring Rob and his family had aired, leading him to become the first non-speaking person to read a Bedtime Story on the BBC children's channel, **CBeebies**. The Association also worked alongside the BBC to shape the portrayal of MND in drama series, **The Split**, which brought MND to a new primetime audience.

We remain incredibly grateful to our Royal Patron, HRH The Princess Royal, our patrons – including Rob and Kevin, our ambassadors and supporters for everything they do to support us.

For those who prefer to access support and information from their own home, our podcast, **MND Matters**, offers monthly episodes recorded by the Association with guests from across the MND community and beyond. By the end of 2022, 22 episodes had been recorded, providing a unique resource, much-needed support and an insight into life with MND.

Promise 5: We won't rest until no one faces MND alone

MND can affect anyone, regardless of their gender, sexual orientation, ethnicity or faith.

It doesn't discriminate and neither do we – our Association exists for everyone.

At the MND Association we firmly believe no one should face MND alone, which is why we're committed to removing any barriers which may deter people from getting the guidance and support they need, whenever they need it.

Throughout 2022, we worked on a number of projects in England and Wales to help us understand the needs of people living with MND in specific faith and ethnic communities.

By building important new connections and raising awareness we have been able to offer people in those communities the help they need, as well as learning important lessons which will shape our work in the future.

Our Collaboration Community, launched in 2022, gives people living with MND and their families the chance to get even closer to our work, shaping our future plans and priorities with their insight, skills and experience.

We continue to embrace partnerships with a wide range of other organisations and learn from those connections. In 2022, the MND Association became a Stonewall Diversity Champion and is very proud to be a Disability Confident Employer.

At the end of 2022, our rich and diverse community was made up of 11,154 members united with one voice behind one vision – a world free from MND.

We would like to thank

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

Remembering

All those members of the MND community who died from MND this year. As we remember their courage and their contribution to the work of the Association, they will continue to inspire our fight against MND and remind us of the need to do everything we can to support those living with the disease and those closest to them.

iii) Future plans and priorities

The strength in our financial position will ensure we can continue with the work needed to progress our fight against MND. The recent advancements in research, leading to real hope for people living with MND, must continue and so Trustees have agreed to commit £5.6 million from the 2022 surplus into designated research funds. These funds will be used to continue to fund vital research which we hope will bring increased and faster access to trials and potential treatments, as well as to support campaigning for wider provision of genetic testing and genetic counselling.

Partnership funding with Government and leading charities, including LifeArc, will continue to help the development of the UK MND Research Institute. This is in addition to the Association's existing portfolio of research grants which totalled £20 million at the end of 2022.

The designation of surplus funds in 2022 came on top of £9 million of funds which were set aside in 2021 to help deliver on our five Promises which encapsulate our ongoing commitment to care, research, awareness raising and campaigning. This includes increased investment to develop and test new models of community based care, development of more personalised care services, review of access to genetic testing for people with MND and increased investment in digital technologies.

To learn more about our commitment to the MND community and our priorities, or to get involved, visit www.mndassociation.org/MNDPromises

iv) Fundraising governance priorities

We have a diverse portfolio of fundraising activities including raising funds from individuals, trusts and foundations, companies, events, local communities and legacies. We approach our supporters via direct mail, email, telephone and directly at events, and manage this fundraising both centrally and locally through our branches and groups.

We comply with current regulations and best practice set out by regulatory and professional membership bodies including the Fundraising Regulator, the Institute of Fundraising, the Data and Marketing Association, the Gambling Commission and the Advertising Standards Authority.

We are registered with the Fundraising Regulator and have signed up to the Fundraising Preference Service and honour any requests from the public to end contact with us. We fundraise in line with the Code of Fundraising Practice and adhere to data protection law. We are committed to ensuring that we are completely open and transparent about our fundraising and spending. As members of the Fundraising Regulator's self-regulatory scheme, we comply with its principles in all our fundraising:

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

Due to the nature of delivering fundraising across multiple sites, we are aware that the potential for breaches of fundraising code of practice and data protection compliance exist. We manage and minimise these risks through training and inductions for new starters and for our branches and groups; through quality checks and audits, our compliance policies and having data protection/compliance champions within each team.

As the MND Association, we acknowledge that the engagement of third parties can help us raise funds, as well as improve efficiency and reduce costs. We require that any third party we work with complies with data protection legislation as set out in the Code of Fundraising Practice including the requirements of the telephone, mailing and fundraising preference services.

We follow a robust procurement process when recruiting third parties to work on our behalf, making sure we apply appropriate due diligence and contracts for this work. We work closely with these third parties, regularly reviewing their work against performance targets and the Fundraising Code of Practice to ensure delivery of the best value for money for the charity and its supporters.

When we benefit from commercial companies raising funds on our behalf through the sale of products, we operate within a written agreement to ensure their activities are not harmful to the Association. Trustees regularly review the fundraising strategy and

are made aware of any significant new activities and/or contracts where values need to be carefully aligned.

We received 17 complaints about our fundraising activity in 2022. All were promptly resolved without the need for escalation to the Fundraising Regulator. Complaints are taken very seriously and reviewed quarterly by the Board of Trustees. However, these 17 represent a tiny fraction of our outgoing fundraising communications. There is a complaints policy, which is available on our website, which forms the basis for the training of all fundraising staff.

All fundraisers at the MND Association are guided in how to protect vulnerable people including how to recognise a person in vulnerable circumstances. All our direct mail, emails and thank you letters contain clear instructions as to how a supporter can easily opt out of receiving further communications from the charity should they choose to do so.

v) Financial review

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

Financial performance

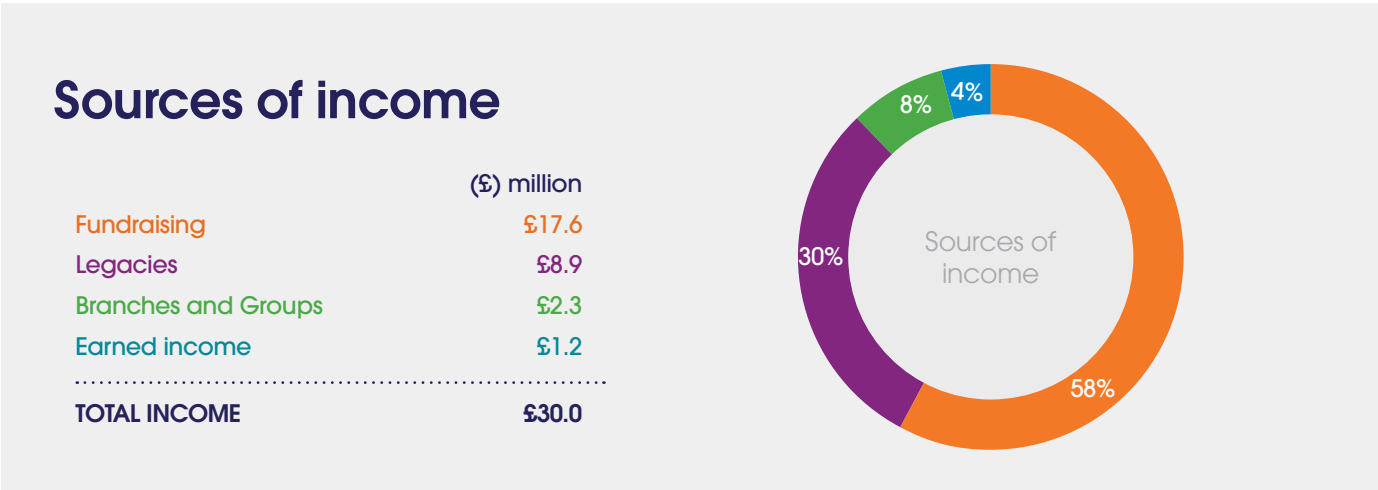
2022 was a phenomenal year for fundraising at the Association, with total income reaching £30 million in the 12 month period for the first time ever. This compared to £28.9 million in 2021.

The increased focus on MND in the media and the high profile fundraising events that took place contributed to a record year. All areas of fundraising had a strong year, most notably legacy donations which accounted for 30% of the income received.

£17.6 million was raised and donated by our incredible supporters and a further £2.3 million was raised by our branches and groups. We are tremendously grateful for their commitment and continued support.

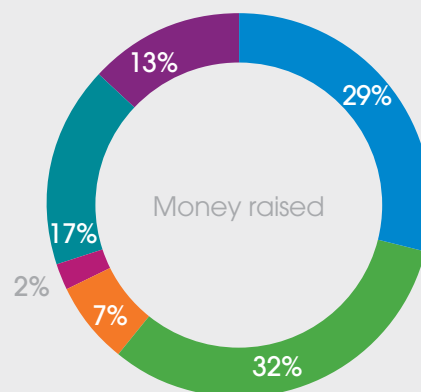
£8.9 million was donated in 2022 in the form of legacy gifts which continue to make such a huge difference to the work we do. We are enormously grateful to the people who choose to remember the work of the Association in their Wills.

For every pound spent directly generating fundraising and legacy income, £7.51 was received.



How we spent the money raised

	(£) million
Care	£6.6
Research	£7.3
Campaigning	£1.5
Volunteer development	£0.5
Fundraising	£3.9
Operational Support Costs	£3.0
TOTAL COSTS	£22.8



Our expenditure year on year increased by £4.8 million. This increase reflected a return to a full year of normal activities following the pandemic, alongside increased spend on our core activities. The biggest uplift was in research expenditure which was almost £2.5 million higher as we continued to support investment in critical research activity. Our care expenditure was also up by almost £1 million as we provided more support to people living with MND, their families and carers at a time when the cost of living crisis has been having such a devastating impact.

We exceeded all our planned commitments to our care grants programme to ensure that people affected by MND continued to receive critical financial support.

The incredibly strong income performance led to a net surplus of £7.2 million. The Board of Trustees has agreed to designate £5.6 million of this surplus to support increased research opportunities, to enable us to do more, faster. More details can be found in the Future Plans and Priorities section.

Despite our extremely positive fundraising success over the last two years, we need to maintain the momentum to support our growing care, research and campaigning work which will cost at least £26 million a year, and allow us to continue to strive towards our mission of a world free from MND.

vi) Principal risks and uncertainties

Risk management

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

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

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

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

Reputational risk

Retaining the Association's reputation is paramount. Due to the diverse nature of our activities this risk relates to several areas including our extensive research programme (for example, our policies on the use of animals and embryonic stem cells in research), the provision of care through our MND Care Centres and Networks, the support provided by our Association visitor network, and the extensive activities of more than 13,000 volunteers – which includes those in our campaigns network – across England, Wales and Northern Ireland. Controls and policies relating to all our activities focus on reputational impacts and these are monitored regularly for compliance.

Financial risk

While the Association has had a record-breaking year for income in 2022, we remain very aware of the risk to future income as household incomes are impacted by significant increases in the costs of utilities, high inflation, increasing interest rates, and the economy moving into a possible recession in 2023. The impact on the Association could lead to reduced income generation at the same time as need for further financial support grows from our community. To mitigate this risk, the Association undertakes weekly income and core expenditure reporting so that we can identify, and react to, any financial pressures which we will manage tightly using our reserves.

While we remain cautious about the financial position in 2023, the robust performance in 2022 has significantly reduced our financial risk and means that the Association will begin the year in a much stronger position than anticipated. The strong financial position has enabled the auditors to confirm that the Association remains a going concern.

External environment risk

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

Compliance risk

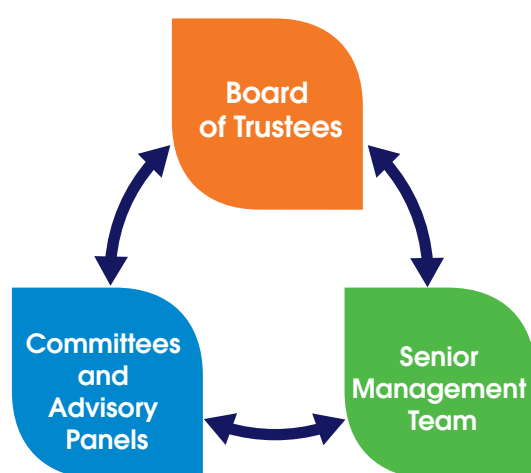
The Association must comply with a range of legal and regulatory requirements including charity law, data protection, fundraising standards, health and safety and safeguarding. To mitigate these risks the Association has robust and embedded processes and policies, which are complemented by regular and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

Structure, Governance and Management

Structure

The Association was originally formed on 6 October 1979 and was incorporated as a company limited by membership guarantee in 1986. The Association is governed by its **Articles of Association** and in the event of it being wound up, every member is liable for an amount not exceeding £1 to facilitate the payment of the debts and liabilities of the Association. At 31 December 2022, there were 11,154 members.

Governance



Our governance structure is designed to ensure that:

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

The Board of Trustees

The Board (members of which are directors under company law) is the governing body of the Motor Neurone Disease Association and ordinarily meets in formal session four times a year.

The Articles of Association provide a degree of flexibility for changes to be made to the composition of the Board, subject to there always being a majority of elected trustees over co-opted trustees and there being no more than ten elected trustees, and the Board reviews its composition against these requirements on an annual basis.

All elected and co-opted trustees are provided with a comprehensive induction to the Association, which includes an overview of the organisational strategy and current priorities, together with briefings on the roles and duties of trustees. They receive subsequent development and training through internal coaching and external providers. The Board maintains an updated skills audit against a defined set of skills and this enables it to identify gaps and plan for future recruitment. The Board seeks to maintain and improve its governance arrangements and uses the Charity Governance Code to benchmark its structure and processes against the code's recommended practices.

Committees of the Board

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

Care Committee

This committee reviews all aspects of the Association's work relating to improving care and providing support for people with MND, their carers and families. It reviews risk and approves grant funding to support the work of MND Care Centres and Networks, up to an agreed limit, with grants above that limit being approved by the Board.

Engagement Committee

This committee reviews strategic activities, policy, and effectiveness relating to the Association's volunteers. This includes all aspects of volunteering including recruitment, retention, empowerment, any potential risks and the development of existing and emerging roles.

Finance and Audit Committee

This committee provides stewardship of all financial aspects of the charity's work, including the fundraising activities of the Association. The committee scrutinises and evaluates the annual budget prior to Board approval. It ensures that the appropriate financial controls and regulatory requirements are adhered to and advises the Board accordingly. The committee also recommends the annual pay award for all employees, which includes the Senior Management Team (except the Chief Executive), to the Board for approval.

Governance Committee

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

Remuneration Committee

This committee is responsible for the annual review of the salary and other benefits of the Chief Executive and oversees the remuneration packages of members of the senior management team.

Biomedical and Healthcare Research Advisory Panels

These panels assess applications for funding for biomedical and healthcare research in accordance with guidelines from the Association of Medical Research Charities (AMRC) and in line with the Association's research strategy. They also monitor the progress of our research grants to ensure the research being conducted is in agreement with the terms of the funding. Those proposals meeting the criteria are then scored, prioritised and recommended to the Board for approval.

Branches, groups and affiliates

At 31 December 2022, the Association had 90 branches and groups and two affiliates (based in Jersey and the Isle of Man). Each branch and group has agreed to abide by our branch and group charter which sets out the parameters of the powers delegated to them by the Board.

Branches and groups, whose financial results are included in these statements, are governed by the Board. The two affiliates are excluded from the consolidation as they are not part of the Association.

Branches and groups provide unique support to people affected by MND at a local level and also fundraise and campaign on their behalf. They raise and spend money locally on support grants, in line with guidelines which are reviewed annually by a support grant group in which volunteers are in the majority. Association staff support them by providing advice and guidance on recruitment and support of volunteers and local structure, organisation and management of their activities.

Environmental impact

The Association initiates and monitors changes to process and practice that reduce its environmental impact.

We moved to our new national office at Francis Crick House in January 2020 and this gave us an opportunity to adopt more sustainable practices.

Since the pandemic, the most sustainable practice has been the use of technology to support hybrid working and thereby reduce travel and meeting costs. In 2022, we introduced enhanced recycling facilities in our national office, as well as carbon captured paper for in-house printing, and biodegradable magazine wrap. We have also introduced 25 hybrid vehicles into our fleet and a new range of eco-friendly products to our online shop. These are either made from sustainable or recycled materials.

Money saved through environmental efficiencies is diverted into achieving the charity's strategic objectives.

Management

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

Safeguarding

The Association provides services to a wide range of people and is committed to meeting the needs of people living with MND, their families and carers. We recognise that some of the people we are in contact with are adults and children or young people who may be at risk of harm. Our safeguarding policy is designed to inform and offer guidance to our staff and volunteers in the management of issues relating to protecting and promoting the welfare of adults and children at risk, and ensures we act appropriately when we become aware of an adult or child who may be at risk of harm. The policy also provides a framework which ensures that our staff and volunteers have the appropriate information and support to enable them to recognise abuse and neglect and to take the necessary steps to prevent it happening. The Association's Safeguarding Board and Board of Trustees regularly review our risk in relation to safeguarding issues and ensure implementation of any actions.

Whistleblowing

We take any evidence of malpractice very seriously and support anyone who is raising genuinely held concerns. We reviewed these policies in detail in 2022 and they are backed up by mandatory staff and volunteer training.

Grants

Grants are awarded for both research projects and care services:

Research – we award project and programme grants, PhD studentships and Lady Edith Wolfson clinical and non-clinical fellowships. Application and decision-making processes, including comprehensive peer review, are published on the Association's website. These processes conclude with formal approval or rejection of applications by the Board.

Care – We provide grants to existing specialist MND Care Centres and Networks. At 31 December 2022 the Association was providing financial support to 22 such centres and networks. Performance is monitored annually for existing Care Centres, with a full grant renewal process every four years.

We also offer grants for people who are living with, or affected by MND, including Cost of Living Support Grants, MND Support (Care) Grants and Quality of Life Grants as well as grants for children and young people.

Investment policy

Investments are held to cover reserves for the management of risk and for future investment opportunities. The investment objective is to provide resources to cover short term demands arising from sudden or unexpected events that could influence fundraising income. The trustees take a prudent approach to risk, holding the Association's investments in cash deposits, near cash and general recognised cash equivalents (including but not limited to Certificates of Deposit and other short-term investments). Counter party limits and acceptable credit ratings are set by the Finance and Audit Committee. Any investment donated to the Association will ordinarily be sold at the earliest opportunity unless there is a specific request from the donor for the shares to be held as fixed asset investments. During the year, the base interest rate increases meant that returns on deposit investments improved, earning £276,000 in 2022 compared with £69,000 in 2021.

In 2022, the Finance and Audit Committee approved an amendment to the Investment Policy that enabled the Association to invest funds in a managed investment portfolio to try and counter the high inflationary impact on our cash reserves. The funds (held with Close Brothers Asset Management) are in a managed portfolio with strict investment objectives, including the prohibition of investment in organisations whose products may be harmful to people with MND or which contribute to the causes of MND. This portfolio is intended to be retained for the long term and so the financial statements will show these as fixed asset investments and all other cash deposits as current asset investments.

Group reserves policy

The trustees have adopted a robust and flexible reserves policy to meet the changing needs of the charity. This states that the general reserve should be in the range of four to six months' general expenditure represented in cash and readily realisable investments, held centrally and within branches. This is a target range of between £7.6 million and £11.5 million. As at the year end, the unrestricted/undesignated reserves balance sat at £11.5 million. Trustees believe that this remains a prudent level given the continuing uncertainty associated with the future economic outlook which could have a detrimental impact on our ability to raise funds.

Statement of Trustees' Responsibilities and Corporate Governance

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group and of the incoming resources and application of resources, including the income and expenditure, of the charitable group for that period. In preparing these financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Charities SORP
- Make judgements and accounting estimates that are reasonable and prudent
- State whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable group will continue in operation.

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

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

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

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

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

This **Trustees' Report**, prepared in accordance with the Charities Act 2011 and the Companies Act 2006 was approved by the Board of Trustees on 20 May 2023 including in their capacity as company directors, the strategic report contained therein, and signed on its behalf by:



Dr Usman Khan

Chair, Board of Trustees

20 May 2023

Organisational information and financial statements

Board of Trustees

Chair: Richard Coleman (until June 2022)

Chair: Dr Usman Khan (from June 2022)

Chair-elect: Usman Khan (until June 2022)

Vice Chair: Jan Warren (until June 2022)

Vice Chair: Catherine Knights (from June 2022)

Honorary Treasurer: James Marshall

Andy Cawdell (*until June 2022*)

Simon Croxford (*from June 2022*)

Elizabeth Ellis

Susan Fletcher-Watts (*from June 2022*)

Devia Gurjar (*until April 2022*)

Dr Katherine Jackson (*from June 2022*)

Usman Khan

Catherine Knights

Ian Lev (*from June 2022*)

James Marshall

Debra Martin

Dr Shaun McGee

Vicky Paeschel (*until June 2022*)

Siobhán Rooney

Dr Nik Sharma (*until September 2022*)

Dr Heather Smith (*until June 2022*)

Katherine Styles

Kirrie Todd (*from May 2022*)

Senior management team

Tanya Curry, Chief Executive (*from Jan 2023*)

Sally Light, Chief Executive (*until Dec 2022*)

Linda Allen, Director of Fundraising

Mark Chapman, Director of Finance

Dr Brian Dickie, Director of Research Development

Nick Goldup, Director of Care Improvement

Chris James, Director of External Affairs

Chris Wade, Director of Engagement (*until April 2023*)

Company secretary

Mark Chapman

Registered office

Francis Crick House
6 Summerhouse Road
Northampton
NN3 6BJ

Professional advisers

Statutory auditors

haysmacintyre LLP
10 Queen Street Place
London
EC4R 1AG

Solicitors

Bates Wells
2-6 Cannon Street
London
EC4M 6YH

Bankers

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

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

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

Auditors' Opinion

We have audited the financial statements of Motor Neurone Disease Association for the period ended 31 December 2022 which comprise the Consolidated Statement of Financial Activities, The Group and Charity Balance Sheets, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice)*.

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 December 2022 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006

Basis for opinion

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

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the group's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

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

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

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

- adequate accounting records have not been kept by the parent charitable company, or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or

- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report

Responsibilities of directors

As explained more fully in the trustees' responsibilities statement set out on page 15, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to regulatory requirements of the Charity Commission, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006 and the Charities Act 2011, Charity SORP and payroll tax.

We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to the posting of inappropriate journal entries and management bias in certain accounting estimates. Audit procedures performed by the engagement team included:

- Inspecting correspondence with regulators and tax authorities;
- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud;
- Evaluating management's controls designed to prevent and detect irregularities;
- Identifying and testing journals, in particular journal entries posted with unusual account combinations, postings by unusual users or with unusual descriptions; and
- Challenging assumptions and judgements made by management in their critical accounting estimates

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

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

Use of our report

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



Richard Weaver (Senior Statutory Auditor)

31 May 2023

For and on behalf of

Haysmacintyre LLP
10 Queen Street Place
London
EC4R 1AG

Consolidated Statement of Financial Activities

(incorporating an income and expenditure account)

For the year ended 31 December 2022

Company Number (02007023) and Charity Number (294354)

	Notes	Unrestricted funds £000	Restricted funds £000	Total Funds 2022 £000	Total funds 2021 £000
Income and endowments from:					
Donations and legacies:	1a				
Donations		14,204	5,315	19,519	19,552
Legacies		8,888		8,888	8,523
Charitable activities					
Other trading activities	1b	906	-	906	743
Investments		276	-	276	69
Other	1c	456		456	56
Total income		24,730	5,315	30,045	28,943
Expenditure on:					
Raising funds		4,910	-	4,910	4,037
Charitable activities:					
Care		5,872	1,930	7,802	6,917
Research		5,038	2,435	7,473	4,805
Campaigning and raising awareness		1,542	410	1,952	1,802
Volunteer development		659	-	659	502
Total expenditure	4	18,021	4,775	22,796	18,063
Net income/ (expenditure)	3	6,709	540	7,249	10,880
Other recognised gains/ (losses):					
Other gains/ (losses)		(9)		(9)	(38)
Net movement in funds		6,700	540	7,240	10,842
Reconciliation of funds:					
Total funds brought forward		20,935	5,039	25,974	15,132
Total funds carried forward	18a, 19	27,635	5,579	33,214	25,974

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

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

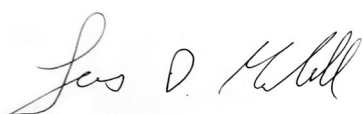
Balance Sheet

As at 31 December 2022

Company Number (02007023) and Charity Number (294354)

		Group		Charity	
	Notes	2022 £000	2021 £000	2022 £000	2021 £000
Fixed assets					
Tangible assets	11a	444	581	444	581
Investments (LT)	11b	5,000	-	5,000	-
Total Tangible Assets		5,444	581	5,444	581
Current assets					
Stocks	13	20	22	-	-
Debtors	14	9,569	7,900	10,335	8,035
Investments	15	19,326	17,238	19,326	17,238
Cash at bank and in hand		16,870	15,434	16,483	15,352
		45,785	40,594	46,144	40,625
Creditors: amounts falling due within one year	16a	12,551	9,794	12,998	9,913
Net current assets		33,234	30,800	33,146	30,712
Total assets less current liabilities		38,678	31,381	38,590	31,293
Creditors: amounts falling due after more than one year	17	5,464	5,407	5,464	5,407
Net assets		33,214	25,974	33,126	25,886
Accumulated funds					
Restricted funds	18a	5,579	5,039	5,579	5,039
Designated funds	18a, 18b	16,147	12,656	16,147	12,656
Unrestricted funds:					
Unrestricted funds	18a	11,400	8,191	11,400	8,191
Funds retained in subsidiary	12a	88	88		
		33,214	25,974	33,126	25,886

The financial statements on pages 19 to 43 were approved and authorised for issue by the Board of Trustees on 20 May 2023, and were signed on its behalf by:



James Marshall
Treasurer



Dr Usman Khan
Chair

The net movement in funds for the Association for the year ending 31 December 2022 was £7,240,000 (2021 : £10,842,000).

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

Statement of Cash Flows

For the year ended 31 December 2022

Company Number (02007023) and Charity Number (294354)

	Notes	2022 £000	2021 £000
Cash flows from operating activities:			
Net income/ (expenditure) for the reporting year		7,240	10,842
Adjustments for:			
Depreciation and amortisation charges	11	263	326
Dividends and interest from investments		(276)	(69)
Gain on disposal of fixed assets	11	-	-
(Increase) / decrease in stock	13	2	9
(Increase) / decrease in debtors	14	(1,669)	(2,356)
Increase / (decrease) in creditors	16a,17	2,813	2,104
Other adjustment		-	-
Net cash generated from operating activities		8,373	10,856
Cash flows from investing activities:			
Cost of additions to investments		-	-
Movement in cash held as investment		-	-
Proceeds from sales of investments		-	-
Decrease in cash element of investment portfolio (Shares not realised)		-	-
Dividends and interest from investments		276	69
Purchase of fixed assets	11	(125)	(72)
Net cash used in investing activities		151	(3)
Increase in cash and cash equivalents in the reporting year		8,524	10,853
Cash and cash equivalents at the start of the year		32,672	21,819
Cash and cash equivalents at the end of the year		41,196	32,672

Analysis of cash and cash equivalents

Group	Balance 1 January 2021 £000	Cash flow changes £000	Balance 1 January 2022 £000	Cash flow changes £000	Balance 31 December 2022 £000
Net cash					
Short term deposits	9,200	8,038	17,238	7,088	24,326
Bank current accounts	12,613	2,818	15,431	1,436	16,867
Cash in hand	6	(3)	3	(0)	3
Net funds	21,819	10,853	32,672	8,524	41,196

Statement of Accounting Policies

Legal Status

The Association is a company limited by guarantee not having a share capital, incorporated in England and Wales (company number: 02007023) and a charity registered in England and Wales (charity number: 294354). The charity's registered office address is 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. The members undertake to contribute to the assets of the company in the event of it being wound up, either whilst members or within one year of the membership ceasing. The maximum contribution required from each member is £1. There were 11,154 members at 31 December 2022 (31 December 2021: 10,984).

Principal accounting policies

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

a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) second edition (effective 1 January 2019) – (Charities SORP FRS 102), and the Companies Act 2006.

The Motor Neurone Disease Association meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Critical accounting judgements and key sources of estimation uncertainty

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

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

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

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

c) Preparation of the accounts on a going concern basis

Despite the economic uncertainty post-pandemic, 2022 proved to be another strong year for the charity with reserves increasing and the Association's financial position remaining strong. As such, the trustees consider there are no material uncertainties about the charity's ability to continue as a going concern. Trustees regularly review potential risks and make strategic changes as and when required. The review of the charity's financial position, reserves levels and future plans through to the end of December 2025 gives trustees confidence that the charity remains a going concern for the foreseeable future.

d) Consolidated financial statements

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

In accordance with the exemption afforded by section 408 of the Companies Act 2006 a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared. The surplus of the parent charity was £7,249,000 (2021: surplus £10,880,000).

e) Income

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

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

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

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted,

Statement of Accounting Policies (continued)

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

f) Investment income

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

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

g) Fund accounting

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

h) Expenditure and irrecoverable VAT

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

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

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

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

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

j) Operating leases

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

k) Intangible fixed assets

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

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

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

l) Tangible fixed assets

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

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

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

m) Investments

Investments are a form of basic financial instruments and are initially shown in the financial statements at market value.

Statement of Accounting Policies (continued)

Movements in the market values of investments are shown as unrealised gains and losses in the Statement of Financial Activities.

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

Fixed asset investments comprise an investment portfolio held with Close Brothers Asset Management (CBAM). Trustees agreed to invest some of our cash funds into long term investments in order to mitigate high inflationary pressure on cash reserves. These investments are not intended to be cashed in within the next 12 months and so are treated as fixed asset investments.

The investment with CBAM held at the year end is carried in the balance sheet at fair value as at that date.

n) Financial instruments

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

o) Cash at bank and in hand

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

p) Debtors

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

q) Stocks

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

r) Creditors and provisions

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

s) Long term liabilities

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

t) Employee benefits

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

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

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

u) Taxation

As a registered charity, the Association benefits from being exempt from tax on surpluses generated by its charitable activities.

In 2019 the Association applied for Group VAT status on the basis that it had become financially beneficial for the whole group to be able to recover some elements of VAT, rather than just the Sales Company.

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.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

Income

1a Donations and legacies

	2022 £000	2021 £000
Individuals	5,675	7,306
Community and other fundraising	6,268	6,240
Appeals	2,062	2,076
Charitable foundations (see note 2)	3,262	1,170
Corporate donations	711	941
Tax recovered	1,541	1,819
	19,519	19,552
Legacies (see note 14)	8,888	8,523
	28,407	28,075

See Statement of Accounting Policies e) for treatment of legacy income

1b Other trading activities

	2022 £000	2021 £000
Charity-organised fundraising	425	418
Merchandise sales and advertising	154	39
Conferences and events	327	286
	906	743

1c Other

	2022 £000	2021 £000
Costs recovered from the International Alliance	(7)	18
HMRC Job Retention Grant	-	25
MRC Early in career research grants	450	-
Other	13	13
	456	56

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

2 Grants receivable from Charitable foundations

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

	2022 £000		2022 £000
Betty Messenger Charitable Foundation	2,000	Assurant Foundation	8
Alan Davidson Foundation	146	The Inman Charity	8
My Name'S Doddie Foundation	100	The Zochonis Charitable Trust	8
The Constance Travis Charitable Trust	50	Lloyds Bank Foundation for England & Wales	8
Darby Rimmer MND Foundation	50	The Paul Bassham Charitable Trust	7
The Netherby Trust	40	Oxygen House Foundation	7
The Basil Samuel Charitable Trust	30	Cecil and Hilda Lewis Charitable Trust	6
Bruce Wake Charitable Trust	30	The Nick Smith Foundation	6
The Barbara Naylor Trust	27	Eddystone Pursuit Sailing Charity	6
The William Brake Foundation	25	The Chalk Cliff Trust	5
The Freshfield Foundation	24	David Lister Charitable Trust	5
Catherine Cirket Discretionary Trust	20	The Dyers' Company Charitable Trust	5
The Childwick Trust	20	Ennismore Foundation	5
The Jones 1986 Charitable Trust	20	The Family Rich Charities Trust	5
Malcolm Gunter Foundation	20	The February Foundation	5
Richard Mackay Charitable Trust	20	The G C Gibson Charitable Trust	5
St James's Place Charitable Foundation	17	Hyde Park Place Estate Charity	5
The Cinquefoil Trust	15	The Iceland Foods Charitable Foundation	5
The Light Fund Charity	15	John James Bristol Foundation	5
The Ofenheim Charitable Trust	13	The Kirby Laing Foundation	5
William Kessler Charitable Trust	13	The L & R Gilley Charitable Trust	5
The Elizabeth and Prince Zaiger Trust	12	M K Rose Charitable Trust	5
The Geoffrey & Pauline Martin Trust	12	The Mary Homfray Charitable Trust	5
Peacock Charitable Trust	11	The Mary Potter Convent Hospital Trust	5
The Annandale Charitable Trust	11	The Oldhurst Trust	5
Advent Charitable Trust	10	Payne-Gallwey Charitable Trust	5
The Batchworth Trust	10	Pilkington Charities Fund	5
The Theodore Maxxy Charitable Trust	10	The Simon Gibson Charitable Trust	5
Edith Murphy Foundation	10	Sir James Knott Trust	5
The Fieldrose Charitable Trust	10	The Sir James Reckitt Charity	5
The Frank Brake Charitable Trust	10	The Talbot Trust	5
The Joron Charitable Trust	10	The William Leech Charity	5
Kusuma Trust UK	10		
Margaret Giffen Charitable Trust	10	Anonymous or less than £5,000	222
Orr Mackintosh Foundation	10		
P F Charitable Trust	10	TOTAL	3,262
Stephen Hawking Foundation	10		

In 2021, grants receivable from Charitable foundations totalled £1,170,000

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

3 Net income for the year

This arises after charging:

	2022 £000	2021 £000
Auditors' remuneration:		
External audit	29	29
Other services	-	-
Operating lease rentals:		
motor vehicles	290	302
land and buildings	207	199
other	10	14
Depreciation and amortisation of owned assets	263	326
Loss on disposal of fixed assets	-	-

4 Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Notes	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2022 £000	Total 2021 £000
Care and care centres		3,754	2,833	1,215	7,802	6,917
Research		594	6,663	216	7,473	4,805
Campaigning and raising awareness		1,540	-	412	1,952	1,802
Volunteering		521	-	138	659	502
Costs of charitable activity		6,409	9,496	1,981	17,886	14,026
Raising funds		3,853	-	1,057	4,910	4,037
Total resources expended 2022		10,262	9,496	3,038	22,796	18,063
Total resources expended 2021	23a	8,640	6,703	2,720		18,063

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

5 Support costs

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

	Care £000	Research £000	Campaigning and raising awareness £000	Volunteering £000	Raising funds £000	Total 2022 £000	Total 2021 £000
Management	217	39	73	25	189	543	446
Governance	70	12	24	8	61	175	61
Finance	208	37	71	23	182	521	419
Information and communications technology	307	54	104	35	267	767	754
Facilities	266	47	90	29	232	664	662
Human resources	145	26	49	17	126	363	374
Conferences and events	2	1	1	1	-	5	4
	1,215	216	412	138	1,057	3,038	2,720

Full details of prior year support costs can be found in note 23b

6 Grants payable

Grants were awarded during the year as follows:

	Note	2022 £000	2021 £000
Grants to institutions (note 6b)	4	7,570	4,989
Grants to individuals		1,926	1,714
		9,496	6,703

Grants made to, and for, individuals affected by motor neurone disease are for expenses such as respite care, building adaptations and equipment rental.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

6 Grants payable (continued)

	2022 £000	2021 £000
Balance at start of year	12,987	9,947
Awarded in year	9,496	6,703
Paid in year	(6,754)	(3,663)
Balance at end of year	15,729	12,987
Falling due within one year (note 16a)	10,265	7,580
Falling due after more than one year (note 17)	5,464	5,407
	15,729	12,987

Commitments

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

Group and Charity	2022 £000	2021 £000
Payable within one year		1
Payable in years two to five	881	881
	881	882

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

6b Grants payable split by benefactor

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

	2022 £000			2022 £000	
Life Arc	1,330	Research	Norfolk/Norwich Care Centre	54	Care
University Of Sheffield	605	Research	Southampton	53	Care
Kings College London	572	Research	The Francis Crick Institution	50	Research
MND Smart	500	Research	University of East Anglia	50	Research
Ule	298	Research	Sussex MND Care & Research Network	50	Care
Trinity College Dublin	295	Research	Leeds Care Centre	49	Care
Serio	290	Research	Newcastle General Hospital	47	Care
Gerbino	285	Research	University College London	46	Research
Talbot	285	Research	Nottingham		
Allen	279	Research	University Hospital	42	Care
Univeristy of Oxford	274	Research	Bristol Care Centre	38	Care
University of Edinburgh	258	Research	University of Liverpool	25	Research
Royal Papworth	210	Research	University of St. Andrews	20	Research
Walker Family Funding	200	Research	Lancashire and South Cumbria	17	Care
De Vos	188	Research	University of Exeter	15	Research
Mc Manus	177	Research	Belfast Health and Social Care Trust	14	Research
University of Oxford	167	Research	The Walton Centre	14	Research
Plymouth Primary Care Trust (S.West)	118	Care	Stoke/North Midlands	13	Care
Chu De Nimes	115	Research	Manchester Care Centre	12	Care
S Wales Care Network (Cardiff)	114	Care	University of Bath	10	Research
University of Sussex	109	Research	Other Small Grants	3	Various
Manchester Metropolitan University	101	Research			
Cambridge	81	Care	Prior year Grant returned	(100)	Research
Kings College	67	Care			
Sheffield Care Centre	67	Care			
The James Cook Uni Hosp (M'Boro)	62	Care			
			TOTAL	7,570	

In 2021, grants payable totalling £4,989,000 were made.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

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

The employment costs of all employees were:

	2022 £000	2021 £000
Gross wages and salaries	6,829	5,999
Social security costs	708	579
Other pension costs	488	430
Medical insurance	39	36
	8,064	7,044

The total number of employees whose emoluments for the year (not including pension contributions) exceeded £70,000 relates to all of the seven members of the senior management team in position throughout 2022. These emoluments are identified as follows:

	2022	2021
£100,000 - £109,999	1	1
£90,000 - £99,999	2	-
£80,000 - £89,999	4	6
£70,000 - £79,999	-	-
£60,000 - £69,999	3	-

Employers pension contributions for the 7 higher paid employees above are £55,925 for the year ended 31 December 2022 (2021: £50,400).

The trustees devolved the day-to-day running of the Association to the 7 members of the senior management team, who served in the year, as identified on page 16 of these accounts. As such, this body is identified as the key management personnel of the Association and included below are the following payments specifically to this group:

	2022 £000	2021 £000
Gross wages and salaries	629	604
Benefits-in-kind	4	4
Pension costs	56	50
Social security costs	76	68
	765	726

Trustee remuneration and expenses	2022 £000	2021 £000
Reimbursement directly to trustees	5	1
Payment to third parties in respect of trustee expenses	6	5
	11	6

Number of trustees holding office during the year	19	17
--	-----------	-----------

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

The charity trustees neither received nor waived any emoluments during the year (2021: £nil). Trustee expenses in the year include travel and subsistence expenses totalling £11,205 (2021: £6,096). These expenses were all incurred in the course of their duties and were reimbursed, or paid directly to third parties on their behalf as shown above. Trustee indemnity insurance is held at a cost of £1,573 (2021: £1,573).

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

8 Staff numbers

The average headcount number of employees for the year is shown below:

	2022 Headcount	2021 Headcount
Care	82	69
Research	14	13
Campaigning and raising awareness	28	31
Volunteering	9	7
Raising funds	71	60
	204	180

Staff numbers above include an appropriate apportionment of support staff.

9 Pension costs

The Association operates defined contribution personal pension schemes for employees. The assets of the schemes are held separately from those of the Association in funds independently administered by Royal London. The amounts paid to the funds represent contributions from both the employer and employees. The employer's contributions in the year were £487,836 (2021: £430,361). There are no other ongoing obligations arising. Amounts outstanding at year end were £0 (2021: £0).

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 2022.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

11a Fixed assets

Group and Charity	Motor vehicles £000	Computers, fixtures, fittings and equipment £000	Total tangible fixed assets £000	Total intangible fixed assets* £000
Cost				
At 1 January 2022	8	1,731	1,739	46
Additions	-	125	125	-
Disposals	-	-	-	-
At 31 December 2022	8	1,856	1,864	46
Depreciation and amortisation				
At 1 January 2022	8	1,149	1,157	46
Charged in the year	-	263	263	-
Eliminated on disposal	-	-	-	-
At 31 December 2022	8	1,412	1,420	46
Net book value				
At 31 December 2022	-	444	444	-
At 31 December 2021	-	581	581	-

* Intangible fixed assets comprises purchased software licences.

11b Fixed Assets - Investments (Long Term)

Group and Charity	2022 £000	2021 £000
Market value at 1 January 2022	-	-
Acquisitions at cost	5,000	-
Sale proceeds from disposals	-	-
Gain / (Loss) in year	-	-
Market value at 31 December 2022	5,000	-
Close Brothers - Asset Portfolio	5,000	-
	5,000	-

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

12 Fixed asset investments

Motor Neurone Disease (Sales) Limited

The Association owns a wholly owned subsidiary company, Motor Neurone Disease (Sales) Limited, which is registered in England and Wales (Company number: 01989172) at Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. This subsidiary operates mail order catalogues selling promotional clothing, gifts and cards and runs Challenge and other fundraising events. All taxable profits are donated to the Association each year under Gift Aid. Audited accounts are filed with the Registrar of Companies, and below is a summary of its trading results for the year ended 31 December 2022:

Motor Neurone Disease (Sales) Limited Income Statement	2022 £000	2021 £000
Turnover	420	144
Cost of sales	(324)	(122)
Gross profit	96	22
Administration costs	(21)	(20)
Profit / (Loss) before interest and tax	75	2
Net interest payable	(3)	(1)
Profit / (Loss) on ordinary activities before tax	72	1
Corporation tax	-	0
Profit / (Loss) for the financial year	72	1

The aggregate of the assets, liabilities and funds was:

	2022 £000	2021 £000
Assets	417	150
Liabilities	(257)	(61)
Funds (representing 2 ordinary shares of £1 each)	160	89
Profit gifted to charity in following year	(72)	(1)
Net funds after transfer of profit	88	88

The investment held by the Charity of £2 (2020: £2) represents shares in the subsidiary company at cost.

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

	2022 £000	2021 £000
Gross income	30,045	28,943
Surplus for the year	7,249	10,880

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

13 Stocks

	Group		Charity	
	2022 £000	2021 £000	2022 £000	2021 £000
Purchased goods for resale	20	22	-	-

14 Debtors

	Group		Charity	
	2022 £000	2021 £000	2022 £000	2021 £000
Loan to subsidiary company	-	-	50	50
Amounts due from subsidiary company	-	-	64	44
Legacies	8,143	6,349	8,678	6,349
Other debtors	337	590	454	631
Income tax reclaimable	578	774	578	774
Prepayments	511	187	511	187
	9,569	7,900	10,335	8,035

15 Current asset investments

The total of current asset investments £19,326,469 (2021: £17,237,543) is constituted by fixed term and other bank and building society deposits with maturity dates within 12 months.

16a Creditors: amounts falling due within one year

	Group		Charity	
	2022 £000	2021 £000	2022 £000	2021 £000
Accruals for grants payable	10,265	7,580	10,265	7,580
Trade creditors	615	995	1,155	1,142
Accruals and deferred income (note 16b)	898	766	968	766
Payroll taxation and social security	280	216	280	216
Provisions and other creditors (note 21)	493	237	330	209
	12,551	9,794	12,998	9,913

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

16b Analysis of deferred income

	Group		Charity	
	2022 £000	2021 £000	2022 £000	2021 £000
Deferred income at 1 January	28	1	28	1
Released during the year	(28)	(1)	(28)	(1)
Deferred during the year	195	28	195	28
Deferred income at 31 December	195	28	195	28

17 Creditors: amounts falling due after one year

	Group		Charity	
	2022 £000	2021 £000	2022 £000	2021 £000
Research & Care Centre Creditors	5,464	5,407	5,464	5,407
	5,464	5,407	5,464	5,407

18a Statement of funds

	Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 1 January 2022 £000	Income £000	Expenditure £000	Balance at 31 December 2022 £000
Group and Charity							
Unrestricted funds:							
General funds	8,477	11,154	(11,352)	8,279	18,401	(15,192)	11,488
Designated funds:							
Care Centre grants	891	2,337	(2,347)	881			881
Ice Bucket Challenge funded projects:							
Research	214	-	(213)	1	66	(67)	-
Care	115	-	(113)	2	21	(23)	-
Campaigning and raising awareness	55	-	-	55	(55)	-	-
Volunteering and new opportunities	20	-	(20)	-	-	-	-
Research & Strategic Investment	3,000	8,717	-	11,717	6,297	(2,748)	15,266
note 18b	4,295	11,054	(2,693)	12,656	6,329	(2,838)	16,147
Total unrestricted funds	12,772	22,208	(14,045)	20,935	24,730	(18,030)	27,635

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

18a Statement of funds (continued)

Group and Charity	Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 1 January 2022 £000	Income £000	Expenditure £000	Balance at 31 December 2022 £000
Restricted funds:							
Research	1,317	3,659	(3,548)	1,428	3,913	(2,435)	2,906
Care	(767)	2,723	(372)	1,584	1,207	(1,930)	861
Volunteering	-	-	-	-	-	-	-
Branches and Groups	1,810	345	(128)	2,027	180	(395)	1,812
Campaigning	-	8	(8)	-	15	(15)	-
Total restricted funds	2,360	6,735	(4,056)	5,039	5,315	(4,775)	5,579
Total funds	15,132	28,943	(18,101)	25,974	30,045	(22,805)	33,214

Charity		Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 1 January 2022 £000	Income £000	Expenditure £000	Balance at 31 December 2022 £000
Unrestricted funds:								
General funds		8,350	11,155	(11,314)	8,191	18,329	(15,120)	11,400
Designated funds	note 18b	4,295	11,054	(2,693)	12,656	6,329	(2,838)	16,147
		12,645	22,209	(14,007)	20,847	24,658	(17,958)	27,547
Restricted funds		2,360	6,735	(4,056)	5,039	5,315	(4,775)	5,579
Total funds		15,005	28,944	(18,063)	25,886	29,973	(22,733)	33,126

Restricted Funds

Restricted funds are utilised as follows:

Research	for grant payments to be made enabling various research projects to continue
Care	for equipment and care / support provided to people living with MND
Branches and Groups	for care for people with MND within local areas
Campaigning	for raising awareness of MND across England, Wales and Northern Ireland

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

18b Designated funds

Designated funds represent:

	2022 £000	2021 £000
i) The amounts committed by the Association in respect of grants payable for the MND Care Centre Network not reflected in the Consolidated Statement of Financial Activities. Care Centre commitments run for up to 4 years and so the funds designated for these are required to meet future commitments on agreed contracts extending to 2025.	881	881
ii) The trustees previously designated the IBC monies of £7.2m together with additional reserves and the small remaining balance at the end of 2021 was utilised in 2022.	-	58
iii) Trustees agreed to designate £3m of the exceptional income in 2020 to research and strategic investment projects which will run through to the end of 2023. A further £9m of the 2021 surplus was also designated for the delivery of our new Promises. The combined allocations of these designations are detailed below:		
Research - supporting Promise 1; clinical trials, access to treatments and translational research	4,570	6,750
Promises 2,3,4,5; supporting equity in provision of care, initiatives to deliver personalised care, policy and campaign work and an inclusive service provision	4,577	4,000
Strategic investments, including provision of access to multi-disciplinary care	519	967
iv) In 2022, the Board approved the designation of a further £5.6m of the 2022 surplus to support increased Research opportunities (increasing access to treatments, genetic testing and counselling and support for new Research aligned with the #United2EndMND coalition)	5,600	-
	16,147	12,656

19 Analysis of net assets between funds

2022

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2022 are represented by:				
Fixed assets	-	-	444	444
Net current assets less long-term liabilities	5,579	16,147	11,044	32,770
Total net assets	5,579	16,147	11,488	33,214

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2022 are represented by:				
Fixed assets	-	-	444	444
Net current assets less long-term liabilities	5,579	16,147	10,956	32,682
Total net assets	5,579	16,147	11,400	33,126

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

19 Analysis of net assets between funds (continued)

2021

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2021 are represented by:				
Fixed assets	-	-	581	581
Net current assets less long-term liabilities	5,039	12,656	7,698	25,393
Total net assets	5,039	12,656	8,279	25,974

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2021 are represented by:				
Fixed assets	-	-	581	581
Net current assets less long-term liabilities	5,039	12,656	7,610	25,305
Total net assets	5,039	12,656	8,191	25,886

20 Leasing commitments

Operating leases

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

	2022 £000	2021 £000
Within one year	323	254
Between two to five years	840	752
Over five years	108	238
	1,271	1,244

The charge to the Statement of Financial Activities is £323,147 (2021: £254,399).

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

21 Provisions for liabilities and charges

Charity	Leasehold dilapidations £000	Bad debts (incl Legacy) £000	Obsolete stock £000	Total £000
At 1 January 2022	99	86	-	185
Additions	-	-	-	-
Utilised	-	-	-	-
Balance at 31 December 2022	99	86	-	185

Group	Leasehold dilapidations £000	Bad debts £000	Obsolete stock £000	Total £000
At 1 January 2022	99	86	-	185
Additions	-	-	-	-
Utilised	-	-	-	-
Balance at 31 December 2022	99	86	-	185

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

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

22. Consolidated Statement of Financial Activities (incorporating an income and expenditure account) For the year ending 31 December 2021

	Unrestricted Funds £000	Restricted Funds £000	Total Funds 2021 £000
Income and endowments from:			
Donations and legacies:			
Donations	12,817	6,735	19,552
Legacies	8,523		8,523
Charitable activities			
Other trading activities	743	-	743
Investments	69	-	69
Other	56	-	56
Total income	22,208	6,735	28,943
Expenditure on:			
Raising funds	4,037	-	4,037
Charitable activities:			
Care	6,545	372	6,917
Research	1,257	3,548	4,805
Campaigning and raising awareness	1,666	136	1,802
Volunteer development	502	-	502
Total expenditure	14,007	4,056	18,063
Net gain / (loss) on investments	-	-	-
Net income for the year	8,201	2,679	10,880
Transfers between funds	-		-
Other recognised gains/ (losses) :			
Gains/ (losses) on revaluation of fixed assets			-
Other gains/ (losses)	(38)		(38)
Net movement in funds	8,163	2,679	10,842
Reconciliation of funds:			
Total funds brought forward	12,772	2,360	15,132
Total funds carried forward	20,935	5,039	25,974

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

23 Prior year figures

23a Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2021 12 months £000
Care and care centres	3,251	2,625	1,041	6,917
Research	536	4,078	191	4,805
Campaigning and raising awareness	1,333	-	469	1,802
Volunteering	389	-	113	502
Costs of charitable activity	5,509	6,703	1,814	14,026
Raising funds	3,131	-	906	4,037
Total resources expended 2021 (12 months)	8,640	6,703	2,720	18,063

23b Support costs

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

	Care £000	Research £000	Campaigning awareness £000	Volunteering £000	Raising funds £000	Total 2021 12 months £000
Management	171	31	77	18	149	446
Governance	24	4	11	2	20	61
Finance	161	29	72	17	140	419
Information and communications technology	289	53	130	31	251	754
Facilities	254	46	114	27	221	662
Human resources	143	26	64	16	125	374
Conferences and events	1	1	1	1	-	4
	1,043	190	469	112	906	2,720

Notes to the Consolidated Financial Statements

For the year ended 31 December 2022

23 Prior year figures (continued)

23c Analysis of net assets between funds

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Group:				
Fund balances at 31 December 2021 are represented by:				
Fixed assets	-	-	581	581
Net current assets less long-term liabilities	5,039	12,656	7,698	25,393
Total net assets	5,039	12,656	8,279	25,974

	£000	£000	£000	£000
Charity:				
Fund balances at 31 December 2021 are represented by:				
Fixed assets	-	-	581	581
Net current assets less long-term liabilities	5,039	12,656	7,610	25,305
Total net assets	5,039	12,656	8,192	25,886

 [mndassociation](#)

 [mndassoc](#)

 [mndassoc](#)

Motor Neurone Disease Association
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton, NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org

www.mndassociation.org

Royal Patron: HRH The Princess Royal

Registered Charity No 294354, Company Limited by Guarantee No 2007023

©MND Association 2022 AnnReport/22

MOTOR NEURONE DISEASE ASSOCIATION

England & Wales - Charity number 294354

Accounts

ANNUAL REPORT AND CONSOLIDATED FINANCIAL STATEMENTS

For the year ended 31 December 2021

Message from the Chair

2021 was a pivotal year for the MND Association, a year which saw us start to emerge from the pandemic with fresh ideas, renewed focus and a bolder, more innovative approach to the work we do.

As always, our incredible community, made up of members, fundraisers, donors, supporters, campaigners and volunteers, has been right behind us, driving us forward and inspiring us to achieve even more on behalf of people living with MND and their families.

Thanks to their support we've raised awareness like never before and campaigned for real change.

As well as successfully calling for a change in the law when it comes to claiming benefits through the *Scrap 6 Months* campaign, the MND Association, people living with MND and our supporters were instrumental in the success of the *United To End MND* campaign which saw the Government pledge £50 million for targeted MND research over the next five years.

The extraordinary efforts of our supporters also led to 2021 becoming a record year for income, generating a significant surplus which has allowed us to bring forward projects in key areas including research, care and the development of cutting-edge technology to help improve quality of life for people affected by this devastating disease.

As we look ahead to the future, people living with MND and their families will remain firmly at the heart of everything we do.

We *will* beat MND together.

A handwritten signature in black ink, appearing to read 'Richard Coleman', with a stylized flourish at the end.

Richard Coleman

Chair, Board of Trustees



BUCKINGHAM PALACE

The dedication and commitment of the whole MND community has continued to shine throughout this year as the Motor Neurone Disease Association takes the next important steps against this devastating disease.

Throughout 2021, the Association has continued to improve the care and support it offers people living with motor neurone disease and their families, while successfully campaigning for a change in the law when it comes to claiming benefits. As Royal Patron, I have also been heartened by the increased awareness of the disease, and the pledge regarding funding for future MND research, both of which give us all so much hope for the future.

In July, I was pleased to be able to support the Association virtually by joining its Showcase event, and to take the opportunity to congratulate and thank fundraisers and donors. In November, I was delighted to meet guests in person, when representatives of my Patronages came to St. James's Palace for a meeting of my Charities Forum, sharing lessons learned during the COVID-19 pandemic.

As we look to the future, we know there is still so much which needs to be done to support all those who are living with, and affected by, MND.

I encourage you to continue your support, in the hope that your involvement with the MND Association will help them to achieve our shared vision of a world free from MND. Thank you.

A handwritten signature in black ink, appearing to read 'Anne', with a long, sweeping underline.

Contents

TRUSTEES' REPORT (INCLUDING THE STRATEGIC REPORT)	5
i. Objectives and activities	5
ii. Achievements and performance in 2021	6
iii. Future plans and priorities	8
iv. Fundraising governance priorities	
v. Financial review	9
vi. Principal risks and uncertainties	10
 STRUCTURE, GOVERNANCE AND MANAGEMENT	 12
STATEMENT OF TRUSTEES' RESPONSIBILITIES AND CORPORATE GOVERNANCE	15
ORGANISATIONAL INFORMATION	16
INDEPENDENT AUDITOR'S REPORT	17
STATEMENT OF FINANCIAL ACTIVITIES	19
CONSOLIDATED BALANCE SHEET	20
CONSOLIDATED CASH FLOW STATEMENT	21
STATEMENT OF ACCOUNTING POLICIES	22
NOTES TO FINANCIAL STATEMENTS	25

Trustees' Report

The Trustees are pleased to submit their Report on the Charity's activities together with the Financial Statements for the year ended 31 December 2021, which have been prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102), the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) – (2nd Edition, effective 1 January 2019) and the Companies Act 2006.

About MND

Motor neurone disease (MND) is a rapidly progressing neurological disease that affects the brain and spinal cord. Approximately 5,000 people in the UK are living with MND and the lifetime risk is up to one in 300 people.

As symptoms progress, MND can leave people locked inside a failing body, unable to move, talk, swallow or even breathe.

Every day, six people are diagnosed with MND. Another six people die.

There are currently no effective treatments. There is no cure.

i) Objectives and activities

About us

The MND Association (the Association) was founded in 1979 by a group of volunteers, all with their own personal experience of MND.

Over the years, the Association has grown into the vibrant community we know today, made up of members, volunteers, campaigners, supporters and staff from across England, Wales and Northern Ireland.

As well as being the biggest charitable funder of MND research in the UK, the Association focuses on improving access to care, providing support and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland.

Our community is united behind one clear vision – *a world free from MND*.

Our charitable objects as stated in our Articles of Association

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

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

Public benefit

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

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

ii) Achievements and performance in 2021

Playing a leading role in the fight against MND

The MND Association continues to play a prominent role in the global fight against MND, by championing ground-breaking research and developing our role as a trusted leader and partner on the world stage.

The Association's consistent and targeted investment in MND research over many decades has contributed to the disease becoming one of the fastest growing areas of neurodegenerative disease research, attracting widespread interest from researchers and pharmaceutical companies. Our constant presence and influence have also prompted other key players within the medical research sector, including leading medical research charity LifeArc, to invest their own funding, providing a springboard for even greater progress.

As at 31 December 2021, the Association's research commitments were made up of 83 research grants at a collective value of £15.1 million. Despite the challenges we faced as a result of the pandemic, we funded the second highest number of new research projects in our history.

Thanks to the incredible support of our community during 2021, the Association was also able to set aside £5 million from the £10.9 million surplus to invest in translational research, helping to bridge the gap between discoveries made in laboratories and the testing of potential new drugs in patient trials.

This continued investment in research is beginning to open up new, potential approaches to treatment, particularly gene therapy strategies which aim to target specific inherited forms of MND. Clinical trials, treating people with MND with mutations in

certain genes, are progressing and should these strategies prove to be effective, may also have the potential to stop the disease manifesting in those who carry these genes.

The MND Association is proud of its role as a leading collaborator in MND research and in December, we brought 1,500 of the world's leading MND experts from 44 countries together for the 32nd International Symposium on ALS/MND - the biggest event of its kind in the world. Held online for a second year due to the pandemic, the four-day event showcased the latest developments and highlighted the progress being made in international research and clinical management.

Looking ahead, the Association will continue to harness the extraordinary momentum in MND research, working alongside our partners around the world and investing in world-class science which we believe will take us closer to the development of effective new treatments and ultimately, a cure for MND.

Improving care and support

While the search for effective new treatments for MND gathers pace, the Association recognises that people living with MND and their families need access to care, support and information they can trust.

This year, we've built on lessons learnt during the pandemic to make it easier for people living with MND, and those closest to them, to access the support they need, when they need it.

We know that co-ordinated multidisciplinary care has a positive impact on life expectancy and quality of life for people living with MND and the Association is committed to making sure that everyone has access regardless of where they live. During 2021, our 22 care centres and networks across England, Wales and Northern Ireland supported 3,883 people living with MND. Where gaps in the network exist, we are working with our partners in local clinical commissioning groups in England, health boards in Wales and health and social care trusts in Northern Ireland to create 14 community specialist roles to help expand services. It is hoped that the first role will be established in June 2022 in Surrey, with others to follow in Swindon, Kent and Northamptonshire.

Ensuring health and social care professionals have the information they need to provide the very best care they can to people living with MND is a key priority. In 2021, we started to offer education events online, opening them up to many more professionals across England, Wales and Northern Ireland. In total, more than 1,500 professionals attended 25 events covering topics including hospice care, familial MND, models of respiratory care in the community and discussions about end of life. Six virtual masterclasses were also held with 187 professionals taking part and we also supported two care centre study days for the South Wales and South-East networks.

We continued to develop the support we offer to children, young people and families, recruiting a new project worker and extending the counselling service available through our partnership with leading children's charity, Barnardo's. During the year, 66 families took up the offer of counselling. We are currently in the process of creating a new volunteer workforce to help reach more children and young people and their families

and after covid delays we hope to deliver two family days in the latter half of 2022.

Between April 2021 and March 2022, we made more than 270 information advice and guidance support calls to families affected by MND, providing emotional support to both the person affected by MND and also directly to children, helping to liaise with schools, offering support when explaining MND to a child, providing information and signposting to external specialist support agencies.

We provided 76 memory and treasure boxes during the last year and are currently designing, in collaboration with students at the University of Lancashire, a new wellbeing and mindfulness box for teenagers that will be available soon.

Throughout the year, we awarded £1.1 million of support grants to 1,682 people living with MND. We distributed 182 Emergency Support Grants worth a total of £45,000 to support people living with MND struggling with additional living costs as a direct result of the pandemic. 160 children and young people affected by MND received 160 grants totalling £38,000, helping to pay for everything from horse-riding sessions to driving lessons.

In communities across England, Wales and Northern Ireland our network of 315 volunteer Association visitors offered one-to-one support to 1,415 people who are living with MND.

During 2021, we trained 80 new Association visitors who took part in virtual classes led by our Area Support Co-ordinators (ASCs). Each week, a different set of topics is covered, and material is provided for additional learning at home.

We launched our podcast, *MND Matters*, giving people living with MND the chance to listen to information and support at the click of a button. The monthly episodes, recorded in-house by a small team of staff and featuring people living with MND and their families, cover everything from conversations about continuing to work when you have been diagnosed with MND, to helpful updates on voice banking, support with bereavement and advances in research.

Across England, Wales and Northern Ireland our volunteers have helped to bring the MND community closer together, hosting support groups in-person and online, making it easier than ever to connect with, and get involved in, the Association and the work we do. Our network of 90 branches and groups have helped support people living with and affected by MND at a local level, providing a helping hand when it is needed most.

Raising awareness, bringing about change

When it comes to describing the cruelty of MND and the devastating impact it has, we rely on people living with MND and their families to share their own very personal experiences, sometimes with audiences of millions.

Thanks to the overwhelming courage of people living with MND and their willingness to support our work, MND has continued to make the headlines in 2021, leading to coverage on primetime TV and countless column inches in the national press. The power of their words has also helped the MND Association make a difference, prompting decision-makers to sit up and take notice.

In 2021, the *Sunday Express* newspaper actively supported the *United To End MND* campaign, which was led by a coalition made up of people living with MND, leading MND researchers, the MND Association, MND Scotland and the My Name's Doddie Foundation. The campaign called upon the Government to invest £50 million into MND research which would be used to create the collaborative UK infrastructure to accelerate drug discovery, drug development and clinical trials. Every Sunday, for 20 weeks, the *Sunday Express* featured the stories of people living with, and affected by MND, which undoubtedly influenced the Government in making the decision to pledge their support.

Our patron, Kevin Sinfield OBE captured our hearts for a second year running at the end of 2021, when he ran the equivalent of four marathons in 24 hours as part of his epic *Extra Mile Challenge*. Kevin organised the challenge, which saw him run the 101 miles from Leicester to Leeds, to honour his best friend and former rugby league team-mate Rob Burrow MBE, who was diagnosed with MND in December 2019.

Alongside his own dedicated team, and with Association supporters following him every step of the way, Kevin raised more than £2.1 million - with half being donated to support the Association's work and the other half to support The Leeds Hospitals Charity.

Kevin and Rob's story of enduring friendship featured extensively on BBC Breakfast, with 2.3 million people tuning in to see Kevin cross the finishing line at Leeds Rhinos Headingley Stadium on the morning of 23 November.

As well as a substantial increase in donations, the coverage led to offers of help, encouraged new donors and funders to support us and prompted many fundraisers to take on challenges of their own, in some cases for the very first time.

We would like to thank Rob and his family, Kevin Sinfield and his wider team, Leeds Rhinos, Leicester Tigers and the many hundreds of people who were inspired to support the Extra Mile Challenge. We would also like to thank the Burrow Seven Racing Club, Pro Elite Sports, Arc Inspirations and many other individuals, schools and teams for their continued support.

We are also incredibly grateful to *BBC Breakfast* editor Richard Frediani, and his team, for their support on and off-screen and for continuing to follow Kevin and Rob's story.

Using technology to improve quality of life

The MND Association is very proud of the partnerships it has with technology giants such as Rolls-Royce, Intel, Dell, Google and Toyota GB, and we continue to work alongside them to tackle some of the challenges people living with MND face.

In the future, we believe some of those challenges, particularly those involving speech and mobility, could be solved using technology. By harnessing the vast expertise of these global companies through our Next Generation Technology Think Tank, we are determined to help people with MND live independent lives to the fullest. One of the innovations which has come out of the Think Tank is an e-book, *I will always be me*, which banks the voices of people living with MND as they read it aloud in as little as 15 minutes.

We're also using technology to extend the range of support we can offer to people living with MND.

With 80% of people affected by MND experiencing some difficulty with their speech, the work we do to improve access to communication aids is critical. The Association loans equipment such as iPads, iPhones, Lightwriters and other devices and provides access to apps. In 2021, we loaned out 165 pieces of communication equipment and apps and 129 pieces of voice banking equipment.

Free training is also offered to professionals who are working with people living with MND.

We're one community with one goal

Our Association is made up of thousands of different voices, from diverse backgrounds and communities right across England, Wales and Northern Ireland.

We have different skills and experiences and our contribution to the work of the Association is as unique as we are – but when we come together as one, we share a voice which is impossible to ignore.

In July, the MND Association launched a new membership strategy to reflect our growing movement and to encourage our members to share their skills and experience to help us fundraise, campaign and raise awareness like never before. As well as helping to spread the word about the Association and the support we provide, people living with MND and their families are being invited to get even closer to the work we do, collaborating with volunteers and staff to co-design important projects. We have involved people living with MND and those closest to them in helping to shape and prioritise our work. In particular, it is encouraging to see the level of involvement and outstanding success where we have collaborated with people living with MND in campaigning for increased government research funds.

During the year, we've embarked on a process of reviewing our services and those of our partners, to ensure that our work is inclusive for all people living with or affected by MND. It is critical that we continually reflect and improve our services so that no-one feels excluded or unable to get the support they need. This extends to reviews of elements of our work as diverse as research grants, to volunteer support to financial support.

We would like to thank

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

Remembering

All those members of the MND community who died from MND this year. As we remember their courage and their contribution to the work of the Association, they will continue to inspire our fight against MND and remind us of the need to do everything

we can to support those living with the disease and those closest to them.

iii) Future plans and priorities

In 2021, the Association's five-year strategy came to an end, bringing with it a chance to assess our priorities and our goals for the future. We opened up important conversations with our community, in particular with people living with MND and their families and listened carefully to their priorities and the difference we need to make in the months and years to come.

Their guidance helped the Association to make five new Promises to the MND community – bold and ambitious Promises which will take us closer to the Association's vision of a world free from MND.

With the support of our community, we won't rest until:

- MND is treatable and ultimately curable
- Everyone gets the care they need when they need it
- Every day with MND counts
- You are heard
- No one faces MND alone.

Heightened awareness of MND led to a groundswell of support for the Association during the year, translating into a marked increase in donations. As a result, the MND Association ended 2021 with a significant surplus to invest in research and the services we offer to people living with and affected by MND.

We are determined to do everything we can to power the fight against MND and harness the extraordinary momentum we have seen in recent years. With that in mind, we plan to commit £9 million from the surplus into our core work. £5 million will support collaborative translational and clinical research programmes, on top of the £500,000 invested in 2021 and a further £1.5 million that is already budgeted in 2022. This is in addition to the Association's portfolio of research grants which totalled £15.1 million in 2021. These additional funds will be targeted to support drug discovery and development, speeding up the clinical trials process and making it easier for people living with MND to access telemedicine to help them get involved in research projects in their own homes.

We will invest more than £1.3 million from the £9 million surplus to review and improve our grants programme, develop a technology grants programme, develop carers' services in collaboration with partners, develop and test new models of community-based care and further develop the MND Connect Helpline. We will invest in volunteer training and recruitment and extend the reach of our services, making our services more inclusive and accessible to all.

To deliver our Promises, we will also be investing £500,000 from the surplus on fundraising innovation to build long term sustainable income and investing in vital digital and infrastructure systems to build resilience and ensure that the Association is able to operate effectively in a fast-moving world. This will help to ensure that we can deliver an effective, high quality and responsive service to people with MND.

To learn more about our commitment to the MND community and our priorities, or to get involved, visit www.mndassociation.org/MNDPromises

iv) Fundraising governance priorities

We have a diverse portfolio of fundraising activities including raising funds from individuals, trusts and foundations, companies, events, local communities and legacies. We approach our supporters via direct mail, email and directly at events, and manage this fundraising both centrally and locally through our branches and groups.

We comply with current regulations and best practice set out by regulatory and professional membership bodies including the Fundraising Regulator, the Institute of Fundraising, the Direct Marketing Association and the Advertising Standards Board.

We are registered with the Fundraising Regulator and have signed up to the Fundraising Preference Service and honour any requests from the public to end contact with us. We fundraise in line with the Code of Fundraising Practice and adhere to data protection law. We are committed to ensuring that we are completely open and transparent about our fundraising and spending. As members of the Fundraising Regulator's self-regulatory scheme, we comply with its principles in all our fundraising:

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

Due to the nature of delivering fundraising across multiple sites, we are aware that the potential for breaches of fundraising code of practice and data protection compliance exist. We manage and minimise these risks through training and inductions for new starters and for our branches and groups; through quality checks and audits, our compliance policies and having data protection/ compliance champions within each team.

As the MND Association, we acknowledge that the engagement of third parties can help us raise funds, as well as improve efficiency and reduce costs. We require that any third party we work with complies with data protection legislation as set out in the Code of Fundraising Practice including the requirements of the telephone, mailing and fundraising preference services.

We follow a robust procurement process when recruiting third parties to work on our behalf, making sure we apply appropriate due diligence and contracts for this work. We work closely with these third parties, regularly reviewing their work against performance targets and the Fundraising Code of Practice to ensure delivery of the best value for money for the charity and its supporters.

When we benefit from commercial companies raising funds on our behalf through the sale of products, we operate within a written agreement to ensure their activities are not harmful to the Association. Trustees regularly review the fundraising strategy and

are made aware of any significant new activities and/or contracts where values need to be carefully aligned.

We received 14 complaints about our fundraising activity in 2021 and all were promptly resolved without the need for escalation to the Fundraising Regulator. Complaints are taken very seriously and reviewed quarterly by the Board of Trustees. However, these 14 represent a tiny fraction of our outgoing fundraising communications. There is a complaints policy, which is available on our website, which forms the basis for the training of all fundraising staff.

All fundraisers at the MND Association are guided in how to protect vulnerable people including how to recognise a person in vulnerable circumstances. All our direct mail, emails and thank you letters contain clear instructions as to how a supporter can easily opt out of receiving further communications from the charity should they choose to do so.

v) Financial review

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

Financial performance

2021 was an exceptional year for fundraising at the Association with total income reaching £28.9 million for the 12-month period compared to £19.9 million in 2020. The increased focus on MND in the media and the high profile fundraising events that took place contributed to a record year. All areas of fundraising had a strong year, most notably legacy donations which accounted for almost 30% of the income received.

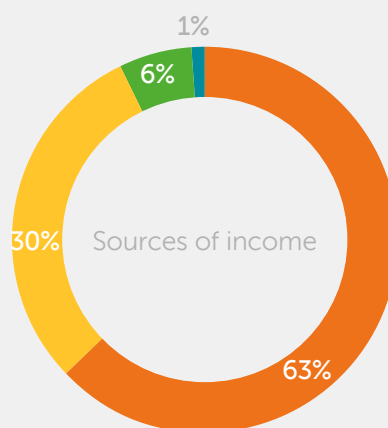
£18.2 million was raised and donated by our incredible supporters and a further £1.8 million was raised by our branches and groups. We are tremendously grateful for their commitment and continued support.

£8.5 million was donated in 2021 in the form of legacy gifts which continue to make such a huge difference to the work we do. We are enormously grateful to the people who choose to remember the work of the Association in their Wills.

£6.48 was raised for every pound spent directly on fundraising in 2021. When legacy income and costs are included, this rises to £9.16.

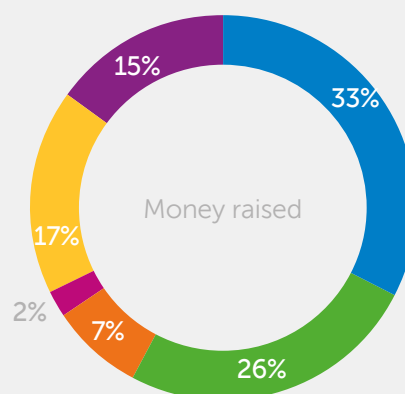
Sources of income

	(£) million
Fundraising	£18.2
Legacies	£8.5
Branches and Groups	£1.8
Earned income	£0.4
TOTAL INCOME FOR 2021	£28.9



How we spent the money raised

	(£) million
Care	£5.9
Research	£4.6
Campaigning	£1.4
Volunteer development	£0.4
Fundraising	£3.1
Operational Support Costs	£2.7
TOTAL COSTS FOR 2021	£18.1



Expenditure returned to pre-pandemic levels (increased by £2.5 million on 2020) as restrictions were eased and major fundraising events and volunteering activities returned. Research expenditure also increased significantly on 2020 as facilities that were closed during the pandemic re-opened and opportunities for new studies arose. We maintained all our commitments to our care grants programme to ensure that people affected by MND continued to receive critical financial support.

The incredibly strong income performance led to a net surplus of £10.8 million. The Board of Trustees has agreed to designate £9 million of this surplus to enable us to do more, more quickly. More details can be found in the *Future Plans and Priorities* section on page 8.

Despite our extremely positive fundraising success over the last two years, we still need to raise funds to support our on-going care, research and campaigning work which will cost approximately £20 million a year.

vi) Principal risks and uncertainties

Risk management

The trustees acknowledge their responsibility for the Association's systems of internal control and risk management and recognise that such a system is designed to actively manage and minimise the risk of failure to achieve the Association's objectives. The Board delegates some appropriate financial powers to the Finance and Audit Committee as detailed in the Scheme of Delegation. The Association has a cautious risk appetite across all its principal risks. The trustees review the key risk indicators for each principal risk area on a regular basis through the delegated Committees of Finance and Audit, Governance, Care and Engagement. Trustees monitor that appropriate action is being taken where risk does not align with appetite.

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

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

Reputational risk

Retaining the Association's reputation is paramount. Due to the diverse nature of our activities this risk relates to several areas including our extensive research programme (for example our policies on the use of animals and embryonic stem cells in research), the provision of care through our MND Care Centres and Networks, the support provided by our Association visitor network, and the extensive activities of our 2,400 volunteers across England, Wales and Northern Ireland. Controls and policies relating to all our activities focus on reputational impacts and these are monitored regularly for compliance.

Financial risk

Whilst the Association has had a strong year in 2021, we remain very aware of the risk to future income as household incomes are impacted by significant increases in the costs of utilities, high inflation, increasing interest rates, and the economy potentially moving into a recession later in 2022. The impact on the Association could lead to reduced income generation at the same time as need for further financial support grows from our community. To mitigate this risk, the Association undertakes weekly income and core expenditure reporting so that we can identify, and react to, any financial pressures which we will manage tightly using our reserves.

While we remain cautious about the financial position in 2022, the robust performance in 2021 has significantly reduced our financial risk and means that the Association will begin the year in a much stronger position than anticipated. The strong financial position has enabled the auditors to confirm that the Association remains a going concern.

External environment risk

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

Compliance risk

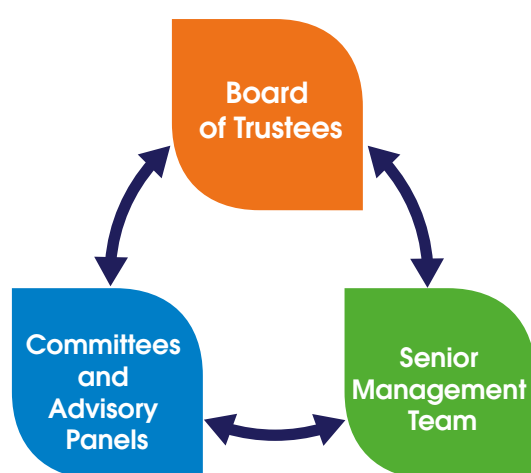
The Association must comply with a range of legal and regulatory requirements including charity law, data protection, fundraising standards, health and safety and safeguarding. To mitigate these risks the Association has robust and embedded processes and policies, which are complemented by regular and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

Structure, Governance and Management

Structure

The Association was originally formed on 6 October 1979 and was incorporated as a company limited by membership guarantee in 1986. The Association is governed by its *Articles of Association* and in the event of it being wound up, every member is liable for an amount not exceeding £1 to facilitate the payment of the debts and liabilities of the Association. At 31 December 2021, there were 10,984 members.

Governance



Our governance structure is designed to ensure that:

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

The Board of Trustees

The Board (members of which are directors under company law) is the governing body of the Motor Neurone Disease Association and ordinarily meets in formal session four times a year.

The Articles of Association provide a degree of flexibility for changes to be made to the composition of the Board, subject to there always being a majority of elected trustees over co-opted trustees and there being no more than ten elected trustees, and the Board reviews its composition against these requirements on an annual basis.

All elected and co-opted trustees are provided with a comprehensive induction to the Association, which includes an overview of the organisational strategy and current priorities, together with briefings on the roles and duties of trustees. They receive subsequent development and training through internal coaching and external providers. The Board maintains an updated skills audit against a defined set of skills and this enables it to identify gaps and plan for future recruitment. The Board seeks to maintain and improve its governance arrangements and uses the Charity Governance Code to benchmark its structure and processes against the code's recommended practices.

Committees of the Board

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

Care Committee

This committee reviews all aspects of the Association's work relating to improving care and providing support for people with MND, their carers and families. It reviews risk and approves grant funding to support the work of MND Care Centres and Networks, up to an agreed limit, with grants above that limit being approved by the Board.

Engagement Committee

This committee reviews strategic activities, policy, and effectiveness relating to the Association's volunteers. This includes all aspects of volunteering including recruitment, retention, empowerment, any potential risks and the development of existing and emerging roles.

Finance and Audit Committee

This committee provides stewardship of all financial aspects of the charity's work, including the fundraising activities of the Association. The committee scrutinises and evaluates the annual budget prior to Board approval. It ensures that the appropriate financial controls and regulatory requirements are adhered to and advises the Board accordingly. The committee also recommends the annual pay award for all employees, which includes the Senior Management Team (except the Chief Executive), to the Board for approval.

Governance Committee

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

Remuneration Committee

This committee is responsible for the annual review of the salary and other benefits of the Chief Executive and oversees the remuneration packages of members of the senior management team.

Biomedical and Healthcare Research Advisory Panels

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

Branches, groups and affiliates

At 31 December 2021, the Association had 90 branches and groups and two affiliates (based in Jersey and the Isle of Man). Each branch and group sign a charter annually called *Agreement for working together*, which sets out the parameters of the powers delegated to them by the Board. Branches and groups, whose financial results are included in these statements, are governed by the Board. The two affiliates are excluded from the consolidation as they are not part of the Association.

Branches and groups provide unique support to people affected by MND at a local level and also fundraise and campaign on their behalf. They raise and spend money locally on support grants, in line with guidelines which are reviewed annually by a support grant group in which volunteers are in the majority. Association staff support them by providing advice and guidance on recruitment and support of volunteers and local structure, organisation and management of their activities.

Environmental impact

The Association initiates and monitors changes to process and practice that reduce its environmental impact. We moved to our new national office at Francis Crick House in January 2020 and this gave us an opportunity to adopt more sustainable practices. These included reducing in-house printing resources to encourage teams to work more digitally. The need for most staff to work from home has seen significant reductions in travel, printing and facilities' expenditure. We will learn from the new digital and homeworking approaches and ensure that we continue to incorporate these methods in our ways of working post-pandemic. Money saved through environmental efficiencies is diverted into achieving the charity's strategic objectives.

Management

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

Safeguarding

The Association provides services to a wide range of people and is committed to meeting the needs of people living with MND, their families and carers. We recognise that some of the people we are in contact with are adults and children or young people who may be at risk of harm. Our safeguarding policy is designed to inform and offer guidance to our staff and volunteers in the management of issues relating to protecting and promoting the welfare of adults and children at risk, and ensures we act appropriately when we become aware of an adult or child who may be at risk of harm. The policy also provides a framework which ensures that our staff and volunteers have the appropriate information and support to enable them to recognise abuse and neglect and to take the necessary steps to prevent it happening. The Association's Safeguarding Board and Board of Trustees regularly review our risk in relation to safeguarding issues and ensure implementation of any actions.

Whistleblowing

We take any evidence of malpractice very seriously and support anyone who is raising genuinely held concerns. We reviewed these policies in detail in 2021 and they are backed up by mandatory staff and volunteer training.

Grants

Grants are awarded for both research projects and care services:

Research – we award project and programme grants, PhD studentships and Lady Edith Wolfson clinical and non-clinical research fellowships. Application and decision-making processes, including comprehensive peer review, are published on the Association's website. These processes conclude with formal approval or rejection of applications by the Board.

Care – We provide grants to existing specialist MND Care Centres and Networks. At 31 December 2021 the Association was providing financial support to 22 such centres and networks. Performance is monitored annually for existing Care Centres, with a full grant renewal process every four years.

We also offer grants for people who are living with, or affected by MND, including Emergency Grants, MND Support (Care) Grants and Quality of Life Grants as well as grants for children and young people.

Investment policy

Investments are held to cover reserves for the management of risk and for future investment opportunities. The investment objective is to provide resources to cover short term demands arising from sudden or unexpected events that could influence fundraising income. The trustees take a prudent approach to risk, holding the Association's investments in cash deposits, near cash and general recognised cash equivalents (including but not limited to Certificates of Deposit and other short-term investments). Counter party limits and acceptable credit ratings are set by the Finance and Audit Committee. Any investment donated to the Association will ordinarily be sold at the earliest opportunity, unless there is a specific request from the donor for the shares to be held as fixed asset investments. During the year, the low interest rate environment meant that returns on deposit investments remained low earning just £69,000 in 2021 versus £121,000 in 2020.

Group reserves policy

The trustees have adopted a robust and flexible reserves policy to meet the changing needs of the charity. This states that the general reserve should be in the range of three to five months' general expenditure represented in cash and readily realisable investments, held centrally and within branches. This is a target range of between £5 million and £8.4 million. As at the year end, the unrestricted/undesignated reserves balance sat at £8.5 million. Trustees believe that this remains a prudent level given the continuing uncertainty associated with the future economic outlook which could have a detrimental impact on our ability to raise funds.

Statement of Trustees' Responsibilities and Corporate Governance

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group and of the incoming resources and application of resources, including the income and expenditure, of the charitable group for that period. In preparing these financial statements, the trustees are required to:

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

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

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

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

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

This Trustees' Report, prepared in accordance with the Charities Act 2011 and the Companies Act 2006 was approved by the Board of Trustees on 28 May 2022 including in their capacity as company directors, the strategic report contained therein, and signed on its behalf by:



Richard Coleman

Chair, Board of Trustees

28 May 2022

Organisational information and financial statements

Board of Trustees

Chair: Richard Coleman

Chair-elect: Dr Usman Khan (*from May 2021*)

Vice Chair: Jan Warren

Honorary Treasurer:

Tim Kidd (*until July 2021*)

James Marshall (*from July 2021*)

Andy Cawdell

Elizabeth Ellis (*from July 2021*)

Alan Graham MBE (*until July 2021*)

Devia Gurjar (*until March 2022*)

Dr Usman Khan (*from May 2021*)

Tim Kidd (*until July 2021*)

Catherine Knights

James Marshall (*from March 2021*)

Debra Martin (*from July 2021*)

Dr Shaun McGee

Vicky Paeschel

Siobhán Rooney

Dr Nik Sharma

Dr Heather Smith

Katy Styles

Senior management team

Sally Light, Chief Executive

Linda Allen, Director of Fundraising

Mark Chapman, Director of Finance

Dr Brian Dickie, Director of Research Development

Nick Goldup, Director of Care Improvement

Chris James, Director of External Affairs

Chris Wade, Director of Engagement

Company secretary

Mark Chapman

Registered office

Francis Crick House
6 Summerhouse Road
Northampton
NN3 6BJ

Professional advisers

Statutory auditors

Haysmacintyre LLP
10 Queen Street Place
London
EC4R 1AG

Solicitors

Bates Wells
2-6 Cannon Street
London
EC4M 6YH

Bankers

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

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

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

Opinion

We have audited the financial statements of Motor Neurone Disease Association for the year ended 31 December 2021 which comprise the Consolidated Statement of Financial Activities, The Group and Charity Balance Sheets, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 December 2021 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

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

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the group's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

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

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

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement set out on page 15, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to the regulatory requirements of the Charity Commission, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the

financial statements such as the Companies Act 2006, Charities Act 2011, Charity SORP and payroll taxes.

We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to the posting of inappropriate journal entries and management bias in certain accounting estimates. Audit procedures performed by the engagement team included:

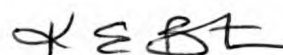
- inspecting correspondence with regulators and tax authorities;
- discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud;
- evaluating management's controls designed to prevent and detect irregularities;
- identifying and testing journals, in particular journal entries posted with unusual descriptions or significant values; and
- challenging assumptions and judgements made by management in their critical accounting estimates.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

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

Use of our report

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



Kathryn Burton (Senior Statutory Auditor)

21 June 2022

For and on behalf of Haysmacintyre LLP,
Statutory Auditor
10 Queen Street Place
London EC4R 1AG

Consolidated Statement of Financial Activities

(incorporating an income and expenditure account)

For the year ended 31 December 2021

	Notes	Unrestricted funds £000	Restricted funds £000	Total Funds 2021 £000	Total funds 2020 £000
Income and endowments from:					
Donations and legacies:	1a				
Donations		12,817	6,735	19,552	12,708
Legacies		8,523		8,523	6,012
Charitable activities					
Other trading activities	1b	743	-	743	705
Investments		69	-	69	121
Other	1c	56	-	56	365
Total income		22,208	6,735	28,943	19,911
Expenditure on:					
Raising funds		4,037	-	4,037	3,686
Charitable activities:					
Care		6,545	372	6,917	6,867
Research		1,257	3,548	4,805	2,799
Campaigning and raising awareness		1,666	136	1,802	1,724
Volunteer development		502	-	502	507
Total expenditure	4	14,007	4,056	18,063	15,583
Net income/ (expenditure)	3	8,201	2,679	10,880	4,328
Other recognised gains/ (losses):					
Other gains/ (losses)		(38)		(38)	40
Net movement in funds		8,163	2,679	10,842	4,368
Reconciliation of funds:					
Total funds brought forward		12,772	2,360	15,132	10,764
Total funds carried forward	18a, 19	20,935	5,039	25,974	15,132

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

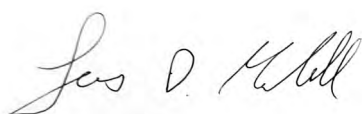
The movement on restricted funds is shown in note 18a.

Balance Sheet

For the year ended 31 December 2021

		Group		Charity	
	Notes	2021 £000	2020 £000	2021 £000	2020 £000
Fixed assets					
Tangible assets	11	581	835	581	835
Total Tangible Assets		581	835	581	835
Current assets					
Stocks	13	22	31	-	-
Debtors	14	7,900	5,544	8,035	5,631
Investments	15	17,238	9,200	17,238	9,200
Cash at bank and in hand		15,434	12,619	15,352	12,447
		40,594	27,394	40,625	27,278
Creditors: amounts falling due within one year	16a	9,794	9,993	9,913	10,004
Net current assets		30,800	17,401	30,712	17,274
Total assets less current liabilities		31,381	18,236	31,293	18,109
Creditors: amounts falling due after more than one year	17	5,407	3,104	5,407	3,104
Net assets	19	25,974	15,132	25,886	15,005
Accumulated funds					
Restricted funds	18a	5,039	2,360	5,039	2,360
Designated funds	18a, 18b	12,656	4,295	12,656	4,295
Unrestricted funds:					
Unrestricted funds	18a	8,191	8,350	8,191	8,350
Funds retained in subsidiary	12a	88	127		
Retained Earnings					
		25,974	15,132	25,886	15,005

The financial statements on pages 19 to 43 were approved and authorised for issue by the Board of Trustees on 28 May 2022, and were signed on its behalf by:



James Marshall
Treasurer



Richard Coleman
Chair

The net movement in funds for the Association for the year ending 31 December 2021 was £10,842,000 (2020 : £4,368,000).

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

Statement of Cash Flows

For the year ended 31 December 2021

	Notes	2021 £000	2020 £000
Cash flows from operating activities:			
Net income/ (expenditure) for the reporting year		10,842	4,368
Adjustments for:			
Depreciation and amortisation charges	11	326	345
Dividends and interest from investments		(69)	(121)
Gain on disposal of fixed assets	11	-	13
(Increase) / decrease in stock	13	9	(2)
(Increase) / decrease in debtors	14	(2,356)	(775)
Increase / (decrease) in creditors	16a,17	2,104	(1,424)
Net cash generated from operating activities		10,856	2,404
Cash flows from investing activities:			
Movement in cash held as investment			-
Dividends and interest from investments		69	121
Purchase of fixed assets	11	(72)	(473)
Net cash used in investing activities		(3)	(352)
Increase in cash and cash equivalents in the reporting year		10,853	2,052
Cash and cash equivalents at the start of the year		21,819	19,767
Cash and cash equivalents at the end of the year		32,672	21,819

Analysis of cash and cash equivalents

Group	Balance 1 January 2020 £000	Cash flow changes £000	Balance 1 January 2021 £000	Cash flow changes £000	Balance 31 December 2021 £000
Net cash					
Short term deposits	9,365	(165)	9,200	8,038	17,238
Bank current accounts	10,394	2,219	12,613	2,818	15,431
Cash in hand	8	(2)	6	(3)	3
Net funds	19,767	2,052	21,819	10,853	32,672

Statement of Accounting Policies

Legal Status

The Association is a company limited by guarantee not having a share capital, incorporated in England and Wales (company number: 02007023) and a charity registered in England and Wales (charity number: 294354). The charity's registered office address is 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. The members undertake to contribute to the assets of the company in the event of it being wound up, either whilst members or within one year of the membership ceasing. The maximum contribution required from each member is £1. There were 10,984 members at 31 December 2021 (31 December 2020: 10,390).

Principal accounting policies

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

a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) second edition (effective 1 January 2019) – (Charities SORP FRS 102), and the Companies Act 2006.

The Motor Neurone Disease Association meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Critical accounting judgements and key sources of estimation uncertainty

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

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

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

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

c) Preparation of the accounts on a going concern basis

Despite the continuing pandemic, 2021 proved to be a very strong year for the charity with reserves increasing and the Association's financial position remaining strong. As such, the trustees consider there are no material uncertainties about the charity's ability to continue as a going concern. Trustees regularly review potential risks and make strategic changes as and when required. The review of the charity's financial position, reserves levels and future plans through to the end of December 2024 gives trustees confidence that the charity remains a going concern for the foreseeable future.

d) Consolidated financial statements

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

In accordance with the exemption afforded by section 408 of the Companies Act 2006 a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared. The surplus of the parent charity was £10,880,000 (2020: surplus £4,328,000).

e) Income

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

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

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

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted,

Statement of Accounting Policies (continued)

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

f) Investment income

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

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

g) Fund accounting

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

h) Expenditure and irrecoverable VAT

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

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

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

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

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

j) Operating leases

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

k) Intangible fixed assets

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

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

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

l) Tangible fixed assets

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

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

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

m) Investments

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

Statement of Accounting Policies (continued)

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

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

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

n) Financial instruments

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

o) Cash at bank and in hand

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

p) Debtors

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

q) Stocks

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

r) Creditors and provisions

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

s) Long term liabilities

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

t) Employee benefits

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

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

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

u) Taxation

As a registered charity, the Association benefits from being exempt from tax on surpluses generated by its charitable activities.

In 2019 the Association applied for Group VAT status on the basis that it had become financially beneficial for the whole group to be able to recover some elements of VAT, rather than just the Sales Company.

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.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

Income

1a Donations and legacies

	2021 £000	2020 £000
Individuals	7,306	3,682
Community and other fundraising	6,240	3,137
Appeals	2,076	1,914
Charitable foundations (see note 2)	1,170	1,896
Corporate donations	941	881
Tax recovered	1,819	1,198
	19,552	12,708
Legacies	8,523	6,012
	28,075	18,720

See Statement of Accounting Policies e) for treatment of legacy income

1b Other trading activities

	2021 £000	2020 £000
Charity-organised fundraising	418	446
Merchandise sales and advertising	39	37
Conferences and events	286	222
	743	705

1c Other

	2021 £000	2020 £000
Costs recovered from the International Alliance	18	11
HMRC Job Retention Grant	25	333
Other	13	21
	56	365

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

2 Grants receivable from Charitable foundations

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

	2021 £000		2021 £000
My Name's Doddie Foundation	200	The Basil Samuel Charitable Trust	8
The Betty Messenger Charitable Foundation	100	Rosybank Charitable Trust	7
Mark Armitage Charitable Trust	94	James Tudor Foundation	7
Constance Travis Charitable Trust	50	The Ofenheim Charitable Trust	7
Darby Rimmer MND Foundation	50	The Nick Smith Foundation	6
The Linbury Trust	50	Vodafone UK Foundation	5
Netherby Trust	40	The William & Mabel Morris Charitable Trust	5
Alan Davidson Foundation	38	B&Q Foundation	5
Heaton-Ellis Trust	31	Douglas Compton James Charitable Trust	5
Bruce Wake Charitable Trust	25	John James Bristol Foundation	5
The William Brake Foundation	25	M K Rose Charitable Trust	5
Ian Karten Charitable Trust	24	Pilkington Charities Fund	5
The Freshfield Foundation	24	Sir James Knott Trust	5
Malcolm Gunter Foundation	20	Sir James Reckitt Charity	5
Richard Mackay Charitable Trust	20	Sir Samuel Scott of Yews Trust	5
The Marie Helen Luen Charitable Trust	20	Stephen Hawking Foundation	5
Edith Murphy Foundation	15	The 29th May 1961 Charitable Trust	5
The Harris Family Charitable Trust	15	The Berni Charitable Trust	5
The Elizabeth and Prince Zaiger Trust	12	The Billmeir Charitable Trust	5
The Zochonis Charitable Trust	12	The Chalk Cliff Trust	5
Peacock Charitable Trust	11	The Christopher H R Reeves Charitable Trust	5
Medicash Foundation	10	The David Lister Charitable Trust	5
Fieldrose Charitable Trust	10	The Eveson Charitable Trust	5
Frank Brake Charitable Trust	10	The G C Gibson Charitable Trust	5
Margaret Giffen Charitable Trust	10	The Jones 1986 Charitable Trust	5
Payne-Gallwey Charitable Trust	10	The Kirby Laing Foundation	5
The Hornby Lonsdale Charitable Trust	10	The Oldhurst Trust	5
The Priory Foundation	10	The Simon Gibson Charitable Trust	5
Lloyds Bank Foundation for England & Wales	9		
Dere Street Barristers Charitable Trust	8	Anonymous	41
Annandale Charitable Trust	8		
The Orr Mackintosh Foundation	8	TOTAL	1,170

In 2020, grants receivable from Charitable foundations totalled £1,896,000

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

3 Net income for the year

This arises after charging:

	2021 £000	2020 £000
Auditors' remuneration:		
External audit	29	38
Other services	-	1
Operating lease rentals:		
Motor vehicles	302	221
Land and buildings	199	160
Other	14	14
Depreciation and amortisation of owned assets	326	345
Loss on disposal of fixed assets	-	(16)

4 Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Notes	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2021 £000	Total 2020 £000
Care and care centres		3,251	2,625	1,041	6,917	6,867
Research		536	4,078	191	4,805	2,799
Campaigning and raising awareness		1,333	-	469	1,802	1,724
Volunteering		389	-	113	502	507
Costs of charitable activity		5,509	6,703	1,814	14,026	11,897
Raising funds		3,131	-	906	4,037	3,686
Total resources expended 2021		8,640	6,703	2,720	18,063	15,583
Total resources expended 2020	23a	8,181	4,416	2,986		15,583

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

5 Support costs

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

	Care £000	Research £000	Campaigning and raising awareness £000	Volunteering £000	Raising funds £000	Total 2021 £000	Total 2020 £000
Management	171	31	77	18	149	446	486
Governance	24	4	11	2	20	61	123
Finance	161	29	72	17	140	419	487
Information and communications technology	289	53	130	31	251	754	725
Facilities	254	46	114	27	221	662	847
Human resources	143	26	64	16	125	374	238
Conferences and events	1	1	1	1	-	4	80
	1,043	190	469	112	906	2,720	2,986

Full details of prior year support costs can be found in note 23b

6 Grants payable

Grants were awarded during the year as follows:

	Note	2021 £000	2020 £000
Grants to institutions	4	4,989	3,003
Grants to individuals		1,714	1,413
		6,703	4,416

Grants made to, and for, individuals affected by motor neurone disease are for expenses such as respite care, building adaptations and equipment rental. These grants benefited 2,479 individuals throughout the Association's network across England, Wales and Northern Ireland.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

6 Grants payable (continued)

	2021 £000	2020 £000
Balance at start of year	9,947	11,915
Awarded in year	6,703	4,416
Paid in year	(3,663)	(6,384)
Balance at end of year	12,987	9,947
Falling due within one year (note 16a)	7,580	6,843
Falling due after more than one year (note 17)	5,407	3,104
	12,987	9,947

Commitments

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

Group and Charity	2021 £000	2020 £000
Payable within one year	1	214
Payable in years two to five	881	911
	882	1,125

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

6 Grants payable (continued)

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

	2021 £000	
Kings College London	1,080	Research & Care
LifeArc	800	Research
University College London	758	Research
University of Sheffield	283	Research
University of Aberdeen	248	Research
University of Sussex	223	Research & Care
University of Nottingham	215	Research
Trinity College Dublin	156	Research
Plymouth Primary Care Trust (S.West)	108	Care
University of Newcastle	94	Research
S Wales Care Network (Cardiff)	92	Care
The Register Renewal - Oxford	85	Research
Southampton Care Centre	83	Care
The James Cook Uni Hosp(M'Boro)	77	Care
Norfolk/Norwich Care Centre	70	Care
Leeds Care Centre	68	Care
Cambridge Care Centre	62	Care
Barts Care Centre	55	Care
Small Grants	51	Research
Bristol Care Centre	51	Care
University of East Anglia	51	Research
Newcastle General Hospital	48	Care
Preston Care Centre	46	Care
Nottingham University Hospital	43	Care
National Hospital for Neurology & Neurosurgery	31	Care
Manchester Care Centre	30	Care
Walton Centre for Neurology & Neurodurgery	30	Research
Sheffield Care Centre	24	Care
Liverpool Care Centre	23	Care
Manchester Metropolitan University	3	Research
University of Edinburgh	1	Care
	4,989	

In 2020, grants payable totalling £3,003,000 were made

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

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

The employment costs of all employees were:

	2021 £000	2020 £000
Gross wages and salaries	5,999	6,024
Social security costs	579	564
Other pension costs	430	411
Medical insurance	36	37
	7,044	7,036

The total number of employees whose emoluments for the year (not including pension contributions) exceeded £60,000 relates to all of the seven members of the senior management team across 2021. These emoluments are identified as follows:

	2021	2020
£100,000 - £109,999	1	1
£90,000 - £99,999	-	-
£80,000 - £89,999	6	3
£70,000 - £79,999	-	3
£60,000 - £69,999	-	-

Employers pension contributions for the higher paid employees above are £50,400 for the year ended 31 December 2021 (2020: £49,469).

The trustees devolved the day-to-day running of the Association to the 7 members of the senior management team, who served in the year, as identified on pages 30 and 31 of these accounts. As such, this body is identified as the key management personnel of the Association and included above are the following payments specifically to this group:

	2021 £000	2020 £000
Gross wages and salaries	604	592
Benefits-in-kind	4	4
Pension costs	50	49
Social security costs	68	66
	726	711

	2021 £000	2020 £000
Trustee remuneration and expenses		
Reimbursement directly to trustees	1	3
Payment to third parties in respect of trustee expenses	5	3
	6	6
Number of trustees holding office during the year	17	15

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

The charity trustees neither received nor waived any emoluments during the year (2020: £nil). Trustee expenses in the year include travel and subsistence expenses totalling £6,096 (2020: £5,578). These expenses were all incurred in the course of their duties and were reimbursed, or paid directly to third parties on their behalf as shown above. Trustee indemnity insurance is held at a cost of £1,573 (2020: £1,573).

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

8 Staff numbers

The average headcount number of employees for the year is shown below:

	2021 Headcount	2020 Headcount
Care	69	66
Research	13	13
Campaigning and raising awareness	31	32
Volunteering	7	8
Raising funds	60	59
	180	178

Staff numbers above include an appropriate apportionment of support staff.

9 Pension costs

The Association operates defined contribution personal pension schemes for employees. The assets of the schemes are held separately from those of the Association in funds independently administered by Standard Life. The amounts paid to the funds represent contributions from both the employer and employees. The employer's contributions in the year were £430,361 (2020: £411,500). There are no other ongoing obligations arising. Amounts outstanding at year end were £0 (2020: £0).

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 2021.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

11 Fixed assets

Group and Charity	Motor vehicles £000	Computers, fixtures, fittings and equipment £000	Total tangible fixed assets £000	Total intangible fixed assets* £000
Cost				
At 1 January 2021	8	1,659	1,667	46
Additions	-	72	72	-
Disposals	-	-	-	-
At 31 December 2021	8	1,731	1,739	46
Depreciation and amortisation				
At 1 January 2021	8	824	832	46
Charged in the year	-	326	326	-
Eliminated on disposal	-	-	-	-
At 31 December 2021	8	1,150	1,158	46
Net book value				
At 31 December 2021	-	581	581	-
At 31 December 2020	-	835	835	-

* Intangible fixed assets comprises purchased software licences.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

12 Fixed asset investments

Motor Neurone Disease (Sales) Limited

The Association owns a wholly owned subsidiary company, Motor Neurone Disease (Sales) Limited, which is registered in England and Wales (Company number: 01989172) at Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. This subsidiary operates mail order catalogues selling promotional clothing, gifts and cards and runs Challenge and other fundraising events. All taxable profits are donated to the Association each year under Gift Aid. Audited accounts are filed with the Registrar of Companies, and below is a summary of its trading results for the year ended 31 December 2021:

Motor Neurone Disease (Sales) Limited	2021	2020
Income Statement	£000	£000
Turnover	144	252
Cost of sales	(122)	(168)
Gross profit	22	84
Administration costs	(20)	(43)
Profit / (Loss) before interest and tax	2	41
Net interest payable	(1)	(1)
Profit / (Loss) on ordinary activities before tax	1	40
Corporation tax	0	0
Profit / (Loss) for the financial year	1	40

The aggregate of the assets, liabilities and funds was:

	2021	2020
	£000	£000
Assets	150	271
Liabilities	(61)	(144)
Funds (representing 2 ordinary shares of £1 each)	89	127

The investment held by the Charity of £2 (2020: £2) represents shares in the subsidiary company at cost.

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

	2021	2020
	£000	£000
Gross income	28,943	19,911
Surplus for the year	10,880	4,328

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

13 Stocks

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Purchased goods for resale	22	31	-	-

14 Debtors

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Loan to subsidiary company	-	-	50	51
Amounts due from subsidiary company	-	-	44	46
Legacies	6,349	4,680	6,349	4,680
Other debtors	590	270	631	267
Income tax reclaimable	774	269	774	269
Prepayments	187	325	187	318
	7,900	5,544	8,035	5,631

15 Current asset investments

The total of current asset investments £17,237,543 (2020: £9,200,169) is constituted by fixed term and other bank and building society deposits with maturity dates within 12 months plus other investments which will be converted to cash with 12 months of the Balance Sheet date.

16a Creditors: amounts falling due within one year

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Accruals for grants payable	7,580	6,843	7,580	6,843
Trade creditors	995	1,022	1,142	1,022
Accruals and deferred income (note 16b)	766	1,969	766	1,966
Payroll taxation and social security	216	27	216	27
Provisions and other creditors (note 21)	237	132	209	146
	9,794	9,993	9,913	10,004

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

16b Analysis of deferred income

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Deferred income at 1 January	1	1	1	1
Released during the year	(1)	(1)	(1)	(1)
Deferred during the year	28	1	28	1
Deferred income at 31 December	28	1	28	1

17 Creditors: amounts falling due after one year

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Research and Care Centre Creditors	5,407	3,104	5,407	3,104
	5,407	3,104	5,407	3,104

18a Statement of funds

Group and Charity	Balance at 1 January 2020 £000	Income £000	Expenditure £000	Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 31 December 2021 £000
Unrestricted funds:							
General funds	6,944	10,361	(8,828)	8,477	11,154	(11,352)	8,279
Designated funds:							
Care Centre grants	1,302	1,821	(2,232)	891	2,337	(2,347)	881
Ice Bucket Challenge funded projects:							
Research	214	-	-	214	-	(213)	1
Care	115	-	-	115	-	(113)	2
Campaigning and raising awareness	55	-	-	55	-	-	55
Volunteering and new opportunities	60		(40)	20	-	(20)	0
Research & Strategic Investment		3,000		3,000	8,717		11,717
note 18b	1,746	4,821	(2,272)	4,295	11,054	(2,693)	12,656
Total unrestricted funds	8,690	15,182	(11,100)	12,772	22,208	(14,045)	20,935

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

18a Statement of funds (continued)

Group and Charity	Balance at 1 January 2020 £000	Income £000	Expenditure £000	Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 31 December 2021 £000
Restricted funds:							
Research	1,340	2,537	(2,560)	1,317	3,659	(3,548)	1,428
Care	(958)	1,527	(1,336)	(767)	2,723	(372)	1,584
Volunteering	14	-	(14)	(0)	-	-	(0)
Branches and Groups	1,658	694	(542)	1,810	345	(128)	2,027
Campaigning	20	11	(31)	(0)	8	(8)	0
Total restricted funds	2,074	4,769	(4,483)	2,360	6,735	(4,056)	5,039
Total funds	10,764	19,951	(15,583)	15,132	28,943	(18,101)	25,974

Charity		Balance at 1 January 2020 £000	Income £000	Expenditure £000	Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 31 December 2021 £000
Unrestricted funds:								
General funds		6,857	10,321	(8,828)	8,350	11,155	(11,314)	8,191
Designated funds	note 18b	1,746	4,821	(2,272)	4,295	11,054	(2,693)	12,656
		8,603	15,142	(11,100)	12,645	22,209	(14,007)	20,847
Restricted funds		2,074	4,769	(4,483)	2,360	6,735	(4,056)	5,039
Total funds		10,677	19,911	(15,583)	15,005	28,944	(18,063)	25,886

Restricted Funds

Restricted funds are utilised as follows:

Research	for grant payments to be made enabling various research projects to continue
Care	for equipment and care / support provided to people living with MND
Branches and Groups	for care for people with MND within local areas
Campaigning	for raising awareness of MND across England, Wales and Northern Ireland

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

18b Designated funds

Designated funds represent:

	2021 £000	2020 £000
i) the amounts committed by the Association in respect of grants payable for the MND Care Centre Network not reflected in the Consolidated Statement of Financial Activities. Care Centre commitments run for up to 4 years and so the funds designated for these are required to meet future commitments on agreed contracts extending to 2024..	881	891
ii) the trustees previously also designated the IBC monies of £7.2m together with additional reserves for the following specific activities:		
Research projects	1	214
Care	2	115
Campaigning and raising awareness	55	55
Engagement of volunteers and to fund emerging new opportunities	0	20
These funds are expected to be fully utilised by the end of 2021.		
iii) Trustees agreed to designate £3m of the exceptional income in 2020 to research and strategic investment projects which will run through to the end of 2023. A further £9m of the 2021 surplus was also designated for the delivery of our new Promises.		
Board approved reallocation of reserves - 2020	2,717	3,000
Board approved reallocation of reserves - 2021	9,000	
	12,656	4,295

19 Analysis of net assets between funds

2021

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2021 are represented by:				
Fixed assets	-	-	581	581
Net current assets less long-term liabilities	5,039	12,656	7,698	25,393
Total net assets	5,039	12,656	8,279	25,974

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2021 are represented by:				
Fixed assets	-	-	581	581
Net current assets less long-term liabilities	5,039	12,656	7,610	25,305
Total net assets	5,039	12,656	8,191	25,886

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

19 Analysis of net assets between funds (continued)

2020

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	835
Net current assets less long-term liabilities	2,360	4,295	7,642	14,297
Total net assets	2,360	4,295	8,477	15,132

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	835
Net current assets less long-term liabilities	2,360	4,295	7,515	14,170
Total net assets	2,360	4,295	8,350	15,005

20 Leasing commitments

Operating leases

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

	2021 £000	2020 £000
Within one year	254	245
Between two to five years	752	587
Over five years	238	-
	1,244	832

The charge to the Statement of Financial Activities is £245,399 (2020: £395,000)

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

21 Provisions for liabilities and charges

Charity	Leasehold dilapidations £000	Bad debts (incl Legacy) £000	Obsolete stock £000	Total £000
At 1 January 2021	99	72	-	171
Additions	-	84	-	84
Utilised	-	(70)	-	(70)
Balance at 31 December 2021	99	86	-	185

Group	Leasehold dilapidations £000	Bad debts £000	Obsolete stock £000	Total £000
At 1 January 2021	99	72	27	198
Additions	-	84	-	84
Utilised	-	(70)	(27)	(97)
Balance at 31 December 2021	99	86	-	185

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

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

22. Consolidated Statement of Financial Activities (incorporating an income and expenditure account) For the year ending 31 December 2020

	Unrestricted Funds £000	Restricted Funds £000	Total Funds 2020 £000
Income and endowments from:			
Donations and legacies:			
Donations	8,095	4,613	12,708
Legacies	5,856	156	6,012
Charitable activities			
Other trading activities	705	-	705
Investments	121	-	121
Other	365	-	365
Total income	15,142	4,769	19,911
Expenditure on:			
Raising funds	3,686	-	3,686
Charitable activities:			
Care	4,989	1,878	6,867
Research	239	2,560	2,799
Campaigning and raising awareness	1,692	32	1,724
Volunteer development	494	13	507
Total expenditure	11,100	4,483	15,583
Net gain / (loss) on investments	-	-	-
Net income for the year	4,042	286	4,328
Transfers between funds	-	-	-
Other recognised gains/ (losses) :			
Gains/ (losses) on revaluation of fixed assets	-	-	-
Other gains/ (losses)	40	-	40
Net movement in funds	4,082	286	4,368
Reconciliation of funds:			
Total funds brought forward	8,690	2,074	10,764
Total funds carried forward	12,772	2,360	15,132

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

23 Prior year figures

23a Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2020 12 months £000
Care and care centres	3,270	2,504	1,093	6,867
Research	653	1,912	234	2,799
Campaigning and raising awareness	1,177	-	547	1,724
Volunteering	351	-	156	507
Costs of charitable activity	5,451	4,416	2,030	11,897
Raising funds	2,730	-	956	3,686
Total resources expended 2020	8,181	4,416	2,986	15,583

23b Support costs

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

	Care £000	Research £000	Campaigning awareness £000	Volunteering £000	Raising funds £000	Total 2020 12 months £000
Management	179	36	88	23	160	486
Governance	46	9	23	5	40	123
Finance	180	36	88	23	160	487
Information and communications technology	268	53	132	34	238	725
Facilities	312	63	153	40	279	847
Human resources	88	17	43	11	79	238
Conferences and events	20	20	20	20	-	80
	1,093	234	547	156	956	2,986

Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

23 Prior year figures (continued)

23c Analysis of net assets between funds

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Group:				
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	835
Net current assets less long-term liabilities	2,360	4,295	7,642	14,298
Total net assets	2,360	4,295	8,477	15,132

	£000	£000	£000	£000
Charity:				
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	835
Net current assets less long-term liabilities	2,360	4,295	7,515	14,170
Total net assets	2,360	4,295	8,350	15,005

 [mndassociation](#)

 [mndassoc](#)

 [mndassoc](#)

Motor Neurone Disease Association
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton, NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org

www.mndassociation.org

Royal Patron: HRH The Princess Royal

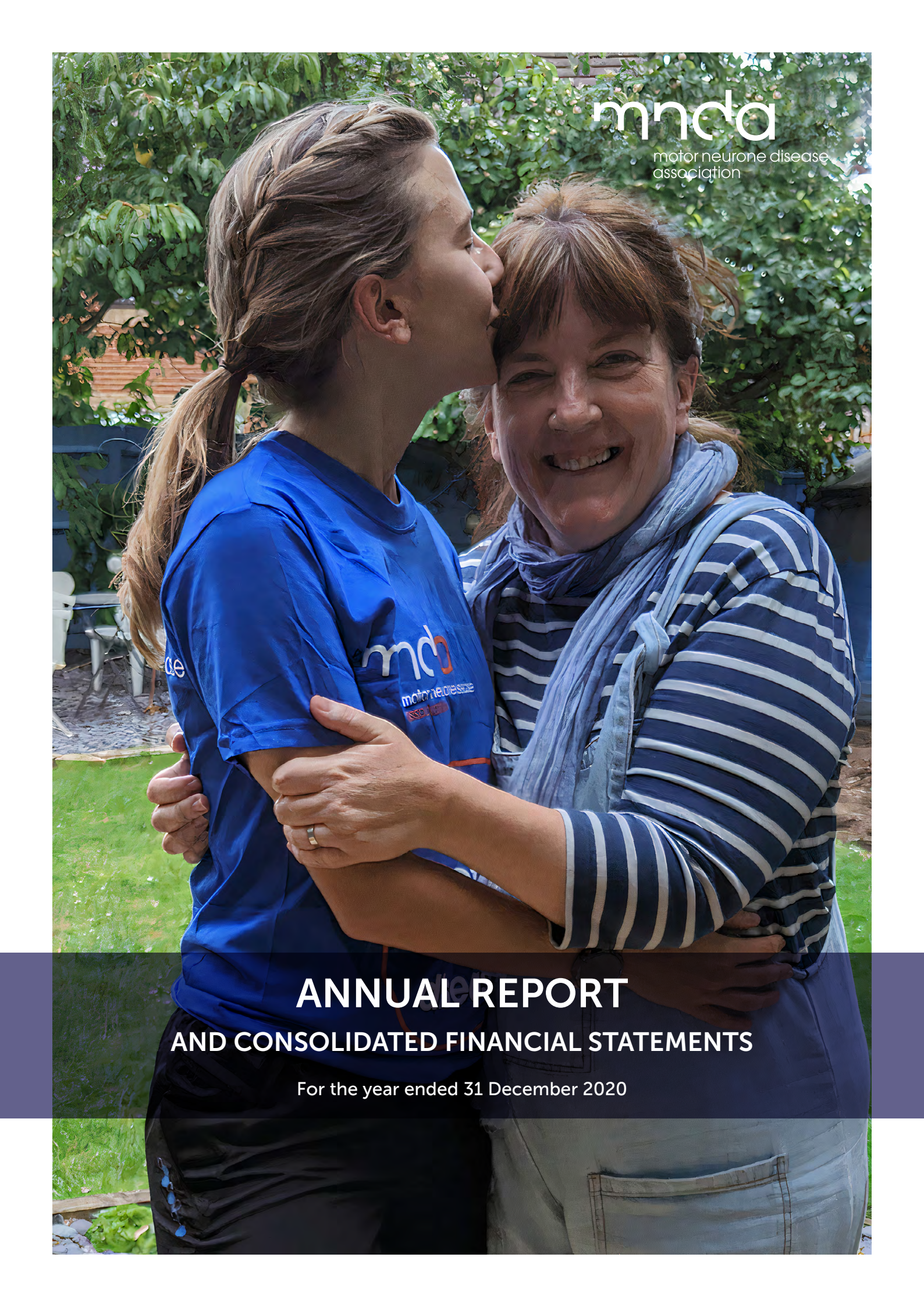
Registered Charity No 294354, Company Limited by Guarantee No 2007023

©MND Association 2022 AnnReport/22

MOTOR NEURONE DISEASE ASSOCIATION

England & Wales - Charity number 294354

Accounts



mnda

motor neurone disease
association

ANNUAL REPORT AND CONSOLIDATED FINANCIAL STATEMENTS

For the year ended 31 December 2020

Message from the Chair

The events of the past 12 months have shown the Association and the wider MND community at its very best – strong, dependable and resilient – and determined to support people living with MND and their families, whatever it takes.

People living with MND are always at the heart of everything we do and this year has certainly been no exception. From the start of the pandemic in March, the needs of people living with MND and those closest to them have been at the very forefront of our minds, inspiring every phone call, every piece of information we have produced and every decision we have taken along the way.

The stories which people living with MND have so bravely shared throughout the year, have captured the hearts of millions and encouraged fundraisers, donors and supporters right across England, Wales and Northern Ireland to show their support for the Association in ways we never thought possible.

We've used the experience as an opportunity to adapt and evolve, using innovation and creativity to drive our work forward. We've harnessed new technology to make our work more accessible, enabling us to engage with many more people living with MND and with audiences all over the world.

Careful and considered decision-making in the past, together with the extraordinary support from the MND community, has been a key factor in our success this year, enabling us to accelerate a number of key projects, particularly in MND research where we continue to play an important and authoritative role on the world stage.

As we look forward to 2021, the Association will emerge from the pandemic united and poised to take advantage of any opportunities that come our way.

As time passes, our voice becomes louder and our determination to succeed ever stronger.

I am confident we will achieve our vision of *a world free from MND*, whatever it takes.



Richard Coleman

Chair, Board of Trustees

Cover image: Caitlin and her mum Kirsty O'Reilly who was diagnosed with MND in August 2019. Caitlin, a university student was one of more than 100 supporters who ran 21 miles during the lead up to Global MND Awareness Day on 21 June 2020, raising an incredible £30,000 for the Association.

As part of the Association's response to coronavirus, staff and volunteers were in touch with more than 4,000 people like Kirsty, to offer help, support and guidance including access to emergency grants, virtual support and well-being groups.



BUCKINGHAM PALACE

Throughout 2020 the Motor Neurone Disease Association has been a symbol of reassurance and resilience to its members, providing guidance and support when most needed.

That strength of spirit, together with the determination to do everything possible to support people living with MND and their families, was very much in evidence in January 2020 when I visited the Cafe Neuro drop-in, run by Association volunteers together with partner organisations, at the St Mary's Hospice Living Well Centre in Barrow-in-Furness. For people with motor neurone disease, the regular sessions which are held there provide important information and support, as well as the chance to meet others facing similar challenges - contact which is so important when living with a disease as devastating as MND.

While the pandemic has meant that, for now at least, face-to-face contact has been greatly reduced, I have been heartened by the tremendous steps taken by the Association, its volunteers and the wider community, to continue its assistance for people living with MND by hosting many support meetings and events online. The response from the Association's fundraisers, donors and supporters has also been a source of great inspiration, as has the vital work being done to keep driving MND research forward.

As we reflect on a year of unprecedented challenges, I would like to thank you all for everything you have done, and continue to do, to support people living with MND and those closest to them. I wish you every success in the coming year.

A handwritten signature in black ink, appearing to read 'Anne', with a long, sweeping underline.

Contents

TRUSTEES' REPORT (INCLUDING THE STRATEGIC REPORT)	5
i. Objectives and activities	5
ii. Achievements and performance in 2020	6
iii. Future plans and priorities	8
iv. Financial review	9
v. Principal risks and uncertainties	10
 STRUCTURE, GOVERNANCE AND MANAGEMENT	 12
STATEMENT OF TRUSTEES' RESPONSIBILITIES AND CORPORATE GOVERNANCE	15
ORGANISATIONAL INFORMATION	16
INDEPENDENT AUDITOR'S REPORT	17
STATEMENT OF FINANCIAL ACTIVITIES	19
CONSOLIDATED BALANCE SHEET	20
CONSOLIDATED CASH FLOW STATEMENT	21
STATEMENT OF ACCOUNTING POLICIES	22
NOTES TO FINANCIAL STATEMENTS	25

Trustees' Report

Strategic report

The trustees present their report and accounts for the year ended 31 December 2020. The accounts have been prepared in accordance with the Accounting and Reporting by Charities: Statement of Recommended Practice (SORP) 2019 and are in accordance with the Companies Act (2006) and relevant accounting standards.

About MND

What we do matters because of the nature of MND:

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord
- It attacks the nerves that control movement so muscles no longer work. It does not usually affect the senses such as sight, sound and feeling
- Around 35% of people with MND experience mild cognitive change causing difficulties with planning, decision-making and language
- A further 15% of people show signs of frontotemporal dementia (FTD) resulting in more pronounced behavioural change, which may interfere with their ability to function on a day-to-day basis
- MND can leave people locked in a failing body, unable to move, talk, swallow and eventually breathe
- A person's lifetime risk of developing MND is around 1 in 300
- It affects people from all communities
- Six people per day are diagnosed with MND in the UK
- It affects up to 5,000 adults in the UK at any one time
- More than 80% of people with MND will experience communication difficulties, including, for most, a complete loss of their voice
- It kills six people per day in the UK, this is just under 2,200 people per year
- MND has no cure

i) Objectives and activities

Our vision

A world free from motor neurone disease.

Our mission

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

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

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

About us

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

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

We are focused on MND care, research and campaigning.

Our values

- People with MND, their families and carers are at the heart of everything we do
- We collaborate, and value everyone's contribution
- We achieve excellence through personal commitment and on-going improvement
- We respect and respond to people's diverse needs, backgrounds and views
- We achieve our aims through building open and transparent relationships

Our charitable objects as stated in our Articles of Association

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

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

Public benefit

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

in this report demonstrate the public benefit deriving from Association activities.

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

ii) Achievements and performance in 2020

Driving MND research

The past year has seen a real explosion of interest in MND research and the MND Association - the biggest charity funder of MND research in the United Kingdom - has been right at the heart of it.

At year end, our research portfolio was worth £14 million and was funding 85 research studies including projects in France, Italy and Finland. There is increasing confidence within the research community that we can start to turn the vast amount of new knowledge about MND into new treatment strategies. Collaboration is going to be essential, which is why we are continuing to fund important multi-centre projects such as Project MINE, AMBROSIA and NECTAR as well as supporting international clinical trials to find new treatments, including the TUDCA-ALS trial of tauroursodeoxycholic acid and the MIROCALS trial of the drug Interleukin-2. We have helped to establish the MAGNET platform trial through our partnership in the European TRICALS consortium – including a commitment to the upcoming PRELUDE trial of lithium carbonate -and our MND Care Centres and Networks are currently being set-up as key sites for recruitment into the MND SMART clinical trial.

Throughout lockdown, there was no let-up in our work. Researchers swapped their laboratories for laptops - analysing and publishing their research data, co-ordinating clinical trials and healthcare studies online, setting up new trials to start when the pandemic subsides and making new applications for funding.

During the year, a number of our junior researchers also contributed to our popular online MND Research Blog, which celebrated its 10th anniversary in April. In that time, the blog's articles have been viewed more than 250,000 times.

Around the world, the MND Association is synonymous with the International Symposium on ALS/MND, an annual, global event which brings clinicians and researchers together to collaborate and share the tremendous progress being made. In December, the Association held its first virtual Symposium which attracted more than 1,800 delegates from 48 countries and included the inaugural Steven Hawking Memorial Lecture. With more people living with MND present, more clinicians and researchers taking part and more interest from pharmaceutical companies, it was a record-breaking event in every sense.

We know MND isn't incurable, but it is underfunded – something we are determined to change. In the months to come we will be working alongside people living with MND and our partners at MND Scotland and the My Name's Doddie

Foundation to urge the Government to increase the amount of targeted funding it commits to MND research as part of our #United2EndMND campaign.

Supporting people affected by MND throughout the pandemic

From the start of the pandemic in March the Association's goal was clear – to continue to provide people living with MND and those closest to them with support, information and a strong sense of community at a very difficult and uncertain time.

The Association responded swiftly to the challenge. Our staff immediately started working from home, using systems and technology already in place to seamlessly continue their work, finding new ways to keep in touch with people living with MND and each other, without any interruption to our services.

A team was brought together to co-ordinate the Association's initial response, working with colleagues, partners and global MND experts to develop clear, concise information, which was delivered across a range of channels and platforms, including a central online hub. By the end of the year, 16,000 people had accessed our hub.

At the same time, 240 volunteers were mobilised to make contact with every person living with MND known to the Association, providing guidance and an important source of comfort and reassurance. Branches and groups moved support meetings online and Association visitors stayed in touch with people living with MND and their families through regular calls, video calls, emails and texts.

Meanwhile, more than 5,000 campaigners across England, Wales and Northern Ireland got involved in our fight to get people living with MND included on the Government's Clinically Extremely Vulnerable List. In Northern Ireland our campaign was successful, leading to people living with MND receiving shielding letters and being prioritised for specific Government advice, supermarket deliveries and Covid vaccinations.

While we were disappointed with the response to our campaign from Westminster and the Senedd Cymru - Welsh Parliament, it did lead to many people living with MND registering themselves online and enabled us to engage with countless new supporters.

We were also extremely grateful for the emergency funding we received from The Wolfson Foundation, The Garfield Weston Foundation, My Name's Doddie Foundation, Alan Davidson Foundation and the Senedd Cymru - The Welsh Government.

As we begin to emerge from lockdown, we continue to monitor the situation carefully, making sure we keep in touch with those affected by MND and update any information accordingly.

Helping people with MND live better lives for longer

While the search for new treatments and a cure for MND continues, we're determined to help people living with MND live better lives for longer.

Through our Next Generation Think Tank, we're building partnerships with some of the biggest companies in the world, including Rolls Royce, Google and Dell, to harness the latest developments in engineering and technology and use them to make life better for people living with MND.

Already, this important work is making a difference. In 2020, our work led to the development of Quips, a prototype computer software package which uses artificial intelligence (AI) to allow people who cannot speak to have a conversation using their voice and to keep their accent. The Association also offered its expertise and support to a Google initiative – Project Euphonia – which is training voice-activated technology to recognise and translate slurred speech. Both of these developments represent giant leaps forward when it comes to helping people living with MND to maintain their independence.

In addition, we were able to offer £1.4 million of support grants to 2,479 people living with MND. Thanks go to the My Name's Doddie Foundation and The Darby Rimmer Foundation for their support of these programmes. During the year, we were also able to loan 400 communication aids and 350 pieces of voice-banking equipment.

Supporting children and young people affected by MND

Children and young people who are affected by MND remain one of our main priorities and this year we have taken great steps forward in the support we are able to offer.

One of our biggest successes has been the launch of a new counselling service which has been set-up with support from The James Milner Foundation and our partners at leading children's charity, Barnardo's. Since its launch, this new service has already slashed waiting times for counselling from 18 months to just five days, meaning young people and their families can get the support they need much faster.

With younger children in mind, we've been working with The Nick Smith Foundation to create memory and treasure boxes designed to help them learn more about MND through a range of activities and games. The boxes also give families the chance to come together to make important memories for the future.

Raising awareness of MND

Millions of people were shown the reality of what it's like to live with MND during 2020 through unprecedented coverage on BBC *Breakfast*, BBC Two, ITV's *Good Morning Britain* and Sky Sports as well as on BBC Radio 4 and in countless column inches in print and online.

This coverage was only possible thanks to the courage and bravery of people living with and affected by MND who were willing to highlight the Association's work by sharing their stories and experiences. We are immensely grateful to all of them for their continued help and support, and to the media for amplifying these messages.

In March, broadcaster Matthew Bannister helped to raise £33,000 for the Association, as well as increasing awareness, by sharing his personal experience of MND for the BBC Radio 4 Appeal.

It was also the year that Rob Burrow MBE, a former player for the rugby league side the Leeds Rhinos, became a household name with appearances on BBC *Breakfast* and in *My Year With MND*, a documentary which aired on primetime TV in October.

His story also inspired his friend and former teammate Kevin Sinfield MBE to run seven marathons in seven days during December, a gruelling challenge which saw him raise £2.5 million for Rob and the Association.

Not only will the money raised as a result of Kevin's challenge help the Association to significantly boost its investment in MND research and accelerate a number of important projects, it also encouraged hundreds of fundraisers to take part in 7 in 7 challenges of their own.

Our commitment to diversity, equity and inclusion (DEI)

The Association – and all of its people – value diversity, are committed to equity and are determined to be inclusive.

Our trustees, directors and senior managers help to nurture a culture of diversity, equity and inclusion, something which is actively championed both internally and externally and with all our partners and stakeholders.

In December 2017, the Association launched its four-year DEI strategy and great progress continues to be made. During 2020 the first committed stage of Disability Confident was achieved and this proved important in ensuring that our new offices were accessible. Disability Confident is a government initiative designed to create a movement of change, encouraging employers to think differently about disability and take action to improve how they recruit, retain and develop disabled people.

DEI training has been rolled out to all trustees and staff, alongside special events on Black Lives Matters, mental health, and faith awareness. We continue to have an open dialogue with our staff about the importance of mental health and wellbeing and are starting to have the same conversations with our volunteers. We have provided managers with the appropriate training and have mental health first-aiders to offer one-to-one support when it is needed.

The Association recognises there is still much more work to do. The Board of Trustees has renewed its commitment to the strategy and, in the months to come, we will continue to develop our work with the full support of our people and our wider community.

Progress against strategy

While the focus of our work inevitably shifted throughout 2020 as a result of the pandemic, the Association had a very successful year, making progress in several key areas.

In March, the Association, together with our partners at the My Name's Doddie Foundation, organised a workshop to discuss

the possibility of developing a framework to drive MND research forward by supporting more collaborative translational research. Following a number of discussions, the Association and the My Name's Doddie Foundation agreed to support a nine-month project, led by the Medicines Discovery Catapult, to develop a roadmap for preclinical drug discovery and translational drug development.

We continued to develop the care and support we offer to bereaved carers and families by launching a tailored support section on our website and hosting a range of new resources from the Association and its partner agencies. A dedicated channel has also been added to the Association's online forum, providing a safe online space for support and discussion.

The Association was also able to maintain its commitment to help health and social care professionals (HSCPs) learn more about MND by offering opportunities for them to attend education events online, including The Annual Stephen Hawking Foundation MND Lecture, developed in collaboration with the Royal College of Nursing.

Further information on the work of the Association is available on our website, www.mndassociation.org and via our Impact Report at www.mndassociation.org/impact.

We would like to thank

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

Remembering

All those members of the MND community who died from MND this year. As we remember their courage and their contribution to the work of the Association, they will continue to inspire our fight against MND and remind us of the need to do everything we can to support those living with the disease and those closest to them.

iii) Future plans and priorities

Despite the challenges we have faced, 2020 has been an exceptional year for the Association.

The extraordinary efforts of the whole MND community, a number of extraordinary one-off gifts and a generous legacy donation, meant that the Association unexpectedly ended the year with a significant surplus.

As a result, we will be able to boost our investment in MND research, have an impact on standards of care and help people with MND live better lives for longer. We'll also continue to work with our partners to take advantage of exciting developments in technology and further develop the support we offer to children and young people.

Despite this success, the situation we face in the coming months remains both volatile and uncertain. Our 2021 budget anticipates a significant drop in our income, with many fundraising

events still being postponed or cancelled. There is much for us still to achieve – our ongoing care, research and campaigning work will cost at least £40 million over the next two years.

The support of the whole MND community remains as important as ever.

Fundraising approach

We have a diverse portfolio of fundraising activities including raising funds from individuals, trusts and foundations, companies, events, local communities and legacies. We approach our supporters via direct mail, email and directly at events, and manage this fundraising both centrally and locally through our branches and groups.

We comply with current regulations and best practice set out by regulatory and professional membership bodies including the Fundraising Regulator, the Institute of Fundraising, the Direct Marketing Association and the Advertising Standards Board.

We are registered with the Fundraising Regulator and have signed up to receive suppressions under the Fundraising Preference Service. We fundraise in line with the Code of Fundraising Practice and adhere to data protection law. We are committed to ensuring that we are completely open and transparent about our fundraising and spending. As members of the Fundraising Regulators' self-regulatory scheme we comply with its principles in all our fundraising:

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

Due to the nature of delivering fundraising across multiple sites, we are aware that the potential for breaches of fundraising code of practice and data protection compliance exist. We manage and minimise these risks through training and inductions for new starters and for our branches and groups; through quality checks and audits, implementing GDPR and other compliance policies and having data protection/compliance champions within each team.

As the MND Association, we acknowledge that the engagement of third parties can help us raise funds, as well as improve efficiency and reduce costs. We require that any third party we work with complies with data protection legislation as set out in the Code of Fundraising Practice including the requirements of the telephone, mailing and fundraising preference services.

We follow a robust procurement process when recruiting third parties to work on our behalf, making sure we apply appropriate due diligence and contracts for this work. We work closely with these third parties, regularly reviewing their work against performance targets and the fundraising code of practice to ensure delivery of the best value for money for the charity and its supporters.

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

We received 18 complaints about our fundraising activity in 2020 and all were promptly resolved without the need for escalation to the Fundraising Regulator. Complaints are taken very seriously and regularly reviewed by the Board of Trustees. However, these 18 represent a tiny fraction of our outgoing fundraising communications. There is a complaints policy, which is available on our website, which forms the basis for the training of all fundraising staff.

All fundraisers at the MND Association are guided in how to protect vulnerable people including how to recognise a person in vulnerable circumstances. All our direct mail, emails and thank you letters contain clear instructions as to how a supporter can easily opt out of receiving further communications from the charity should they choose to do so.

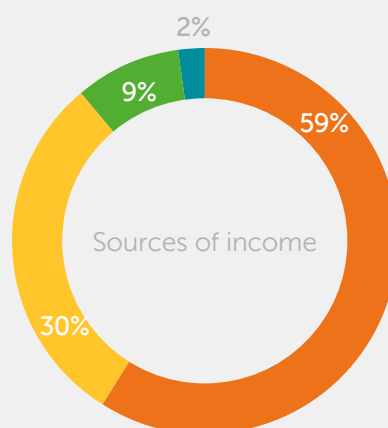
iv) Financial review

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

Financial performance

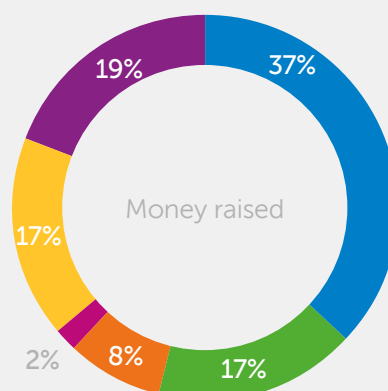
Sources of income

	(£) million
Central fundraising	£11.7 million
Legacies	£6.0 million
Branches and Groups	£1.8 million
Earned income	£0.4 million
TOTAL INCOME FOR 2020	£19.9 MILLION



How we spent the money raised

	(£) million
Care and support (including by branches and groups)	£5.8 million
Research	£2.6 million*
Campaigning and raising awareness	£1.2 million
Volunteer development	£0.3 million
Fundraising	£2.7 million
Support Costs	£3.0 million
TOTAL COSTS FOR 2020	£15.6 MILLION



* This amount is less than originally planned due to the temporary closure of laboratories and pausing of projects as a direct result of the pandemic.

Our income generation in 2020 was our strongest since 2014, the year of the Ice Bucket Challenge, with total income of £19.9 million for the 12-month period. In spite of the challenges presented by the pandemic, our supporters continued to provide much needed funds. Income was strong across all fundraising areas and almost a third of this income came in the last two months of the year when we received an incredibly generous legacy donation, and fundraising received a boost from increased media activity around MND.

Due to the uncertainty of the pandemic, expenditure was controlled tightly at £15.6 million and while the Association saw many cost reductions in recruitment, training, facilities, travel, volunteering and conference events we maintained the budgeted levels of care grant expenditure to ensure that people affected by MND continued to receive critical financial support. We also met our commitments to research grant funding to the extent that restrictions around the pandemic permitted.

For every pound spent on fundraising in 2020, £4.60 was raised. When legacy income and costs are included, this rises to £6.69.

£11.7 million was raised and donated by our fundraisers, supporters and funders and a further £1.8 million was raised by our branches and groups. We are so grateful for their continued support.

£6 million was donated in 2020 in the form of legacy gifts which continue to make a huge difference to our work. We are enormously grateful to the individuals who remembered the work of the Association in their Wills.

The net surplus position in 2020 of £4.4 million will enable the Association to accelerate and broaden our research plans, continue to meet the annual care grant commitments for people affected by MND in 2021, provide investment in future technology to support people with MND and invest in other initiatives aligned with our new strategy. Significant upsides in 2020 income are however unlikely to be sustainable and so while we remain grateful for all the support in achieving this result, we are very conscious that our work in the future will depend heavily on the continued contribution of all our generous supporters.

v) Principal risks and uncertainties

Risk management

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

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

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

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

Reputational risk

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

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

Financial risk

The main financial risk in 2020 was the expectation that the Association would incur a significant deficit due to the anticipated drop in income during the pandemic and that this would draw heavily on our reserves. The Association implemented weekly income reporting and enforced tight controls on non-core activity expenditure to ensure that we tracked and could take actions to minimise this risk.

As shown previously, due to the incredible level of support seen through both fundraising and legacy channels combined with our tight cost control, the Association was able to record a surplus in the year of £4.4 million. This incredibly positive outturn meant that we could meet all our care grant commitments and research funding commitments on new and existing projects that were able to continue through the pandemic.

While we remain cautious about the financial position in 2021, the strong performance in 2020 has significantly reduced our financial risk and means that the Association will begin the year in a much stronger position than anticipated. As such, we will be able to accelerate the level of planned research activity with an extra £2 million of the surplus from 2020 set aside in 2021 for new research projects. A further £1 million has also been identified for use in key strategic projects, this will include support for technological advances to support people living with MND.

External environment risk

The Association supports people living with MND across England, Wales and Northern Ireland. Recent structural changes in the NHS, and the constraints on health services, local authority and financial support budgets, have led to geographical variation in service availability. In order to mitigate this risk, we actively campaign throughout the three nations to ensure that the delivery of care for people living with MND is provided by the appropriate agency, in the right place and at the right time. The trustees recognise the uncertainties resulting from the UK's departure from the EU. In particular, the potential risks on voluntary and corporate fundraising, UK participation in EU-funded research and the availability of skilled health and social care staff to support people living with MND. The full impact of the UK leaving the EU is still uncertain and we continue to monitor developments carefully and take precautionary action where we can.

Compliance risk

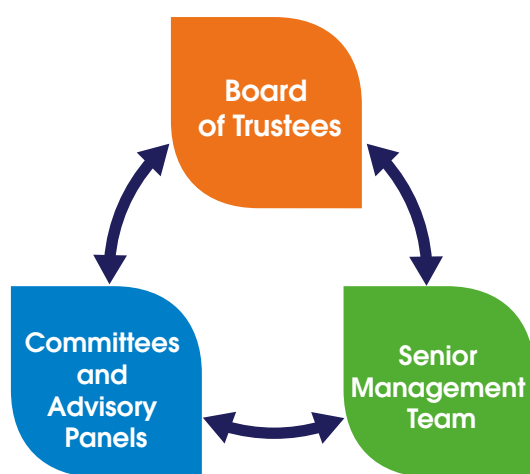
The Association must comply with a range of legal and regulatory requirements including charity law, data protection, fundraising standards, health and safety and safeguarding. To mitigate these risks the Association has robust and embedded processes and policies, which are complemented by regular and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

Structure, Governance and Management

Structure

The Association was originally formed on 6 October 1979 and was incorporated as a company limited by membership guarantee in 1986. The Association is governed by its *Articles of Association* and in the event of it being wound up, every member is liable for an amount not exceeding £1 to facilitate the payment of the debts and liabilities of the Association. At 31 December 2020, there were 10,390 members.

Governance



Our governance structure is designed to ensure that:

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

The Board of Trustees

The Board (members of which are directors under company law) is the governing body of the Motor Neurone Disease Association. The Board ordinarily meets in formal session four times a year.

The Articles of Association provide a degree of flexibility for changes to be made to the composition of the Board, subject to there always being a majority of elected trustees over co-opted trustees and there being no more than ten elected trustees, and the Board reviews its composition against these requirements on an annual basis. During 2020 the Board agreed to change the composition to nine elected and six co-opted trustees. In line with

the Articles of Association, a Chair Elect was recruited during 2021, who will take the position of Chair in 2022 when the current Chair is required to stand down

All elected and co-opted trustees are provided with a comprehensive induction to the Association, which includes an overview of the organisational strategy and current priorities, together with briefings on the roles and duties of trustees. They receive subsequent development and training through internal coaching and external providers. The Board maintains an updated skills audit against a defined set of skills and this enables it to identify gaps and plan for future recruitment. The Board seeks to maintain and improve its governance arrangements and uses the Charity Governance Code to benchmark its structure and processes against the code's recommended practices. Although compliant in almost all areas, action plans are developed to ensure that appropriate improvements are made, in addition to which the Governance Committee considers the implications of any changes to the code and undertakes an annual review of performance against the code.

Committees of the Board

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

Care Committee

This committee reviews all aspects of the Association's work relating to improving care and providing support for people with MND, their carers and families. It reviews risk and approves grant funding to support the work of MND Care Centres and Networks, up to an agreed limit, with grants above that limit being approved by the Board.

Engagement Committee

This committee reviews strategic activities, policy, and effectiveness relating to the Association's volunteers. This includes all aspects of volunteering including recruitment, retention, empowerment, any potential risks and the development of existing and emerging roles.

Finance and Audit Committee

This committee provides stewardship of all financial aspects of the charity's work, including the fundraising activities of the Association. The committee scrutinises and evaluates the annual budget prior to Board approval. It ensures that the appropriate

financial controls and regulatory requirements are adhered to and advises the Board accordingly. The committee also recommends the annual pay award for all employees, which includes the Senior Management Team (except the Chief Executive), to the Board for approval.

Governance Committee

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

Remuneration Committee

This committee is responsible for the annual review of the salary and other benefits of the Chief Executive and oversees the remuneration packages of members of the senior management team.

These salaries are assessed using the Hays evaluation tool and then benchmarked externally against comparable roles within similar sized charities.

Biomedical and Healthcare Research Advisory Panels

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

Additional external partnerships

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

Branches, groups and affiliates

At 31 December 2020, the Association had 89 branches and groups and two affiliates (based in Jersey and the Isle of Man). Each branch and group sign a charter annually called *Agreement for working together*, which sets out the parameters of the powers delegated to them by the Board.

Branches and groups, whose financial results are included in these statements, are governed by the Board. The two affiliates are excluded from the consolidation as they are not part of the Association.

Branches and groups provide unique support to people affected by MND at local level and also fundraise and campaign on

their behalf. They raise and spend money locally on support grants, in line with guidelines which are reviewed annually by a support grant group in which volunteers are in the majority. Association staff support them by providing advice and guidance on recruitment and support of volunteers and local structure, organisation and management of their activities.

Environmental impact

The Association initiates and monitors changes to process and practice that reduce its environmental impact. We moved to our new national office at Francis Crick House in January 2020 and this gave us an opportunity to encourage staff to adopt more sustainable practices. These included reducing in-house printing resources to encourage teams to work more digitally and introducing laptops for all staff, encouraging digital solutions as much as possible and using cloud storage. This approach has enabled us to respond to the pandemic quickly and positively. The need for most staff to work from home has seen significant reductions in travel, printing and facilities' expenditure. We will learn from the new digital and homeworking approaches and ensure that we continue to incorporate these methods in our ways of working post-pandemic.

Money saved through environmental efficiencies can be diverted into achieving the charity's strategic objectives.

Management

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

Safeguarding

The MND Association is committed to meeting the needs of people living with MND, their families and carers. We have a safeguarding policy in place and a safeguarding board to ensure everyone is treated properly, in accordance with our values. We review our policy regularly and our Board of Trustees regularly reviews our risk and ensures implementation of any actions.

Whistleblowing

We take any evidence of malpractice very seriously and support anyone who is raising genuinely held concerns. We reviewed these policies in detail in 2020 and they are backed up by mandatory staff and volunteer training.

Grants

Grants are awarded for both research projects and care services:

Research – we award project and programme grants, PhD studentships and Lady Edith Wolfson clinical and non-clinical research fellowships. Application and decision-making processes, including comprehensive peer review, are published on the Association's website. These processes conclude with formal approval or rejection of applications by the Board.

Care – We provide grants to existing specialist MND Care Centres and Networks. At 31 December 2020 the Association was providing financial support to 22 such centres and networks. Performance is monitored annually for existing Care Centres, with a full grant renewal process every four years.

Investment policy

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

Group reserves policy

The trustees have adopted a robust and flexible reserves policy to meet the changing needs of the charity. This states that the general reserve should be in the range of four to six months' general expenditure represented in cash and readily realisable investments, held centrally and within branches. This is a target range of between £6.4 million and £8.4 million. As at the year end, the unrestricted/undesignated reserves balance sat at £8.5 million. Trustees believe that this remains a prudent level given the continuing uncertainty associated with the pandemic.

Statement of Trustees' Responsibilities and Corporate Governance

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

Company law requires the trustees to prepare financial statements for each financial year. Under company law the trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charitable company and the group and of the incoming resources and application of resources, including the income and expenditure, of the charitable group for that period. In preparing these financial statements, the trustees are required to:

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

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

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

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

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

Re-appointment of auditors

The appointment of auditors is reviewed annually with Haysmacintyre LLP having indicated its willingness to be reappointed as statutory auditor and as such a resolution of reappointment will be proposed for consideration at the Annual General Meeting of members convened in July 2021 subject to the limitations in place due to the coronavirus pandemic. Members will be informed of confirmed plans directly.

This *Trustees' Report*, prepared in accordance with the Charities Act 2011 and the Companies Act 2006 was approved by the Board of Trustees on 22 May 2021 including in their capacity as company directors, the strategic report contained therein, and signed on its behalf by:



Richard Coleman

Chair, Board of Trustees

22 May 2021

Organisational information and financial statements

Board of Trustees

Chair: Richard Coleman

Vice Chair: Jan Warren

Honorary Treasurer: Tim Kidd

Emma Adams (*until July 2020*)

Wendy Balmain (*until May 2020*)

Andy Cawdell

Alan Graham MBE

Devia Gurjar (*from February 2020*)

Dr Usman Khan (*from May 2021*)

Catherine Knights

Jim Marshall (*from May 2021*)

Dr Shaun McGee (*from May 2020*)

Vicky Paeschel

Siobhán Rooney

Dr Nik Sharma

Dr Heather Smith

Katy Styles

Senior management team

Sally Light, Chief Executive

Linda Allen, Director of Fundraising

Mark Chapman, Director of Finance

Dr Brian Dickie, Director of Research Development

Nick Goldup, Director of Care Improvement

Chris James, Director of External Affairs

Chris Wade, Director of Engagement

Company secretary

Mark Chapman

Registered office

Francis Crick House
6 Summerhouse Road
Northampton
NN3 6BJ

Professional advisers

Statutory auditors

Haysmacintyre LLP
10 Queen Street Place
London
EC4R 1AG

Solicitors

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

Bankers

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

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

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

Opinion

We have audited the financial statements of Motor Neurone Disease Association for the year ended 31 December 2020 which comprise the Consolidated Statement of Financial Activities, The Group and Charity Balance Sheets, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

1. give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 December 2020 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended;
2. have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
3. have been prepared in accordance with the requirements of the Companies Act 2006.

Basis for opinion

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

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the group's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

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

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

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement set out on page 15, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to the regulatory

requirements of the Charity Commission, and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Companies Act 2006, Charities Act 2011, Charity SORP and payroll taxes.

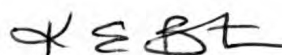
We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls), and determined that the principal risks were related to the posting of inappropriate journal entries and management bias in certain accounting estimates. Audit procedures performed by the engagement team included:

- Inspecting correspondence with regulators and tax authorities;
- Discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud;
- Evaluating management's controls designed to prevent and detect irregularities;
- Identifying and testing journals, in particular journal entries posted with unusual account combinations, postings by unusual users or with unusual descriptions; and
- Challenging assumptions and judgements made by management in their critical accounting estimates.

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

Use of our report

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



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

7 June 2021

Consolidated Statement of Financial Activities

(incorporating an income and expenditure account)

For the year ended 31 December 2020

	Notes	Unrestricted funds £000	Restricted funds £000	Total Funds 2020 £000	Total funds 2019 £000
Income and endowments from:					
Donations and legacies:	1a				
Donations		8,095	4,613	12,708	12,222
Legacies		5,856	156	6,012	5,333
Charitable activities					
Other trading activities	1b	705	-	705	873
Investments		121	-	121	181
Other	1c	365	-	365	24
Total income		15,142	4,769	19,911	18,633
Expenditure on:					
Raising funds		3,686	-	3,686	3,669
Charitable activities:					
Care		4,989	1,878	6,867	7,054
Research		239	2,560	2,799	4,319
Campaigning and raising awareness		1,692	32	1,724	1,883
Volunteer development		494	14	507	1,192
Total expenditure	4	11,100	4,483	15,583	18,117
Net income/ (expenditure)	3	4,042	286	4,328	516
Other recognised gains/ (losses):					
Other gains/ (losses)		40	-	40	(13)
Net movement in funds		4,082	286	4,368	503
Reconciliation of funds:					
Total funds brought forward		8,690	2,074	10,764	10,261
Total funds carried forward	18a, 19	12,772	2,360	15,132	10,764

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

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

Balance Sheet

For the year ended 31 December 2020

		Group		Charity	
	Notes	2020 £000	2019 £000	2020 £000	2019 £000
Fixed assets					
Intangible assets	11	-	2	-	2
Tangible assets	11	835	718	835	718
Total Tangible Assets		835	720	835	720
Current assets					
Stocks	13	31	29	-	-
Debtors	14	5,544	4,769	5,631	4,702
Investments	15	9,200	9,365	9,200	9,365
Cash at bank and in hand		12,619	10,402	12,447	10,339
		27,394	24,565	27,278	24,406
Creditors: amounts falling due within one year	16a	9,993	11,149	10,004	11,077
Net current assets		17,401	13,416	17,275	13,329
Total assets less current liabilities		18,236	14,136	18,109	14,049
Creditors: amounts falling due after more than one year	17	3,104	3,372	3,104	3,372
Net assets	19	15,132	10,764	15,005	10,677
Accumulated funds					
Restricted funds	18a	2,360	2,074	2,360	2,074
Designated funds	18a, 18b	4,295	1,746	4,295	1,746
Unrestricted funds:					
Unrestricted funds	18a	8,350	6,944	8,350	6,857
Funds retained in subsidiary	12a	127			
		15,132	10,764	15,005	10,677

The financial statements on pages 19 to 43 were approved and authorised for issue by the Board of Trustees on 22 May 2021, and were signed on its behalf by:



Tim Kidd
Treasurer



Richard Coleman
Chair

The net movement in funds for the Association for the year ending 31 December 2020 was £4,368,000 (2019: £503,000).

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

Statement of Cash Flows

For the year ended 31 December 2020

	Notes	2020 £000	2019 £000
Cash flows from operating activities:			
Net income/ (expenditure) for the reporting year		4,368	503
Adjustments for:			
Depreciation and amortisation charges	11	345	147
Dividends and interest from investments		(121)	(181)
Gain on disposal of fixed assets	11	13	17
(Increase) / decrease in stock	13	(2)	4
(Increase) / decrease in debtors	14	(775)	11
Increase / (decrease) in creditors	16a,17	(1,424)	167
Net cash generated from operating activities		2,404	668
Cash flows from investing activities:			
Movement in cash held as investment		-	235
Dividends and interest from investments		121	181
Purchase of fixed assets	11	(473)	(574)
Net cash used in investing activities		(352)	(158)
Increase in cash and cash equivalents in the reporting year		2,052	510
Cash and cash equivalents at the start of the year		19,767	19,257
Cash and cash equivalents at the end of the year		21,819	19,767

Analysis of cash and cash equivalents

Group	Balance 1 January 2019 £000	Cash flow changes £000	Balance 1 January 2020 £000	Cash flow changes £000	Balance 31 December 2020 £000
Net cash					
Short term deposits	10,867	(1,502)	9,365	(165)	9,200
Bank current accounts	8,363	2,031	10,394	2,219	12,613
Cash in hand	27	(19)	8	(2)	6
Net funds	19,257	510	19,767	2,052	21,819

Statement of Accounting Policies

Legal Status

The Association is a company limited by guarantee not having a share capital, incorporated in England and Wales (company number: 02007023) and a charity registered in England and Wales (charity number: 294354). The charity's registered office address is 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. The members undertake to contribute to the assets of the company in the event of it being wound up, either whilst members or within one year of the membership ceasing. The maximum contribution required from each member is £1. There were 10,390 members at 31 December 2020 (31 December 2019: 9,992).

Principal accounting policies

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

a) Basis of preparation

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) second edition (effective 1 January 2019) – (Charities SORP FRS 102), and the Companies Act 2006.

The Motor Neurone Disease Association meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

b) Critical accounting judgements and key sources of estimation uncertainty

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

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

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

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

c) Preparation of the accounts on a going concern basis

Despite the pandemic, 2020 proved to be a very strong year for the charity with reserves remaining high and the Association's financial position remaining strong. As such, the trustees consider there are no material uncertainties about the charity's ability to continue as a going concern. Trustees regularly review potential risks and make strategic changes as and when required. The review of the charity's financial position, reserves levels and future plans gives trustees confidence that the charity remains a going concern for the foreseeable future.

d) Consolidated financial statements

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

In accordance with the exemption afforded by section 408 of the Companies Act 2006 a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared. The surplus of the parent charity was £4,328,000 (2019: surplus £516,000).

e) Income

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

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

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

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the charity that a distribution will be made,

Statement of Accounting Policies (continued)

or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material (see note 14).

f) Investment income

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

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

g) Fund accounting

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

h) Expenditure and irrecoverable VAT

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

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

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

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

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

j) Operating leases

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

k) Intangible fixed assets

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

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

Software licences	Four years
-------------------	------------

l) Tangible fixed assets

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

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

Fixtures and fittings	Five years
Computer and other equipment	Two years
Computer software	Four years

Statement of Accounting Policies (continued)

m) Investments

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

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

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

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

n) Financial instruments

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

o) Cash at bank and in hand

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

p) Debtors

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

q) Stocks

Stocks are stated at the lower of cost and net realisable value. In general, cost is determined on a first in first out basis and includes transport and handling costs. Net realisable value is the price at which stocks can be sold in the normal course of business after

allowing for the costs of realisation. Provision is made where necessary for obsolete, slow moving and defective stocks.

r) Creditors and provisions

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

s) Long term liabilities

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

t) Employee benefits

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

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

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

u) Taxation

As a registered charity, the Association benefits from being exempt from tax on surpluses generated by its charitable activities..

In 2019 the Association applied for Group VAT status on the basis that it had become financially beneficial for the whole group to be able to recover some elements of VAT, rather than just the Sales Company..

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.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

Income

1a Donations and legacies

	2020 £000	2019 £000
Individuals	3,682	3,422
Community and other fundraising	3,137	3,929
Appeals	1,914	1,435
Charitable foundations (see note 2)	1,896	1,790
Corporate donations	881	769
Tax recovered	1,198	877
	12,708	12,222
Legacies	6,012	5,333
	18,720	17,555

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

1b Other trading activities

	2020 £000	2019 £000
Charity-organised fundraising	446	311
Merchandise sales and advertising	37	77
Conferences and events	222	485
Advertising		
	705	873

1c Other

	2020 £000	2019 £000
Costs recovered from the International Alliance	11	14
HMRC Job Retention Grant	333	-
Other (Incl. HMRC Grant)	21	10
	365	24

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

2 Grants receivable from Charitable foundations

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

	2020 £000		2020 £000
Wolfson Foundation	500	Medicash Foundation	6
My Name's Doddie Foundation	270	Eden Rivers Trust	6
Alan Davidson Foundation	150	The Doctor Philip Welch Charity	5
Garfield Weston Foundation	75	The Klahr Charitable Trust	5
Betty Messenger Charitable Foundation	50	The 29th May 1961 Charitable Trust	5
Constance Travis Charitable Trust	50	Alan Boswell Group Charitable Trust	5
Darby Rimmer MND Foundation	50	The Basil Samuel Charitable Trust	5
The James Milner Foundation	50	The Berni Charitable Trust	5
The Linbury Trust	50	The Billmeir Charitable Trust	5
The Sinclair Charity	50	The Bothwell Charitable Trust	5
The Welsh Government VSEF small grants	46	Brian Wilson Charitable Trust	5
The Freshfield Foundation	44	The Christopher H R Reeves Charitable Trust	5
Association for the Independence of the Disabled Ltd (AID)	26	David Lister Charitable Trust	5
Bruce Wake Charitable Trust	25	The Delfont Foundation	5
The William Brake Charitable Trust	25	The Foster Wood Foundation	5
The Biss Davies Charitable Trust	20	The G & T Trust Fund	5
Fieldrose Charitable Trust	20	The G C Gibson Charitable Trust	5
Greendale Charitable Foundation	20	The George A Moore Foundation	5
Malcolm Gunter Foundation	18	The Harris Family Charitable Trust	5
Edith Murphy Foundation	15	The Hobson Charity Limited	5
The Stephen Hawking Foundation	14	The Holbeck Charitable Trust	5
The February Foundation	13	Hyde Park Place Estate Charity	5
The Elizabeth and Prince Zaiger Trust	12	John James Bristol Foundation	5
James Tudor Foundation	12	The Jones 1986 Charitable Trust	5
Peacock Charitable Trust	11	M K Rose Charitable Trust	5
The Eveson Charitable Trust	10	Margaret Giffen Charitable Trust	5
Frank Brake Charitable Trust	10	The Revere Charitable Trust	5
The Friends of Frenchay Hospital	10	The Richard Lawes Foundation	5
The Hornby Lonsdale Charitable Trust	10	The Screwfix Foundation	5
Leeds Irish Charity Association	10	The Simon Gibson Charitable Trust	5
The Master Charitable Trust	10	The Stanley Grundy Foundation Ltd	5
P F Charitable Trust	10	The Steel Charitable Trust	5
South Warwickshire NHS Foundation Trust	10	The Willie and Mabel Morris Charitable Trust	5
The Pamela Cordelia Smith Charitable Trust	7		
The Ofenheim Charitable Trust	7		
Andor Charitable Trust	6		
		Anonymous Grants	13
		TOTAL	1,896

In 2019, grants receivable from Charitable foundations totalled £1,790,000

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

3 Net income for the year

This arises after charging:

	2020 £000	2019 £000
Auditors' remuneration:		
External audit	38	27
Other services	1	4
Operating lease rentals:		
Motor vehicles	221	180
Land and buildings	160	149
Other	14	14
Depreciation and amortisation of owned assets	345	147
Loss on disposal of fixed assets	(16)	(17)

4 Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Notes	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2020 £000	Total 2019 £000
Care and care centres		3,270	2,504	1,093	6,867	7,054
Research		653	1,912	234	2,799	4,319
Campaigning and raising awareness		1,177	-	547	1,724	1,883
Volunteering		351	-	156	507	1,192
Costs of charitable activity		5,451	4,416	2,030	11,897	14,448
Raising funds		2,730	-	956	3,686	3,669
Total resources expended 2020		8,181	4,416	2,986	15,583	18,117
Total resources expended 2019	23a	9,414	5,785	2,918		18,117

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

5 Support costs

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

	Care £000	Research £000	Campaigning and raising awareness £000	Volunteering £000	Raising funds £000	Total 2020 £000	Total 2019 £000
Management	179	36	88	23	160	486	380
Governance	46	9	23	5	40	123	183
Finance	180	36	88	23	160	487	449
Information and communications technology	268	53	132	34	238	726	724
Facilities	312	63	153	40	279	847	748
Human resources	88	17	43	11	79	238	286
Conferences and events	20	20	20	20	-	80	148
	1,093	234	547	156	956	2,986	2,918

Full details of prior year support costs can be found in note 23b

6 Grants payable

Grants were awarded during the year as follows:

	Note	2020 £000	2019 £000
Grants to institutions	4	3,003	4,524
Grants to individuals		1,413	1,261
		4,416	5,785
Donations to institutions		-	-
		4,416	5,785

Grants made to, and for, individuals affected by motor neurone disease are for expenses such as respite care, building adaptations and equipment rental. These grants benefited 2,479 individuals throughout the Association's network across England, Wales and Northern Ireland.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

6 Grants payable (continued)

	2020 £000	2019 £000
Balance at start of year	11,915	12,821
Awarded in year	4,416	5,785
Paid in year	(6,384)	(6,692)
Balance at end of year	9,947	11,915
Falling due within one year (note 16a)	6,843	8,543
Falling due after more than one year (note 17)	3,104	3,372
	9,947	11,915

Commitments

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

Group and Charity	2020 £000	2019 £000
Payable within one year	214	214
Payable in years two to five	911	1,362
	1,125	1,576

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

6 Grants payable (continued)

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

	2020 £000	
University of Oxford	842	Research
Kings College London	566	Research & Care
University of Sheffield	232	Research
Institute of Psychiatry	137	Research
University Hospital Birmingham	129	Care
University of Nottingham	105	Research
Plymouth Primary Care	105	Care
S Wales Care Network	96	Care
University of East Anglia	90	Research
University of Sussex	78	Research
Cardiff University	71	Research
University of St Andrews	68	Research
Leeds Care Centre	68	Care
The James Cook University Hospital	67	Care
University of Liverpool	65	Research
National Hospital London	64	Care
University of York	62	Research
Walton Centre for Neurology & Neurosurgery	58	Care
UCL Institute of Neurology	52	Care
Flemming - Marie Curie	48	Research
	3,003	

In 2019, grants payable totalling £4,524,000 were made.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

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

The employment costs of all employees were:

	2020 £000	2019 £000
Gross wages and salaries	6,024	6,111
Social security costs	564	570
Other pension costs	411	430
Medical insurance	37	38
	7,036	7,149

The total number of employees whose emoluments for the year (not including pension contributions) exceeded £60,000 relates to all of the seven members of the senior management team across 2020. These emoluments are identified as follows:

	2020 £000	2019 £000
£100,000 - £109,999	1	-
£90,000 - £99,999	-	1
£80,000 - £89,999	3	2
£70,000 - £79,999	3	3
£60,000 - £69,999	-	1

Employers pension contributions for the higher paid employees above are £49,469 for the year ended 31 December 2020 (2019: £49,853).

The trustees devolved the day-to-day running of the Association to the seven members of the senior management team, who served in the year, as identified on page 16 of these accounts. As such, this body is identified as the key management personnel of the Association and included above are the following payments specifically to this group:

	2020 £000	2019 £000
Gross wages and salaries	592	637
Benefits-in-kind	4	4
Pension costs	49	50
Social security costs	66	70
	711	761

Trustee remuneration and expenses	2020 £000	2019 £000
Reimbursement directly to trustees	3	16
Payment to third parties in respect of trustee expenses	3	24
	6	40

Number of trustees holding office during the year	15	19
---	----	----

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

The charity trustees neither received nor waived any emoluments during the year (2019: £nil). Trustee expenses in the year include travel and subsistence expenses totalling £5,578 (2019: £40,434). These expenses were all incurred in the course of their duties and were reimbursed, or paid directly to third parties on their behalf as shown above. Trustee indemnity insurance is held at a cost of £1,573 (2019: £535).

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

8 Staff numbers

The average headcount number of employees for the year is shown below:

	2020 £000	2019 £000
Care	66	61
Research	13	13
Campaigning and raising awareness	32	31
Volunteering	8	22
Raising funds	59	59
	178	186

Staff numbers above include an appropriate apportionment of support staff.

Movement between Volunteering and Care reflects, in part, the changes under *Project Responsive*, the restructuring project which took place in 2019 to provide better support to people living with MND.

9 Pension costs

The Association operates defined contribution personal pension schemes for employees. The assets of the schemes are held separately from those of the Association in funds independently administered by Standard Life. The amounts paid to the funds represent contributions from both the employer and employees. The employer's contributions in the year were £411,500 (2019: £430,165). There are no other ongoing obligations arising. Amounts outstanding at year end were £0 (2019: £0).

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 2020.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

11 Fixed assets

Group and Charity	Motor vehicles £000	Computers, fixtures, fittings and equipment £000	Total tangible fixed assets £000	Total intangible fixed assets* £000
Cost				
At 1 January 2020	8	1,202	1,210	46
Additions	-	473	473	-
Disposals	-	(16)	(16)	-
At 31 December 2020	8	1,659	1,667	46
Depreciation and amortisation				
At 1 January 2020	8	484	492	44
Charged in the year	-	343	343	2
Eliminated on disposal	-	(3)	(3)	-
At 31 December 2020	8	824	832	46
Net book value				
At 31 December 2020	-	835	835	-
At 31 December 2019	-	718	718	2

* Intangible fixed assets comprises purchased software licences.

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

12 Fixed asset investments

Motor Neurone Disease (Sales) Limited

The Association owns a wholly owned subsidiary company, Motor Neurone Disease (Sales) Limited, which is registered in England and Wales (Company number: 01989172) at Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. This subsidiary operates mail order catalogues selling promotional clothing, gifts and cards and runs *Challenge* and other fundraising events. All taxable profits are donated to the Association each year under Gift Aid. Audited accounts are filed with the Registrar of Companies, and below is a summary of its trading results for the year ended 31 December 2020:

Motor Neurone Disease (Sales) Limited Income Statement	2020 £000	2019 £000
Turnover	252	288
Cost of sales	(168)	(273)
Gross profit	84	15
Administration costs	(43)	(16)
Profit / (Loss) before interest and tax	41	(1)
Net interest payable	(1)	(1)
Profit / (Loss) on ordinary activities before tax	40	(2)
Corporation tax (relating to 2018)	0	(11)
Profit / (Loss) for the financial year	40	(13)

The aggregate of the assets, liabilities and funds was:

	2020 £000	2019 £000
Assets	271	337
Liabilities	(144)	(250)
Funds (representing 2 ordinary shares of £1 each)	127	87

The investment held by the Charity of £2 (2019: £2) represents shares in the subsidiary company at cost.

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

	2020 £000	2019 £000
Gross income	19,911	18,633
Surplus for the year	4,328	516

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

13 Stocks

	Group		Charity	
	2020 £000	2019 £000	2020 £000	2019 £000
Purchased goods for resale	31	29	-	-

14 Debtors

	Group		Charity	
	2020 £000	2019 £000	2020 £000	2019 £000
Loan to subsidiary company	-	-	51	50
Amounts due from subsidiary company	-	-	46	17
Legacies	4,680	3,638	4,680	3,319
Other debtors	270	278	267	245
Income tax reclaimable	269	438	269	636
Prepayments	325	426	318	435
	5,544	4,769	5,631	4,702

15 Current asset investments

The total of current asset investments £9,200,169 (2019: £9,365,197) is constituted by fixed term and other bank and building society deposits with maturity dates within 12 months plus other investments which will be converted to cash with 12 months of the Balance Sheet date.

16a Creditors: amounts falling due within one year

	Group		Charity	
	2020 £000	2019 £000	2020 £000	2019 £000
Accruals for grants payable	6,843	8,543	6,843	8,543
Trade creditors	1,022	708	1,022	708
Accruals and deferred income (note 16b)	1,969	1,488	1,966	1,416
Payroll taxation and social security	27	129	27	129
Provisions and other creditors (note 21)	132	281	146	281
	9,993	11,149	10,004	11,077

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

16b Analysis of deferred income

	Group		Charity	
	2020 £000	2019 £000	2020 £000	2019 £000
Deferred income at 1 January	19	18	3	3
Released during the year	(19)	(18)	(3)	(3)
Deferred during the year	1	19	1	3
Deferred income at 31 December	1	19	1	3

17 Creditors: amounts falling due after one year

	Group		Charity	
	2020 £000	2019 £000	2020 £000	2019 £000
Research & Care Centre Creditors	3,104	3,372	3,104	3,372
	3,104	3,372	3,104	3,372

18a Statement of funds

Group and Charity	Balance at 1 January 2019 £000			Balance at 1 January 2020 £000			Balance at 31 December 2020 £000
	Income £000	Expenditure £000		Income £000	Expenditure £000		
Unrestricted funds:							
General funds	6,634	12,212	(11,902)	6,944	10,361	(8,828)	8,477
Designated funds:							
Care Centre grants	1,069	2,729	(2,496)	1,302	1,821	(2,232)	891
Ice Bucket Challenge funded projects:							
Research	350	-	(136)	214	-	-	214
Care	315	-	(200)	115	-	-	115
Campaigning and raising awareness	55	-	(0)	55	-	-	55
Volunteering and new opportunities	74	-	(14)	60	-	(40)	20
Research & Strategic Investment					3,000	-	3,000
note 18b	1,863	2,729	(2,846)	1,746	4,821	(2,272)	4,295
Total unrestricted funds	8,497	14,941	(14,748)	8,690	15,182	(11,100)	12,772

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

18a Statement of funds (continued)

Group and Charity	Balance at 1 January 2019 £000	Income £000	Expenditure £000	Balance at 1 January 2020 £000	Income £000	Expenditure £000	Balance at 31 December 2020 £000
Restricted funds:							
Research	178	2,225	(1,063)	1,340	2,537	(2,560)	1,317
Care	218	935	(2,111)	(958)	1,527	(1,336)	(767)
Volunteering	-	15	(1)	14	-	(14)	(0)
Branches and Groups	1,347	487	(176)	1,658	694	(542)	1,810
Campaigning	21	30	(31)	20	11	(31)	(0)
Total restricted funds	1,764	3,692	(3,382)	2,074	4,769	(4,483)	2,360
Total funds	10,261	18,633	(18,130)	10,764	19,951	(15,583)	15,132

Charity		Balance at 1 January 2019 £000	Income £000	Expenditure £000	Balance at 1 January 2020 £000	Income £000	Expenditure £000	Balance at 31 December 2020 £000
Unrestricted funds:								
General funds		6,534	12,212	(11,889)	6,857	10,321	(8,828)	8,350
Designated funds	note 18b	1,863	2,729	(2,846)	1,746	4,821	(2,272)	4,295
		8,397	14,941	(14,735)	8,603	15,142	(11,100)	12,645
Restricted funds		1,764	3,692	(3,382)	2,074	4,769	(4,483)	2,360
Total funds		10,161	18,633	(18,117)	10,677	19,911	(15,583)	15,005

Restricted Funds

Restricted funds are utilised as follows:

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

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

18b Designated funds

Designated funds represent:

	2020 £000	2019 £000
i) the amounts committed by the Association in respect of grants payable for the MND Care Centre Network not reflected in the Consolidated Statement of Financial Activities. Care Centre commitments run for up to four years and so the funds designated for these are required to meet future commitments on agreed contracts extending to 2024.	891	1,302
ii) the trustees previously also designated the IBC monies of £7.2m together with additional reserves for the following specific activities:		
Research projects	214	214
Care	115	115
Campaigning and raising awareness	55	55
Engagement of volunteers and to fund emerging new opportunities	20	60
These funds are expected to be fully utilised by the end of 2021.		
iii) Trustees agreed to designate £3m of the exceptional income in 2020 to research and strategic investment projects which will run through to the end of 2023.		
Board approved reallocation of reserves	3,000	
	4,295	1,746

19 Analysis of net assets between funds

2020

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	835
Net current assets less long-term liabilities	2,360	4,295	7,642	14,297
Total net assets	2,360	4,295	8,477	15,132
Charity:	£000	£000	£000	£000
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	835
Net current assets less long-term liabilities	2,360	4,295	7,515	14,170
Total net assets	2,360	4,295	8,350	15,005

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

19 Analysis of net assets between funds (continued)

2020

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Group:				
Fund balances at 31 December 2019 are represented by:				
Fixed assets	-	-	720	720
Net current assets less long-term liabilities	2,074	1,746	6,224	10,044
Total net assets	2,074	1,746	6,944	10,764

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2019 are represented by:				
Fixed assets	-	-	720	720
Net current assets less long-term liabilities	2,074	1,746	6,137	9,957
Total net assets	2,074	1,746	6,857	10,677

20 Leasing commitments

Operating leases

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

	2020 £000	2019 £000
Within one year	245	244
Between two to five years	587	637
Over five years	-	32
	832	913

The charge to the Statement of Financial Activities is £395,000 (2019: £343,000)

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

21 Provisions for liabilities and charges

Charity	Leasehold dilapidations £000	Bad debts £000	Obsolete stock £000	Total £000
At 1 January 2020	260	71	-	331
Additions	-	1	-	1
Utilised	(161)	-	-	(161)
Balance at 31 December 2020	99	72	-	171

Group	Leasehold dilapidations £000	Bad debts £000	Obsolete stock £000	Total £000
At 1 January 2020	260	71	25	356
Additions	-	1	2	3
Utilised	(161)	-	-	(161)
Balance at 31 December 2020	99	72	27	198

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

Consolidated Statement of Financial Activities

(incorporating an income and expenditure account)

For the year ended 31 December 2020

22. Consolidated Statement of Financial Activities

		Unrestricted Funds £000	Restricted Funds £000	Total Funds 2019 £000
Income and endowments from:				
Donations and legacies:	1a			
Donations		9,560	2,662	12,222
Legacies		4,303	1,030	5,333
Charitable activities		-	-	-
Other trading activities	1b	873	-	873
Investments		181	-	181
Other	1c	24	-	24
Total income		14,941	3,692	18,633
Expenditure on:				
Raising funds		3,493	176	3,669
Charitable activities:				
Care		4,943	2,111	7,054
Research		3,256	1,063	4,319
Campaigning and raising awareness		1,852	31	1,883
Volunteer development		1,191	1	1,192
Other		-	-	-
Total expenditure	4	14,735	3,382	18,117
Net gain / (loss) on investments	12	-	-	-
Net income for the year	3	206	310	516
Transfers between funds		-	-	-
Other recognised gains/ (losses) :				
Gains/ (losses) on revaluation of fixed assets		-	-	-
Other gains/ (losses)		(13)	-	(13)
Net movement in funds		193	310	503
Reconciliation of funds:				
Total funds brought forward		8,497	1,764	10,261
Total funds carried forward	18a, 19	8,690	2,074	10,764

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

23 Prior year figures

23a Analysis of expenditure incurred in raising funds and charitable activities

Total expenditure incurred is further analysed as follows:

	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2019 12 months £000
Care and care centres	3,508	2,527	1,019	7,054
Research	846	3,258	215	4,319
Campaigning and raising awareness	1,379	-	504	1,883
Volunteering	833	-	359	1,192
Costs of charitable activity	6,566	5,785	2,097	14,448
Raising funds	2,848	-	821	3,669
Total resources expended 2019 (12 months)	9,414	5,785	2,918	18,117

23b Support costs

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

	Care £000	Research £000	Campaigning awareness £000	Volunteering £000	Raising funds £000	Total 2019 12 months £000
Management	135	24	64	44	113	380
Governance	65	12	31	21	54	183
Finance	159	29	76	52	133	449
Information and communications technology	256	47	122	85	214	724
Facilities	265	48	126	87	222	748
Human resources	102	18	48	33	85	286
Conferences and events	37	37	37	37	-	148
	1,019	215	504	359	821	2,918

Notes to the Consolidated Financial Statements

For the year ended 31 December 2020

23 Prior year figures (continued)

23c Analysis of net assets between funds

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Group:				
Fund balances at 31 December 2019 are represented by:				
Fixed assets	-	-	720	720
Net current assets less long-term liabilities	2,074	1,746	6,224	10,044
Total net assets	2,074	1,746	6,944	10,764

	£000	£000	£000	£000
Charity:				
Fund balances at 31 December 2019 are represented by:				
Fixed assets	-	-	720	720
Net current assets less long-term liabilities	2,074	1,746	6,137	9,957
Total net assets	2,074	1,746	6,857	10,677

 mndassociation

 mndassoc

 mndassoc

Motor Neurone Disease Association
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton, NN3 6BJ

Tel: 01604 611860

Email: enquiries@mndassociation.org

www.mndassociation.org

Royal Patron: HRH The Princess Royal

Registered Charity No 294354, Company Limited by Guarantee No 2007023

©MND Association 2021 AnnReport/21