



DRAFT VERSION

Annual Report and Consolidated Financial Statements

For the year ended 31 December 2024

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, and our patron 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



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 line underneath.

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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. 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: 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 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 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 Marriott 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.

Our Promise: 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 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 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: 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.

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 advisors 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

Our Promise: 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.

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 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.

Our patrons and ambassadors

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: 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.

2024 was a year for reflection around EDI within the charity's internal processes. We want to hold ourselves to the highest standards so that we're in the best position to meet the needs of the whole 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 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 trustee Ed Cooke who died in February 2025.

iii) Future plans and priorities

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.

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: To 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:

- 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

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 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 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

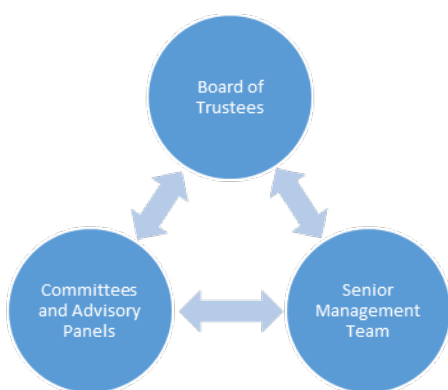
The Association must comply with a range of legal and regulatory requirements including charity law, data protection, fundraising standards, health and safety and safeguarding. To mitigate these risks the Association has robust and embedded processes and policies, which are complemented by regular and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

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 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.

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.

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.

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.

2024	Scope	Energy consumed / miles travelled	Govt emissions conversion	Emissions	Tonnes of carbon dioxide equivalent	% of impact on our carbon footprint	Emissions ratio
Fuel for business mileage	1	197,314.6 1 miles	0.2686	52,998.7 kg of CO ₂ e	53	82.785	53
	2	53,265.16 kWh	0.20705	11,028.552 11 kg oc CO ₂ e	11.03	17.22	11

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.

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.

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). Counter party 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 / Bonds 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 general 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/undesignated reserves balance sat at £22.8 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 and the costs of services we provide.

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 2024, no further designation was required. 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 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

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 2024 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

Dr Usman Khan

Catherine Knights

Ian Lev

James Marshall

Dr Shaun McGee

Kirrie Todd

Ed Cooke (from June 2024 until Feb 2025)

Alan Graham (from June 2024)

Michael Hope (from June 2024)

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

Moulton Park

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 , 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 Queen Street
For and on behalf of HaysMac LLP, Statutory Auditor
London

EC4R 1AG

Motor Neurone Disease Association

Charity No. 294354

Company No. 02007023

Consolidated Statement of Financial Activities (incorporating an income and expenditure account) For the year ended 31 December 2024

		Unrestricted Funds £000	Restricted Funds £000	Total Funds 2024 £000	Total Funds 2023 £000
Income and endowments from:					
Donations and legacies:					
Donations	1a	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.

Motor Neurone Disease Association


Charity No. 294354
Company No. 02007023

Balance Sheet

As at 31 December 2024

	Notes	Group 2024 £'000	2023 £'000	Charity 2024 £'000	2023 £'000
Fixed assets					
Tangible assets	11a	167	304	167	304
Investments (LT)	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 (ST)	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	19	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 xx to xx 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



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.

Motor Neurone Disease Association
Statement of Cash Flows
For the year ended 31 December 2024

		2024	2023		
	Notes	£000	£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					
	Balance		Balance		Balance
	1 January	Cash flow	1 January	Cash flow	31 December
	2023	changes	2024	changes	2024
Group	£000	£000	£000	£000	£000
Net cash					
Short term deposits	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
<hr/>					
Net funds	41,196	8,234	49,430	10,355	59,785

Motor Neurone Disease Association

Statement of Accounting Policies

Legal Status

The Association is a company limited by guarantee not having a share capital, incorporated in England and Wales (company number: 02007023) and a charity registered in England and Wales (charity number: 294354). The charity's registered office address is 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.

Motor Neurone Disease Association

Statement of Accounting Policies (continued)

d) Consolidated financial statements

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

In accordance with the exemption afforded by section 408 of the Companies Act 2006 a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared. The surplus of the parent charity was £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 executor(s) to the charity that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity, or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is treated as a contingent asset and disclosed if material (see note 14).

f) Investment income

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

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

g) Fund accounting

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

Motor Neurone Disease Association

Statement of Accounting Policies (continued)

h) Expenditure and irrecoverable VAT

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

- Costs of raising funds includes cost of goods sold and cost of hosting fundraising events
- Care spend includes the costs of grants made to our Care 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
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l) Tangible fixed assets

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

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

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

Motor Neurone Disease Association

Statement of Accounting Policies (continued)

m) Investments

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

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

Fixed asset investments comprise 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

n) Financial instruments

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

o) Cash at bank and in hand

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

p) Debtors

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

q) Stocks

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

r) Creditors and provisions

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

Motor Neurone Disease Association

Statement of Accounting Policies

s) Long term liabilities

FRS 102 requires long term liabilities to take into account the time value of money and, 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.

Motor Neurone Disease 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 - General

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

Motor Neurone Disease Association

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

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

Motor Neurone Disease Association

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
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:

	Note	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

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	Research	Campaigning and raising awareness	Volunteering	Raising funds	Total 2024	Total 2023
	£000	£000	£000	£000	£000	£000	£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, Technology & 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

Motor Neurone Disease Association

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

6 Grants payable

Grants were awarded during the year as follows:

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

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

	2024	2023
	£000	£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	<u>23,858</u>	<u>18,124</u>
Falling due within one year (note 16a)	14,398	10,850
Falling due after more than one year (note 17)	9,460	7,274
	<u>23,858</u>	<u>18,124</u>

Commitments

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

	2024	2023
	£000	£000
Group and Charity		
Payable within one year	1,286	1,084
	<u>1,286</u>	<u>1,084</u>

Motor Neurone Disease Association

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

10,412

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

Motor Neurone Disease Association

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 (continued)

Trustee remuneration and expenses	£000	£000
Reimbursement directly to trustees	2	3
Payment to third parties in respect of trustee expenses	6	2
	<u>8</u>	<u>5</u>
Number of trustees holding office during the year	14	16

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

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

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

Staff numbers above include an appropriate apportionment of support staff.

Motor Neurone Disease Association

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

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 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.

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 @ 1st January	5,208	5,000
Acquisitions at cost		
Sale proceeds from disposals	-	-
Gain / (Loss) in year	243	208
Market value @ 31st December	5,451	5,208
TrinityBridge - Asset Portfolio	5,451	5,208
	5,451	5,208

Motor Neurone Disease Association

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

Motor Neurone Disease Association

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

13 Stocks

	Group		Charity	
	2024	2023	2024	2023
	£000	£000	£000	£000
Purchased goods for resale	<u>29</u>	<u>23</u>	<u>-</u>	<u>-</u>

14 Debtors

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

Motor Neurone Disease Association

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

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	2023	2024	2023
	£000	£000	£000	£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
	<u>17,120</u>	<u>13,494</u>	<u>16,649</u>	<u>13,332</u>

16b Analysis of deferred income

	Group		Charity	
	2024	2023	2024	2023
	£000	£000	£000	£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	<u>180</u>	<u>8</u>	<u>265</u>	<u>8</u>

17 Creditors: amounts falling due after one year

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

Motor Neurone Disease Association

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

18a Statement of funds

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
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
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	(0)			(0)			-
Branches and Groups	1,812	430	(423)	1,819	685	(514)	1,990
Campaigning	-	34	(34)	0	14	(14)	0
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	16,147	7,351	(3,276)	20,222	1,286	(2,124)	19,384
note 18b	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

Motor Neurone Disease Association

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 & Developmentssystems 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

Motor Neurone Disease Association

Notes to the Consolidated Financial Statements

For the year ended 31 December 2024

19 Analysis of net assets between funds

2024

Group:

Fund balances at 31 December 2024
are represented by:

Fixed assets
Net current assets less long-term liabilities

Total net assets

Charity:

Fund balances at 31 December 2024
are represented by:

Fixed assets
Net current assets less long-term liabilities

Total net assets

2023

Group:

Fund balances at 31 December 2023
are represented by:

Fixed assets
Net current assets less long-term liabilities

Total net assets

Charity:

Fund balances at 31 December 2023
are represented by:

Fixed assets
Net current assets less long-term liabilities

Total net assets

All linked perform a sense check as last job

Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
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-	-	167	167
8,961	19,384	22,665	51,010

8,961	19,384	22,832	51,177
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£000	£000	£000	£000
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-	-	167	167
8,961	19,384	22,594	50,939

8,961	19,384	22,761	51,106
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Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
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-	-	304	304
8,441	20,222	15,366	44,029

8,441	20,222	15,670	44,333
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£000	£000	£000	£000
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-	-	304	304
8,441	20,222	15,296	43,959

8,441	20,222	15,600	44,263
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Motor Neurone Disease Association

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	2023
	£000	£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 (2023: £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.

Motor Neurone Disease Association

Charity No. 294354
Company No. 02007023

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