

## and Consolidated Financial Statements

For the year ended 31 December 2022



## Message from the Chair

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

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

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

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

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

Dr Usman Khan

Chair, Board of Trustees



#### **BUCKINGHAM PALACE**

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

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

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

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

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

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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 2022, which have been prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102), the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) - (2nd Edition, effective 1 January 2019) and the Companies Act 2006.

#### **About MND**

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

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

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

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

## Objectives and activities

#### About us

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

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

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

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

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

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

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

#### Public benefit

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

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

## ii) Achievements and performance in 2022

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

#### We would like to thank

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

#### Remembering

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

## iii) Future plans and priorities

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

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

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

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

## iv) Fundraising governance priorities

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

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

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

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

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

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

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

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

We received 17 complaints about our fundraising activity in 2022. All were promptly resolved without the need for escalation to the Fundraising Regulator. Complaints are taken very seriously and reviewed guarterly by the Board of Trustees. However, these 17 represent a tiny fraction of our outgoing fundraising communications. There is a complaints policy, which is available on our website, which forms the basis for the training of all fundraising staff.

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

## v) Financial review

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

#### Financial performance

2022 was a phenomenal year for fundraising at the Association, with total income reaching £30 million in the 12 month period for the first time ever. This compared to £28.9 million in 2021.

The increased focus on MND in the media and the high profile fundraising events that took place contributed to a record year. All areas of fundraising had a strong year, most notably legacy donations which accounted for 30% of the income received.

£17.6 million was raised and donated by our incredible supporters and a further £2.3 million was raised by our branches and groups. We are tremendously grateful for their commitment and continued support.

£8.9 million was donated in 2022 in the form of legacy gifts which continue to make such a huge difference to the work we do. We are enormously grateful to the people who choose to remember the work of the Association in their Wills.

For every pound spent directly generating fundraising and legacy income, £7.51 was received.

#### 8% 4% Sources of income (£) million **Fundraising** £17.6 Sources of 30% £8.9 Legacies income **Branches and Groups** £2.3 Earned income £12 **TOTAL INCOME** £30.0

#### How we spent the money raised (£) million 13% Care £6.6 Research £7.3 £1.5 Campaigning Volunteer development £0.5 Money raised **Fundraising** £3.9 **Operational Support Costs** £3.0 **TOTAL COSTS** £22.8 32%

Our expenditure year on year increased by £4.8 million. This increase reflected a return to a full year of normal activities following the pandemic, alongside increased spend on our core activities. The biggest uplift was in research expenditure which was almost £2.5 million higher as we continued to support investment in critical research activity. Our care expenditure was also up by almost £1 million as we provided more support to people living with MND, their families and carers at a time when the cost of living crisis has been having such a devastating impact.

We exceeded all our planned commitments to our care grants programme to ensure that people affected by MND continued to receive critical financial support.

The incredibly strong income performance led to a net surplus of £7.2 million. The Board of Trustees has agreed to designate £5.6 million of this surplus to support increased research opportunities, to enable us to do more, faster. More details can be found in the Future Plans and Priorities section.

Despite our extremely positive fundraising success over the last two years, we need to maintain the momentum to support our growing care, research and campaigning work which will cost at least £26 million a year, and allow us to continue to strive towards our mission of a world free from MND

## vi) Principal risks and uncertainties

## Risk management

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

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

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

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

#### Reputational risk

Retaining the Association's reputation is paramount. Due to the diverse nature of our activities this risk relates to several areas including our extensive research programme (for example, our policies on the use of animals and embryonic stem cells in research), the provision of care through our MND Care Centres and Networks, the support provided by our Association visitor network, and the extensive activities of more than 13.000 volunteers – which includes those in our campaigns network across England, Wales and Northern Ireland. Controls and policies relating to all our activities focus on reputational impacts and these are monitored regularly for compliance.

#### Financial risk

While the Association has had a record-breaking year for income in 2022, we remain very aware of the risk to future income as household incomes are impacted by significant increases in the costs of utilities, high inflation, increasing interest rates, and the economy moving into a possible recession in 2023. The impact on the Association could lead to reduced income generation at the same time as need for further financial support grows from our community. To mitigate this risk, the Association undertakes weekly income and core expenditure reporting so that we can identify, and react to, any financial pressures which we will manage tightly using our reserves.

While we remain cautious about the financial position in 2023, the robust performance in 2022 has significantly reduced our financial risk and means that the Association will begin the year in a much stronger position than anticipated. The strong financial position has enabled the auditors to confirm that the Association remains a going concern.

#### External environment risk

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

## Compliance risk

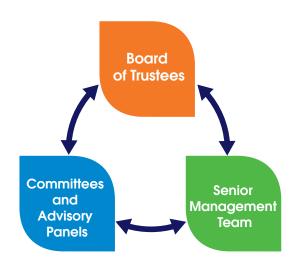
The Association must comply with a range of legal and regulatory requirements including charity law, data protection, fundraising standards, health and safety and safeguarding. To mitigate these risks the Association has robust and embedded processes and policies, which are complemented by regular and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

# Structure, Governance and Management

#### Structure

The Association was originally formed on 6 October 1979 and was incorporated as a company limited by membership quarantee in 1986. The Association is governed by its **Articles of Association** and in the event of it being wound up, every member is liable for an amount not exceeding £1 to facilitate the payment of the debts and liabilities of the Association. At 31 December 2022, there were 11,154 members.

#### Governance



Our governance structure is designed to ensure that:

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

#### The Board of Trustees

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

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

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

#### Committees of the Board

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

#### **Care Committee**

This committee reviews all aspects of the Association's work relating to improving care and providing support for people with MND, their carers and families. It reviews risk and approves grant funding to support the work of MND Care Centres and Networks, up to an agreed limit, with grants above that limit being approved by the Board.

#### **Engagement Committee**

This committee reviews strategic activities, policy, and effectiveness relating to the Association's volunteers. This includes all aspects of volunteering including recruitment, retention, empowerment, any potential risks and the development of existing and emerging roles.

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

This committee provides stewardship of all financial aspects of the charity's work, including the fundraising activities of the Association. The committee scrutinises and evaluates the annual budget prior to Board approval. It ensures that the appropriate financial controls and regulatory requirements are adhered to and advises the Board accordingly. The committee also recommends the annual pay award for all employees, which includes the Senior Management Team (except the Chief Executive), to the Board for approval.

#### **Governance Committee**

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

#### **Remuneration Committee**

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

#### Biomedical and Healthcare Research Advisory Panels

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

#### Branches, groups and affiliates

At 31 December 2022, the Association had 90 branches and groups and two affiliates (based in Jersey and the Isle of Man). Each branch and group has agreed to abide by our branch and group charter which sets out the parameters of the powers delegated to them by the Board.

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

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

## **Environmental impact**

The Association initiates and monitors changes to process and practice that reduce its environmental impact.

We moved to our new national office at Francis Crick House in January 2020 and this gave us an opportunity to adopt more sustainable practices.

Since the pandemic, the most sustainable practice has been the use of technology to support hybrid working and thereby reduce travel and meeting costs. In 2022, we introduced enhanced recycling facilities in our national office, as well as carbon captured paper for in-house printing, and biodegradable magazine wrap. We have also introduced 25 hybrid vehicles into our fleet and a new range of eco-friendly products to our online shop. These are either made from sustainable or recycled materials.

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

#### Management

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

#### Safeguarding

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

#### Whistleblowing

We take any evidence of malpractice very seriously and support anyone who is raising genuinely held concerns. We reviewed these policies in detail in 2022 and they are backed up by mandatory staff and volunteer training.

#### **Grants**

Grants are awarded for both research projects and care services:

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

Care – We provide grants to existing specialist MND Care Centres and Networks. At 31 December 2022 the Association was providing financial support to 22 such centres and networks. Performance is monitored annually for existing Care Centres, with a full grant renewal process every four years.

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

## Investment policy

Investments are held to cover reserves for the management of risk and for future investment opportunities. The investment objective is to provide resources to cover short term demands arising from sudden or unexpected events that could influence fundraising income. The trustees take a prudent approach to risk, holding the Association's investments in cash deposits, near cash and general recognised cash equivalents (including but not limited to Certificates of Deposit and other short-term investments). Counter party limits and acceptable credit ratings are set by the Finance and Audit Committee. Any investment donated to the Association will ordinarily be sold at the earliest opportunity unless there is a specific request from the donor for the shares to be held as fixed asset investments. During the year, the base interest rate increases meant that returns on deposit investments improved, earning £276,000 in 2022 compared with £69,000 in 2021.

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

#### Group reserves policy

The trustees have adopted a robust and flexible reserves policy to meet the changing needs of the charity. This states that the general reserve should be in the range of four to six months' general expenditure represented in cash and readily realisable investments, held centrally and within branches. This is a target range of between £7.6 million and £11.5 million. As at the year end, the unrestricted/undesignated reserves balance sat at £11.5 million. Trustees believe that this remains a prudent level given the continuing uncertainty associated with the future economic outlook which could have a detrimental impact on our ability to raise funds.

# Statement of Trustees' Responsibilities and **Corporate Governance**

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

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

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

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

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

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

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

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

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

Dr Usman Khan

Chair, Board of Trustees

20 May 2023

## Organisational information and financial statements

**Board of Trustees** 

Chair: Richard Coleman (until June 2022)

Chair: Dr Usman Khan (from June 2022)

Chair-elect: Usman Khan (until June 2022)

Vice Chair: Jan Warren (until June 2022)

Vice Chair: Catherine Knights (from June 2022)

Honorary Treasurer: James Marshall

Andy Cawdell (until June 2022)

Simon Croxford (from June 2022)

Elizabeth Ellis

Susan Fletcher-Watts (from June 2022)

Devia Gurjar (until April 2022)

Dr Katherine Jackson (from June 2022)

Usman Khan

Catherine Knights

lan Lev (from June 2022)

James Marshall

Debra Martin

Dr Shaun McGee

Vicky Paeschel (until June 2022)

Siobhán Rooney

Dr Nik Sharma (until September 2022)

Dr Heather Smith (until June 2022)

Katherine Styles

Kirrie Todd (from May 2022)

#### Senior management team

Tanya Curry, Chief Executive (from Jan 2023)

Sally Light, Chief Executive (until Dec 2022)

Linda Allen, Director of Fundraising

Mark Chapman, Director of Finance

Dr Brian Dickie, Director of Research Development

Nick Goldup, Director of Care Improvement

Chris James, Director of External Affairs

Chris Wade, Director of Engagement (until April 2023)

#### Company secretary

Mark Chapman

## Registered office

Francis Crick House 6 Summerhouse Road Northampton NN3 6BJ

#### Professional advisers

## Statutory auditors

haysmacintyre LLP 10 Oueen 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 NN47XD

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

## **Auditors' Opinion**

We have audited the financial statements of Motor Neurone Disease Association for the period ended 31 December 2022 which comprise the Consolidated Statement of Financial Activities, The Group and Charity Balance Sheets, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 December 2022 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006

#### Basis for opinion

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

#### Conclusions relating to going concern

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

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

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

#### Other information

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

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

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

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

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

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

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

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

- adequate accounting records have not been kept by the parent charitable company, or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or

- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit[; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemptions in preparing the trustees' report and from the requirement to prepare a strategic report

## Responsibilities of directors

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

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

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

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

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

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

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

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

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

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

#### Use of our report

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

Richard Weaver (Senior Statutory Auditor)

31 May 2023

For and on behalf of

Haysmacintyre LLP 10 Oueen Street Place London EC4R 1AG

# **Consolidated Statement of Financial Activities**

(incorporating an income and expenditure account) For the year ended 31 December 2022 Company Number (02007023) and Charity Number (294354)

	Notes	Unrestricted funds £000	Restricted funds £000	Total Funds 2022 £000	Total funds 2021 £000
Income and endowments from:					
Donations and legacies:	1a				
Donations		14,204	5,315	19,519	19,552
Legacies		8,888		8,888	8,523
Charitable activities					
Other trading activities	1b	906	-	906	743
Investments		276	-	276	69
Other	1c	456		456	56
Total income		24,730	5,315	30,045	28,943
Expenditure on:					
Raising funds		4,910	-	4,910	4,037
Charitable activities:					
Care		5,872	1,930	7,802	6,917
Research		5,038	2,435	7,473	4,805
Campaigning and raising awareness		1,542	410	1,952	1,802
Volunteer development		659	-	659	502
Total expenditure	4	18,021	4,775	22,796	18,063
Net income/ (expenditure)	3	6,709	540	7,249	10,880
Other recognised gains/ (losses):					
Other gains/ (losses)		(9)		(9)	(38)
Net movement in funds		6,700	540	7,240	10,842
Reconciliation of funds:					
Total funds brought forward		20,935	5,039	25,974	15,132
Total funds carried forward	18a, 19	27,635	5,579	33,214	25,974

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

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

## **Balance Sheet**

As at 31 December 2022

Company Number (02007023) and Charity Number (294354)

		G	iroup	c	Charity
	Notes	2022 £000	2021 £000	2022 £000	2021 £000
Fixed assets					
Tangible assets	11a	444	581	444	581
Investments (LT)	11b	5,000	-	5,000	-
Total Tangible Assets		5,444	581	5,444	581
Current assets					
Stocks	13	20	22	-	-
Debtors	14	9,569	7,900	10,335	8,035
Investments	15	19,326	17,238	19,326	17,238
Cash at bank and in hand		16,870	15,434	16,483	15,352
		45,785	40,594	46,144	40,625
<b>Creditors:</b> amounts falling due within one year	16a	12,551	9,794	12,998	9,913
Net current assets		33,234	30,800	33,146	30,712
Total assets less current liabilities		38,678	31,381	38,590	31,293
Creditors: amounts falling due after					
more than one year	17	5,464	5,407	5,464	5,407
Net assets	19	33,214	25,974	33,126	25,886
Accumulated funds					
Restricted funds	18a	5,579	5,039	5,579	5,039
Designated funds	18a, 18b	16,147	12,656	16,147	12,656
Unrestricted funds:					
Unrestricted funds	18a	11,400	8,191	11,400	8,191
Funds retained in subsidiary	12a	88	88		
		33,214	25,974	33,126	25,886

The financial statements on pages 19 to 43 were approved and authorised for issue by the Board of Trustees on 20 May 2023, and were signed on its behalf by:

James Marshall

Jes O. Kell

Dr Usman Khan

Treasurer

Chair

The net movement in funds for the Association for the year ending 31 December 2022 was £7,240,000 (2021: £10,842,000).

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

# **Statement of Cash Flows**

For the year ended 31 December 2022 Company Number (02007023) and Charity Number (294354)

ivet cash used in investing activities		151	(3)
Net cash used in investing activities		151	(3)
Purchase of fixed assets	11	(125)	(72)
Dividends and interest from investments		276	69
Decrease in cash element of investment portfolio (Shares not realised)		-	-
Proceeds from sales of investments		-	-
Movement in cash held as investment			
Cost of additions to investments		-	-
Cash flows from investing activities:			
Net cash generated from operating activities		8,373	10,856
Other adjustment		-	-
Increase / (decrease) in creditors	16a,17	2,813	2,104
(Increase) / decrease in debtors	14	(1,669)	(2,356)
(Increase) / decrease in stock	13	2	9
Gain on disposal of fixed assets	11	-	-
Dividends and interest from investments		(276)	(69)
Depreciation and amortisation charges	11	263	326
Adjustments for:		7,210	10,0 12
Cash flows from operating activities:  Net income/ (expenditure) for the reporting year		7,240	10,842
Cash flaves from an avating a stigities.			
	Notes	2022 £000	2021 £000

## Analysis of cash and cash equivalents

Group	Balance 1 January 2021 £000	Cash flow changes £000	Balance 1 January 2022 £000	Cash flow changes £000	Balance 31 December 2022 £000
Net cash					
Short term deposits	9,200	8,038	17,238	7,088	24,326
Bank current accounts	12,613	2,818	15,431	1,436	16,867
Cash in hand	6	(3)	3	(0)	3
Net funds	21,819	10,853	32,672	8,524	41,196

## **Statement of Accounting Policies**

#### Legal Status

The Association is a company limited by guarantee not having a share capital, incorporated in England and Wales (company number: 02007023) and a charity registered in England and Wales (charity number: 294354). The charity's registered office address is 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. The members undertake to contribute to the assets of the company in the event of it being wound up, either whilst members or within one year of the membership ceasing. The maximum contribution required from each member is £1. There were 11,154 members at 31 December 2022 (31 December 2021: 10,984).

## Principal accounting policies

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

#### a) Basis of preparation

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

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

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

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

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

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

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

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

Despite the economic uncertainty post-pandemic, 2022 proved to be another strong year for the charity with reserves increasing and the Association's financial position remaining strong. As such, the trustees consider there are no material uncertainties about the charity's ability to continue as a going concern. Trustees regularly review potential risks and make strategic changes as and when required. The review of the charity's financial position, reserves levels and future plans through to the end of December 2025 gives trustees confidence that the charity remains a going concern for the foreseeable future.

#### d) Consolidated financial statements

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

In accordance with the exemption afforded by section 408 of the Companies Act 2006 a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared. The surplus of the parent charity was £7,249,000 (2021: surplus £10,880,000).

#### e) Income

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

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

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

For legacies, entitlement is taken as the earlier of the date on which either: the charity is aware that probate has been granted,

## Statement of Accounting Policies (continued)

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

#### f) Investment income

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

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

#### g) Fund accounting

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

#### h) Expenditure and irrecoverable VAT

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

- Costs of raising funds includes cost of goods sold and cost of hosting fundraising events
- Care spend includes the costs of grants made to our Care Centre Network and to individuals
- Research spend is represented by grants made to third parties in respect of biomedical and healthcare research. Single or multi-year grants are accounted for when the trustees have agreed to pay the grant without condition
- Campaigning and raising awareness costs include the costs of advertising, promoting and lobbyingto ensure that the 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 accumlated 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

#### I) Tangible fixed assets

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

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

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

#### m) Investments

Investments are a form of basic financial instruments and are initially shown in the financial statements at market value.

## Statement of Accounting Policies (continued)

Movements in the market values of investments are shown as unrealised gains and losses in the Statement of Financial Activities.

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

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

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

#### n) Financial instruments

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

#### o) Cash at bank and in hand

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

#### p) Debtors

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

#### q) Stocks

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

#### r) Creditors and provisions

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

#### s) Long term liabilities

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

#### t) Employee benefits

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

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

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

#### u) Taxation

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

In 2019 the Association applied for Group VAT status on the basis that it had become financially beneficial for the whole group to be able tor 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.

For the year ended 31 December 2022

#### Income

## 1a Donations and legacies

	2022 £000	2021 £000
Individuals	5,675	7,306
Community and other fundraising	6,268	6,240
Appeals	2,062	2,076
Charitable foundations (see note 2)	3,262	1,170
Corporate donations	711	941
Tax recovered	1,541	1,819
	19,519	19,552
Legacies (see note 14)	8,888	8,523
	28,407	28,075

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

## 1b Other trading activities

	906	743
Conferences and events	327	286
-		
Merchandise sales and advertising	154	39
Charity-organised fundraising	425	418
	2022 £000	2021 £000

## 1c Other

	2022 £000	2021 £000
Costs recovered from the International Alliance	(7)	18
HMRC Job Retention Grant	-	25
MRC Early in career research grants	450	-
Other	13	13
	456	56

For the year ended 31 December 2022

## 2 Grants receivable from Charitable foundations

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

	2022 £000		2022 £000
Betty Messenger Charitable Foundation	2,000	Assurant Foundation	8
Alan Davidson Foundation	146	The Inman Charity	8
My Name'5 Doddie Foundation	100	The Zochonis Charitable Trust	8
The Constance Travis Charitable Trust	50	Lloyds Bank Foundation for England & Wales	8
Darby Rimmer MND Foundation	50	The Paul Bassham Charitable Trust	7
The Netherby Trust	40	Oxygen House Foundation	7
The Basil Samuel Charitable Trust	30	Cecil and Hilda Lewis Charitable Trust	6
Bruce Wake Charitable Trust	30	The Nick Smith Foundation	6
The Barbara Naylor Trust	27	Eddystone Pursuit Sailing Charity	6
The William Brake Foundation	25	The Chalk Cliff Trust	5
The Freshfield Foundation	24	David Lister Charitable Trust	5
Catherine Cirket Discretionary Trust	20	The Dyers' Company Charitable Trust	5
The Childwick Trust	20	Ennismore Foundation	5
The Jones 1986 Charitable Trust	20	The Family Rich Charities Trust	5
Malcolm Gunter Foundation	20	The February Foundation	5
Richard Mackay Charitable Trust	20	The G C Gibson Charitable Trust	5
St James's Place Charitable Foundation	17	Hyde Park Place Estate Charity	5
The Cinquefoil Trust	15	The Iceland Foods Charitable Foundation	5
The Light Fund Charity	15	John James Bristol Foundation	5
The Ofenheim Charitable Trust	13	The Kirby Laing Foundation	5
William Kessler Charitable Trust	13	The L & R Gilley Charitable Trust	5
The Elizabeth and Prince Zaiger Trust	12	M K Rose Charitable Trust	5
The Geoffrey & Pauline Martin Trust	12	The Mary Homfray Charitable Trust	5
Peacock Charitable Trust	11	The Mary Potter Convent Hospital Trust	5
The Annandale Charitable Trust	11	The Oldhurst Trust	5
Advent Charitable Trust	10	Payne-Gallwey Charitable Trust	5
The Batchworth Trust	10	Pilkington Charities Fund	5
The Theodore Maxxy Charitable Trust	10	The Simon Gibson Charitable Trust	5
Edith Murphy Foundation	10	Sir James Knott Trust	5
The Fieldrose Charitable Trust	10	The Sir James Reckitt Charity	5
The Frank Brake Charitable Trust	10	The Talbot Trust	5
The Joron Charitable Trust	10	The William Leech Charity	5
Kusuma Trust UK	10		
Margaret Giffen Charitable Trust	10	Annonymous or less than £5,000	222
Orr Mackintosh Foundation	10		
P F Charitable Trust	10	TOTAL	3,262
Stephen Hawking Foundation	10		

In 2021, grants receivable from Charitable foundations totalled £1,170,000

For the year ended 31 December 2022

## Net income for the year

This arises after charging:

	2022 £000	2021 £000
Auditors' remuneration:		
External audit	29	29
Other services	-	-
Operating lease rentals:		
motor vehicles	290	302
land and buildings	207	199
other	10	14
Depreciation and amortisation of owned assets	263	326
Loss on disposal of fixed assets	-	=

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

Total expenditure incurred is further analysed as follows:

Total resources expended 2021	23a	8,640	6,703	2,720		18,063
Total resources expended 2022		10,262	9,496	3,038	22,796	18,063
Raising funds		3,853	-	1,057	4,910	4,037
Costs of charitable activity		6,409	9,496	1,981	17,886	14,026
Volunteering		521	-	138	659	502
Campaigning and raising awareness		1,540	-	412	1,952	1,802
Research		594	6,663	216	7,473	4,805
Care and care centres		3,754	2,833	1,215	7,802	6,917
	Notes	£000	£000	£000	£000	£000
		directly	(note 6)	(note 5)	2022	2021
		Activities undertaken	funding of activities	Support costs	Total	Total
			Grant			

For the year ended 31 December 2022

## Support costs

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

	Care £000	Research £000	Campaigning and raising awareness £000	Volunteering £000	Raising funds £000	Total 2022 £000	Total 2021 £000
Management	217	39	73	25	189	543	446
Governance	70	12	24	8	61	175	61
Finance	208	37	71	23	182	521	419
Information and communications technology	307	54	104	35	267	767	754
Facilities	266	47	90	29	232	664	662
Human resources	145	26	49	17	126	363	374
Conferences and events	2	1	1	1	-	5	4
	1,215	216	412	138	1,057	3,038	2,720

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

## Grants payable

Grants were awarded during the year as follows:

	Note	2022 £000	2021 £000
Grants to institutions (note 6b)	4	7,570	4,989
Grants to individuals		1,926	1,714
		9,496	6,703

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

For the year ended 31 December 2022

## Grants payable (continued)

	2022 £000	2021 £000
Balance at start of year	12,987	9,947
Awarded in year	9,496	6,703
Paid in year	(6,754)	(3,663)
Balance at end of year	15,729	12,987
Falling due within one year (note 16a)	10,265	7,580
Falling due after more than one year (note 17)	5,464	5,407
	15,729	12,987

#### **Commitments**

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

	2022	2021
Group and Charity	£000	£000
Payable within one year		1
Payable in years two to five	881	881
	881	882

For the year ended 31 December 2022

## 6b Grants payable split by benefactor

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

	2022 £000			2022 £000	
Life Arc	1,330	Research	Norfolk/Norwich Care Centre	54	Care
University Of Sheffield	605	Research	Southampton	53	Care
Kings College London	572	Research	The Francis Crick Institution	50	Research
MND Smart	500	Research	University of East Anglia	50	Research
Ule	298	Research	Sussex MND Care &		
Trinity College Dublin	295	Research	Research Network	50	Care
Serio	290	Research	Leeds Care Centre	49	Care
Gerbino	285	Research	Newcastle General Hospital	47	Care
Talbot	285	Research	University College London	46	Research
Allen	279	Research	Nottingham University Hospital	42	Care
Univeristy of Oxford	274	Research	Bristol Care Centre	38	Care
University of Edinburgh	258	Research	University of Liverpool	25	Research
Royal Papworth	210	Research	University of St. Andrews	20	Research
Walker Family Funding	200	Research	Lancashire and South Cumbria	17	Care
De Vos	188	Research	University of Exeter	15	Research
Mc Manus	177	Research	Belfast Health and		
University of Oxford	167	Research	Social Care Trust	14	Research
Plymouth Primary			The Walton Centre	14	Research
Care Trust (S.West)	118	Care	Stoke/North Midlands	13	Care
Chu De Nimes	115	Research	Manchester Care Centre	12	Care
S Wales Care Network (Cardiff)	114	Care	University of Bath	10	Research
University of Sussex	109	Research	Other Small Grants	3	Various
Manchester Metrpolitan University	101	Research		(4.0.0)	
Cambridge	81	Care	Prior year Grant returned	(100)	Research
Kings College	67	Care			
Sheffield Care Centre	67	Care	TOTAL	7,570	
The James Cook	(2)				

Uni Hosp (M'Boro)

Care

For the year ended 31 December 2022

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

The employment costs of all employees were:

	2022	2021
	£000	£000
Gross wages and salaries	6,829	5,999
Social security costs	708	579
Other pension costs	488	430
Medical insurance	39	36
	8,064	7,044

The total number of employees whose emoluments for the year (not including pension contributions) exceeded £70,000 relates to all of the seven members of the senior management team in position throughout 2022. These emoluments are identified as follows:

	2022	2021
£100,000 - £109,999	1	1
£90,000 - £99,999	2	-
£80,000 - £89,999	4	6
£70,000 - £79,999	-	-
£60,000 - £69,999	3	-

Employers pension contributions for the 7 higher paid employees above are £55,925 for the year ended 31 December 2022 (2021: £50,400).

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

	2022 £000	2021 £000
Gross wages and salaries	629	604
Benefits-in-kind	4	4
Pension costs	56	50
Social security costs	76	68
	765	726
Trustee remuneration and expenses	2022 £000	2021 £000
Reimbursement directly to trustees	5	1
Payment to third parties in respect of trustee expenses	6	5
	11	6
Number of trustees holding office during the year	19	17

For the year ended 31 December 2022

The charity trustees neither received nor waived any emoluments during the year (2021: £nil). Trustee expenses in the year include travel and subsistence expenses totalling £11,205 (2021: £6,096). These expenses were all incurred in the course of their duties and were reimbursed, or paid directly to third parties on their behalf as shown above. Trustee indemnity insurance is held at a cost of £1,573 (2021: £1,573).

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

#### Staff numbers

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

	2022	2021
	Headcount	Headcount
Care	82	69
Research	14	13
Campaigning and raising awareness	28	31
Volunteering	9	7
Raising funds	71	60
	204	180

Staff numbers above include an appropriate apportionment of support staff.

#### Pension costs

The Association operates defined contribution personal pension schemes for employees. The assets of the schemes are held separately from those of the Association in funds independently administered by Royal London. The amounts paid to the funds represent contributions from both the employer and employees. The employer's contributions in the year were £487,836 (2021: £430,361). There are no other ongoing obligations arising. Amounts outstanding at year end were £0 (2021: £0).

#### Taxation 10

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

The subsidiary company is liable for corporation tax on the profits retained. This was £nil in 2022.

For the year ended 31 December 2022

#### 11a Fixed assets

Motor vehicles £000	Computers, fixtures, fittings and equipment £000	Total tangible fixed assets £000	Total intangible fixed assets* £000
8	1,731	1,739	46
-	125	125	-
-	-	-	
8	1,856	1,864	46
8	1,149	1,157	46
-	263	263	-
_	-	-	
8	1,412	1,420	46
-	444	444	
-	581	581	-
	8 - - - 8 8	Motor vehicles £000  8 1,731 - 125  8 1,856  8 1,149 - 263  8 1,412	Motor vehicles £000         fixtures, fittings and equipment £000         tangible fixed assets £000           8         1,731         1,739           -         125         125           -         -         -           8         1,856         1,864           8         1,149         1,157           -         263         263           -         -         -           8         1,412         1,420

<sup>\*</sup> Intangible fixed assets comprises purchased software licences.

## 11b Fixed Assets - Investments (Long Term)

Group and Charity	2022 £000	2021 £000
Market value at 1 January 2022	-	-
Acquisitions at cost	5,000	-
Sale proceeds from disposals	-	-
Gain / (Loss) in year	-	-
Market value at 31 December 2022	5,000	
Close Brothers - Asset Portfolio	5,000	_
	5,000	

For the year ended 31 December 2022

#### Fixed asset investments

## Motor Neurone Disease (Sales) Limited

The Association owns a wholly owned subsidiary company, Motor Neurone Disease (Sales) Limited, which is registered in England and Wales (Company number: 01989172) at Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. This subsidiary operates mail order catalogues selling promotional clothing, gifts and cards and runs Challenge and other fundraising events. All taxable profits are donated to the Association each year under Gift Aid. Audited accounts are filed with the Registrar of Companies, and below is a summary of its trading results for the year ended 31 December 2022:

Motor Neurone Disease (Sales) Limited Income Statement	2022 £000	2021 £000
Turnover	420	144
Cost of sales	(324)	(122)
Gross profit	96	22
Administration costs	(21)	(20)
Profit / (Loss) before interest and tax	75	2
Net interest payable	(3)	(1)
Profit / (Loss) on ordinary activities before tax	72	1
Corporation tax	-	0
Profit / (Loss) for the financial year	72	1
The aggregate of the assets, liabilities and funds was:  Assets Liabilities	2022 £000 417 (257)	2021 £000 150 (61)
Funds (representing 2 ordinary shares of £1 each)	160	89
Profit gifted to charity in following year	(72)	(1)
Net funds after transfer of profit	88	88
The investment held by the Charity of £2 (2020: £2) represents shares in the subsidiary com. The parent charity's gross income and results for the year are as follows:	pany at cost.	
	2022 £000	2021 £000
Gross income	30,045	28,943
Surplus for the year	7,249	10,880

For the year ended 31 December 2022

#### 13 Stocks

		Group		Charity	
	2022 £000	2021 £000	2022 £000	2021 £000	
Purchased goods for resale	20	22	-	-	

## 14 Debtors

	Group		Charity	
	2022 £000	2021 £000	2022 £000	2021 £000
Loan to subsidiary company	-	-	50	50
Amounts due from subsidiary company	-	-	64	44
Legacies	8,143	6,349	8,678	6,349
Other debtors	337	590	454	631
Income tax reclaimable	578	774	578	774
Prepayments	511	187	511	187
	9,569	7,900	10,335	8,035

## 15 Current asset investments

The total of current asset investments £19,326,469 (2021: £17,237,543) is constituted by fixed term and other bank and building society deposits with maturity dates within 12 months.

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

	Group			Charity	
	2022 £000	2021 £000	2022 £000	2021 £000	
Accruals for grants payable	10,265	7,580	10,265	7,580	
Trade creditors	615	995	1,155	1,142	
Accruals and deferred income (note 16b)	898	766	968	766	
Payroll taxation and social security	280	216	280	216	
Provisions and other creditors (note 21)	493	237	330	209	
	12,551	9,794	12,998	9,913	

For the year ended 31 December 2022

## 16b Analysis of deferred income

	Group			Charity	
	2022 £000	2021 £000	2022 £000	2021 £000	
Deferred income at 1 January	28	1	28	1	
Released during the year	(28)	(1)	(28)	(1)	
Deferred during the year	195	28	195	28	
Deferred income at 31 December	195	28	195	28	

## Creditors: amounts falling due after one year

	Group			Charity	
	2022 £000	2021 £000	2022 £000	2021 £000	
Research & Care Centre Creditors	5,464	5,407	5,464	5,407	
	5,464	5,407	5,464	5,407	

## 18a Statement of funds

Group and Charity		Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 1 January 2022 £000	Income £000	Expenditure £000	Balance at 31 December 2022 £000
Unrestricted funds:								
General funds		8,477	11,154	(11,352)	8,279	18,401	(15,192)	11,488
Designated funds:  Care Centre grants  Ice Bucket Challenge funded projects:		891	2,337	(2,347)	881			881
Research		214	-	(213)	1	66	(67)	-
Care		115	-	(113)	2	21	(23)	-
Campaigning and raising awareness		55	-	-	55	(55)	-	-
Volunteering and new opportunities		20	-	(20)	-	-	-	-
Research & Strategic Investment		3,000	8,717	-	11,717	6,297	(2,748)	15,266
	note 18b	4,295	11,054	(2,693)	12,656	6,329	(2,838)	16,147
Total unrestricted funds		12,772	22,208	(14,045)	20,935	24,730	(18,030)	27,635

For the year ended 31 December 2022

## 18a Statement of funds (continued)

Group and Charity		Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 1 January 2022 £000	Income £000	Expenditure £000	Balance at 31 December 2022 £000
Restricted funds:								
Research		1,317	3,659	(3,548)	1,428	3,913	(2,435)	2,906
Care		(767)	2,723	(372)	1,584	1,207	(1,930)	861
Volunteering		-	-	-	-	-	-	-
Branches and Groups		1,810	345	(128)	2,027	180	(395)	1,812
Campaigning		_	8	(8)	-	15	(15)	
Total restricted funds		2,360	6,735	(4,056)	5,039	5,315	(4,775)	5,579
Total funds		15,132	28,943	(18,101)	25,974	30,045	(22,805)	33,214
Charity		Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 1 January 2022 £000	Income £000	Expenditure £000	Balance at 31 December 2022 £000
Unrestricted funds:								
General funds		8,350	11,155	(11,314)	8,191	18,329	(15,120)	11,400
Designated funds	note 18b	4,295	11,054	(2,693)	12,656	6,329	(2,838)	16,147
		12,645	22,209	(14,007)	20,847	24,658	(17,958)	27,547
Restricted funds		2,360	6,735	(4,056)	5,039	5,315	(4,775)	5,579
Total funds		15,005	28,944	(18,063)	25,886	29,973	(22,733)	33,126

## **Restricted Funds**

Restricted funds are utilised as follows:

Research for grant payments to be made enabling various research projects to continue

Care for equipment and care / support provided to people living with MND

Branches and Groups for care for people with MND within local areas

for raising awareness of MND across England, Wales and Northern Ireland Campaigning

For the year ended 31 December 2022

## 18b Designated funds

Designated funds represent:

	2022 £000	2021 £000
<ul> <li>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.</li> </ul>	881	881
ii) The trustees previously designated the IBC monies of £7.2m together with additional reserves and the small remaining balance at the end of 2021 was utilised in 2022.	-	58
iii) Trustees agreed to designate £3m of the exceptional income in 2020 to research and strategic investment projects which will run through to the end of 2023.  A further £9m of the 2021 surplus was also designated for the delivery of our new Promises.  The combined allocations of these designations are detailed below:		
Research - supporting Promise 1; clinical trials, access to treatments and translational research	4,570	6,750
Promises 2,3,4,5; supporting equity in provision of care, initiatives to deliver personalised care, policy and campaign work and an inclusive service provision	4,577	4,000
Strategic investments, including provision of access to multi-disciplinary care	519	967
iv) In 2022, the Board approved the designation of a further £5.6m of the 2022 surplus to support increased Research opportunities (increasing access to treatments, genetic testing		
and counselling and support for new Research aligned with the #United2EndMND coalition)	5,600	-
	16,147	12,656

## 19 Analysis of net assets between funds

#### 2022

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2022 are represented by:				
Fixed assets	-	-	444	444
Net current assets less long-term liabilities	5,579	16,147	11,044	32,770
Total net assets	5,579	16,147	11,488	33,214
Charity:	£000	£000	£000	£000
Fund balances at 31 December 2022 are represented by:				
Fixed assets	-	=	444	444
Net current assets less long-term liabilities	5,579	16,147	10,956	32,682
Total net assets	5,579	16,147	11,400	33,126

For the year ended 31 December 2022

## Analysis of net assets between funds (continued)

#### 2021

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2021 are represented by:				
Fixed assets	-	-	581	581
Net current assets less long-term liabilities	5,039	12,656	7,698	25,393
Total net assets	5,039	12,656	8,279	25,974
Charity:	£000	£000	£000	£000
Fund balances at 31 December 2021 are represented by:				
Fixed assets	-	-	581	581
Net current assets less long-term liabilities	5,039	12,656	7,610	25,305
Total net assets	5,039	12,656	8,191	25,886

## 20 Leasing commitments

## **Operating leases**

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

	2022 £000	2021 £000
Within one year	323	254
Between two to five years	840	752
Over five years	108	238
	1,271	1,244

The charge to the Statement of Financial Activities is £323,147 (2021: £254,399).

For the year ended 31 December 2022

## Provisions for liabilities and charges

	Leasehold dilapidations	Bad debts (incl Legacy)	Obsolete stock	Total
Charity	£000	£000	£000	£000
At 1 January 2022	99	86	-	185
Additions	-	-	-	-
Utilised	-	-	-	_
Balance at 31 December 2022	99	86	-	185
	Leasehold	Bad	Obsolete	
_	dilapidations	debts	stock	Total
Group	£000	£000	£000	£000
At 1 January 2022	99	86	-	185
Additions	-	-	-	-
Utilised	-	-		
Balance at 31 December 2022	99	86	-	185

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

For the year ended 31 December 2022

## 22. Consolidated Statement of Financial Activities (incorporating an income and expenditure account) For the year ending 31 December 2021

	Unrestricted Funds £000	Restricted Funds £000	Total Funds 2021 £000
Income and endowments from:			
Donations and legacies:			
Donations	12,817	6,735	19,552
Legacies	8,523		8,523
Charitable activities			
Other trading activities	743	-	743
Investments	69	-	69
Other	56	-	56
Total income	22,208	6,735	28,943
Expenditure on:			
Raising funds	4,037	-	4,037
Charitable activities:			
Care	6,545	372	6,917
Research	1,257	3,548	4,805
Campaigning and raising awareness	1,666	136	1,802
Volunteer development	502	_	502
Total expenditure	14,007	4,056	18,063
Net gain / (loss) on investments	-	-	-
Net income for the year	8,201	2,679	10,880
Transfers between funds	-		
Other recognised gains/ (losses):			
Gains/ (losses) on revaluation of fixed assets			-
Other gains/ (losses)	(38)		(38)
Net movement in funds	8,163	2,679	10,842
Reconciliation of funds:			
Total funds brought forward	12,772	2,360	15,132
Total funds carried forward	20,935	5,039	25,974

For the year ended 31 December 2022

## 23 Prior year figures

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

Total expenditure incurred is further analysed as follows:

	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2021 12 months £000
Care and care centres	3,251	2,625	1,041	6,917
Research	536	4,078	191	4,805
Campaigning and raising awareness	1,333	-	469	1,802
Volunteering	389	-	113	502
Costs of charitable activity	5,509	6,703	1,814	14,026
Raising funds	3,131	-	906	4,037
Total resources expended 2021 (12 months)	8,640	6,703	2,720	18,063

## 23b Support costs

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

	Care £000	Research £000	Campaigning awareness £000	Volunteering £000	Raising funds £000	Total 2021 12 months £000
Management	171	31	77	18	149	446
Governance	24	4	11	2	20	61
Finance	161	29	72	17	140	419
Information and communications technology	289	53	130	31	251	754
Facilities	254	46	114	27	221	662
Human resources	143	26	64	16	125	374
Conferences and events	1	1	1	1	-	4
	1,043	190	469	112	906	2,720

For the year ended 31 December 2022

## Prior year figures (continued)

## 23c Analysis of net assets between funds

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2021 are represented by:	2000	2000	2000	2000
Fixed assets	-	=	581	581
Net current assets less long-term liabilities	5,039	12,656	7,698	25,393
Total net assets	5,039	12,656	8,279	25,974
Charity:	£000	£000	£000	£000
Fund balances at 31 December 2021 are represented by:				
Fixed assets	-	-	581	581
Net current assets less long-term liabilities	5,039	12,656	7,610	25,305
Total net assets	5,039	12,656	8,192	25,886







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

Tel: 01604 250505 Email: enquiries@mndassociation.org

#### www.mndassociation.org

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