

# ANNUAL REPORT AND CONSOLIDATED FINANCIAL STATEMENTS

For the year ended 31 December 2021

# Message from the Chair

2021 was a pivotal year for the MND Association, a year which saw us start to emerge from the pandemic with fresh ideas, renewed focus and a bolder, more innovative approach to the work we do.

As always, our incredible community, made up of members, fundraisers, donors, supporters, campaigners and volunteers, has been right behind us, driving us forward and inspiring us to achieve even more on behalf of people living with MND and their families.

Thanks to their support we've raised awareness like never before and campaigned for real change.

As well as successfully calling for a change in the law when it comes to claiming benefits through the *Scrap 6 Months* campaign, the MND Association, people living with MND and our supporters were instrumental in the success of the *United To End MND* campaign which saw the Government pledge £50 million for targeted MND research over the next five years.

The extraordinary efforts of our supporters also led to 2021 becoming a record year for income, generating a significant surplus which has allowed us to bring forward projects in key areas including research, care and the development of cutting-edge technology to help improve quality of life for people affected by this devastating disease.

As we look ahead to the future, people living with MND and their families will remain firmly at the heart of everything we do.

We *will* beat MND together.



**Richard Coleman**

Chair, Board of Trustees





## BUCKINGHAM PALACE

The dedication and commitment of the whole MND community has continued to shine throughout this year as the Motor Neurone Disease Association takes the next important steps against this devastating disease.

Throughout 2021, the Association has continued to improve the care and support it offers people living with motor neurone disease and their families, while successfully campaigning for a change in the law when it comes to claiming benefits. As Royal Patron, I have also been heartened by the increased awareness of the disease, and the pledge regarding funding for future MND research, both of which give us all so much hope for the future.

In July, I was pleased to be able to support the Association virtually by joining its Showcase event, and to take the opportunity to congratulate and thank fundraisers and donors. In November, I was delighted to meet guests in person, when representatives of my Patronages came to St. James's Palace for a meeting of my Charities Forum, sharing lessons learned during the COVID-19 pandemic.

As we look to the future, we know there is still so much which needs to be done to support all those who are living with, and affected by, MND.

I encourage you to continue your support, in the hope that your involvement with the MND Association will help them to achieve our shared vision of a world free from MND. Thank you.

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

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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 2021, which have been prepared in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102), the Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) – (2nd Edition, effective 1 January 2019) and the Companies Act 2006.

## About MND

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

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

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

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

## i) Objectives and activities

### About us

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

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

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

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

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

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

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

## Public benefit

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

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

## ii) Achievements and performance in 2021

### Playing a leading role in the fight against MND

The MND Association continues to play a prominent role in the global fight against MND, by championing ground-breaking research and developing our role as a trusted leader and partner on the world stage.

The Association's consistent and targeted investment in MND research over many decades has contributed to the disease becoming one of the fastest growing areas of neurodegenerative disease research, attracting widespread interest from researchers and pharmaceutical companies. Our constant presence and influence have also prompted other key players within the medical research sector, including leading medical research charity LifeArc, to invest their own funding, providing a springboard for even greater progress.

As at 31 December 2021, the Association's research commitments were made up of 83 research grants at a collective value of £15.1 million. Despite the challenges we faced as a result of the pandemic, we funded the second highest number of new research projects in our history.

Thanks to the incredible support of our community during 2021, the Association was also able to set aside £5 million from the £10.9 million surplus to invest in translational research, helping to bridge the gap between discoveries made in laboratories and the testing of potential new drugs in patient trials.

This continued investment in research is beginning to open up new, potential approaches to treatment, particularly gene therapy strategies which aim to target specific inherited forms of MND. Clinical trials, treating people with MND with mutations in

certain genes, are progressing and should these strategies prove to be effective, may also have the potential to stop the disease manifesting in those who carry these genes.

The MND Association is proud of its role as a leading collaborator in MND research and in December, we brought 1,500 of the world's leading MND experts from 44 countries together for the 32nd International Symposium on ALS/MND - the biggest event of its kind in the world. Held online for a second year due to the pandemic, the four-day event showcased the latest developments and highlighted the progress being made in international research and clinical management.

Looking ahead, the Association will continue to harness the extraordinary momentum in MND research, working alongside our partners around the world and investing in world-class science which we believe will take us closer to the development of effective new treatments and ultimately, a cure for MND.

## Improving care and support

While the search for effective new treatments for MND gathers pace, the Association recognises that people living with MND and their families need access to care, support and information they can trust.

This year, we've built on lessons learnt during the pandemic to make it easier for people living with MND, and those closest to them, to access the support they need, when they need it.

We know that co-ordinated multidisciplinary care has a positive impact on life expectancy and quality of life for people living with MND and the Association is committed to making sure that everyone has access regardless of where they live. During 2021, our 22 care centres and networks across England, Wales and Northern Ireland supported 3,883 people living with MND. Where gaps in the network exist, we are working with our partners in local clinical commissioning groups in England, health boards in Wales and health and social care trusts in Northern Ireland to create 14 community specialist roles to help expand services. It is hoped that the first role will be established in June 2022 in Surrey, with others to follow in Swindon, Kent and Northamptonshire.

Ensuring health and social care professionals have the information they need to provide the very best care they can to people living with MND is a key priority. In 2021, we started to offer education events online, opening them up to many more professionals across England, Wales and Northern Ireland. In total, more than 1,500 professionals attended 25 events covering topics including hospice care, familial MND, models of respiratory care in the community and discussions about end of life. Six virtual masterclasses were also held with 187 professionals taking part and we also supported two care centre study days for the South Wales and South-East networks.

We continued to develop the support we offer to children, young people and families, recruiting a new project worker and extending the counselling service available through our partnership with leading children's charity, Barnardo's. During the year, 66 families took up the offer of counselling. We are currently in the process of creating a new volunteer workforce to help reach more children and young people and their families

and after covid delays we hope to deliver two family days in the latter half of 2022.

Between April 2021 and March 2022, we made more than 270 information advice and guidance support calls to families affected by MND, providing emotional support to both the person affected by MND and also directly to children, helping to liaise with schools, offering support when explaining MND to a child, providing information and signposting to external specialist support agencies.

We provided 76 memory and treasure boxes during the last year and are currently designing, in collaboration with students at the University of Lancashire, a new wellbeing and mindfulness box for teenagers that will be available soon.

Throughout the year, we awarded £1.1 million of support grants to 1,682 people living with MND. We distributed 182 Emergency Support Grants worth a total of £45,000 to support people living with MND struggling with additional living costs as a direct result of the pandemic. 160 children and young people affected by MND received 160 grants totalling £38,000, helping to pay for everything from horse-riding sessions to driving lessons.

In communities across England, Wales and Northern Ireland our network of 315 volunteer Association visitors offered one-to-one support to 1,415 people who are living with MND.

During 2021, we trained 80 new Association visitors who took part in virtual classes led by our Area Support Co-ordinators (ASCs). Each week, a different set of topics is covered, and material is provided for additional learning at home.

We launched our podcast, *MND Matters*, giving people living with MND the chance to listen to information and support at the click of a button. The monthly episodes, recorded in-house by a small team of staff and featuring people living with MND and their families, cover everything from conversations about continuing to work when you have been diagnosed with MND, to helpful updates on voice banking, support with bereavement and advances in research.

Across England, Wales and Northern Ireland our volunteers have helped to bring the MND community closer together, hosting support groups in-person and online, making it easier than ever to connect with, and get involved in, the Association and the work we do. Our network of 90 branches and groups have helped support people living with and affected by MND at a local level, providing a helping hand when it is needed most.

## Raising awareness, bringing about change

When it comes to describing the cruelty of MND and the devastating impact it has, we rely on people living with MND and their families to share their own very personal experiences, sometimes with audiences of millions.

Thanks to the overwhelming courage of people living with MND and their willingness to support our work, MND has continued to make the headlines in 2021, leading to coverage on primetime TV and countless column inches in the national press. The power of their words has also helped the MND Association make a difference, prompting decision-makers to sit up and take notice.

In 2021, the *Sunday Express* newspaper actively supported the *United To End MND* campaign, which was led by a coalition made up of people living with MND, leading MND researchers, the MND Association, MND Scotland and the My Name's Doddie Foundation. The campaign called upon the Government to invest £50 million into MND research which would be used to create the collaborative UK infrastructure to accelerate drug discovery, drug development and clinical trials. Every Sunday, for 20 weeks, the *Sunday Express* featured the stories of people living with, and affected by MND, which undoubtedly influenced the Government in making the decision to pledge their support.

Our patron, Kevin Sinfield OBE captured our hearts for a second year running at the end of 2021, when he ran the equivalent of four marathons in 24 hours as part of his epic *Extra Mile Challenge*. Kevin organised the challenge, which saw him run the 101 miles from Leicester to Leeds, to honour his best friend and former rugby league team-mate Rob Burrow MBE, who was diagnosed with MND in December 2019.

Alongside his own dedicated team, and with Association supporters following him every step of the way, Kevin raised more than £2.1 million - with half being donated to support the Association's work and the other half to support The Leeds Hospitals Charity.

Kevin and Rob's story of enduring friendship featured extensively on BBC Breakfast, with 2.3 million people tuning in to see Kevin cross the finishing line at Leeds Rhinos Headingley Stadium on the morning of 23 November.

As well as a substantial increase in donations, the coverage led to offers of help, encouraged new donors and funders to support us and prompted many fundraisers to take on challenges of their own, in some cases for the very first time.

We would like to thank Rob and his family, Kevin Sinfield and his wider team, Leeds Rhinos, Leicester Tigers and the many hundreds of people who were inspired to support the Extra Mile Challenge. We would also like to thank the Burrow Seven Racing Club, Pro Elite Sports, Arc Inspirations and many other individuals, schools and teams for their continued support.

We are also incredibly grateful to *BBC Breakfast* editor Richard Frediani, and his team, for their support on and off-screen and for continuing to follow Kevin and Rob's story.

## Using technology to improve quality of life

The MND Association is very proud of the partnerships it has with technology giants such as Rolls-Royce, Intel, Dell, Google and Toyota GB, and we continue to work alongside them to tackle some of the challenges people living with MND face.

In the future, we believe some of those challenges, particularly those involving speech and mobility, could be solved using technology. By harnessing the vast expertise of these global companies through our Next Generation Technology Think Tank, we are determined to help people with MND live independent lives to the fullest. One of the innovations which has come out of the Think Tank is an e-book, *I will always be me*, which banks the voices of people living with MND as they read it aloud in as little as 15 minutes.

We're also using technology to extend the range of support we can offer to people living with MND.

With 80% of people affected by MND experiencing some difficulty with their speech, the work we do to improve access to communication aids is critical. The Association loans equipment such as iPads, iPhones, Lightwriters and other devices and provides access to apps. In 2021, we loaned out 165 pieces of communication equipment and apps and 129 pieces of voice banking equipment.

Free training is also offered to professionals who are working with people living with MND.

## We're one community with one goal

Our Association is made up of thousands of different voices, from diverse backgrounds and communities right across England, Wales and Northern Ireland.

We have different skills and experiences and our contribution to the work of the Association is as unique as we are – but when we come together as one, we share a voice which is impossible to ignore.

In July, the MND Association launched a new membership strategy to reflect our growing movement and to encourage our members to share their skills and experience to help us fundraise, campaign and raise awareness like never before. As well as helping to spread the word about the Association and the support we provide, people living with MND and their families are being invited to get even closer to the work we do, collaborating with volunteers and staff to co-design important projects. We have involved people living with MND and those closest to them in helping to shape and prioritise our work. In particular, it is encouraging to see the level of involvement and outstanding success where we have collaborated with people living with MND in campaigning for increased government research funds.

During the year, we've embarked on a process of reviewing our services and those of our partners, to ensure that our work is inclusive for all people living with or affected by MND. It is critical that we continually reflect and improve our services so that no-one feels excluded or unable to get the support they need. This extends to reviews of elements of our work as diverse as research grants, to volunteer support to financial support.

## We would like to thank

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

## Remembering

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



we can to support those living with the disease and those closest to them.

### iii) Future plans and priorities

In 2021, the Association's five-year strategy came to an end, bringing with it a chance to assess our priorities and our goals for the future. We opened up important conversations with our community, in particular with people living with MND and their families and listened carefully to their priorities and the difference we need to make in the months and years to come.

Their guidance helped the Association to make five new Promises to the MND community – bold and ambitious Promises which will take us closer to the Association's vision of a world free from MND.

With the support of our community, we won't rest until:

- MND is treatable and ultimately curable
- Everyone gets the care they need when they need it
- Every day with MND counts
- You are heard
- No one faces MND alone.

Heightened awareness of MND led to a groundswell of support for the Association during the year, translating into a marked increase in donations. As a result, the MND Association ended 2021 with a significant surplus to invest in research and the services we offer to people living with and affected by MND.

We are determined to do everything we can to power the fight against MND and harness the extraordinary momentum we have seen in recent years. With that in mind, we plan to commit £9 million from the surplus into our core work. £5 million will support collaborative translational and clinical research programmes, on top of the £500,000 invested in 2021 and a further £1.5 million that is already budgeted in 2022. This is in addition to the Association's portfolio of research grants which totalled £15.1 million in 2021. These additional funds will be targeted to support drug discovery and development, speeding up the clinical trials process and making it easier for people living with MND to access telemedicine to help them get involved in research projects in their own homes.

We will invest more than £1.3 million from the £9 million surplus to review and improve our grants programme, develop a technology grants programme, develop carers' services in collaboration with partners, develop and test new models of community-based care and further develop the MND Connect Helpline. We will invest in volunteer training and recruitment and extend the reach of our services, making our services more inclusive and accessible to all.

To deliver our Promises, we will also be investing £500,000 from the surplus on fundraising innovation to build long term sustainable income and investing in vital digital and infrastructure systems to build resilience and ensure that the Association is able to operate effectively in a fast-moving world. This will help to ensure that we can deliver an effective, high quality and responsive service to people with MND.

To learn more about our commitment to the MND community and our priorities, or to get involved, visit [www.mndassociation.org/MNDPromises](http://www.mndassociation.org/MNDPromises)

### iv) Fundraising governance priorities

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

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

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

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

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

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

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

When we benefit from commercial companies raising funds on our behalf through the sale of products, we operate within a written agreement to ensure their activities are not harmful to the Association. Trustees regularly review the fundraising strategy and



are made aware of any significant new activities and/or contracts where values need to be carefully aligned.

We received 14 complaints about our fundraising activity in 2021 and all were promptly resolved without the need for escalation to the Fundraising Regulator. Complaints are taken very seriously and reviewed quarterly by the Board of Trustees. However, these 14 represent a tiny fraction of our outgoing fundraising communications. There is a complaints policy, which is available on our website, which forms the basis for the training of all fundraising staff.

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

## v) Financial review

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

## Financial performance

2021 was an exceptional year for fundraising at the Association with total income reaching £28.9 million for the 12-month period compared to £19.9 million in 2020. The increased focus on MND in the media and the high profile fundraising events that took place contributed to a record year. All areas of fundraising had a strong year, most notably legacy donations which accounted for almost 30% of the income received.

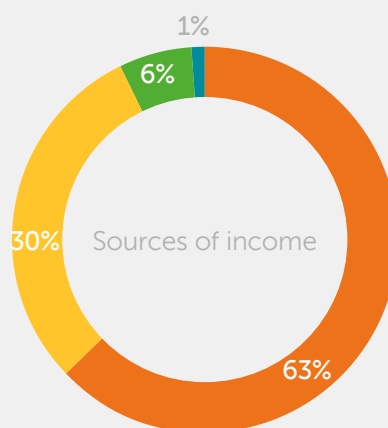
£18.2 million was raised and donated by our incredible supporters and a further £1.8 million was raised by our branches and groups. We are tremendously grateful for their commitment and continued support.

£8.5 million was donated in 2021 in the form of legacy gifts which continue to make such a huge difference to the work we do. We are enormously grateful to the people who choose to remember the work of the Association in their Wills.

£6.48 was raised for every pound spent directly on fundraising in 2021. When legacy income and costs are included, this rises to £9.16.

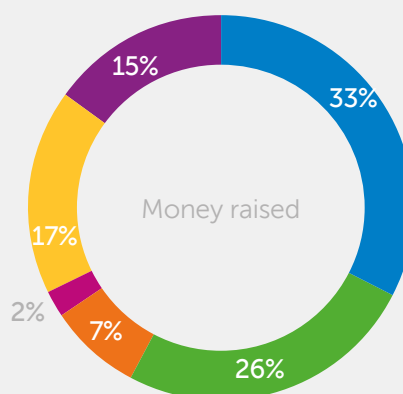
## Sources of income

	(£) million
Fundraising	£18.2
Legacies	£8.5
Branches and Groups	£1.8
Earned income	£0.4
<b>TOTAL INCOME FOR 2021</b>	<b>£28.9</b>



## How we spent the money raised

	(£) million
Care	£5.9
Research	£4.6
Campaigning	£1.4
Volunteer development	£0.4
Fundraising	£3.1
Operational Support Costs	£2.7
<hr/>	
<b>TOTAL COSTS FOR 2021</b>	<b>£18.1</b>



Expenditure returned to pre-pandemic levels (increased by £2.5 million on 2020) as restrictions were eased and major fundraising events and volunteering activities returned. Research expenditure also increased significantly on 2020 as facilities that were closed during the pandemic re-opened and opportunities for new studies arose. We maintained all our commitments to our care grants programme to ensure that people affected by MND continued to receive critical financial support.

The incredibly strong income performance led to a net surplus of £10.8 million. The Board of Trustees has agreed to designate £9 million of this surplus to enable us to do more, more quickly. More details can be found in the *Future Plans and Priorities* section on page 8.

Despite our extremely positive fundraising success over the last two years, we still need to raise funds to support our on-going care, research and campaigning work which will cost approximately £20 million a year.

## vi) Principal risks and uncertainties

### Risk management

The trustees acknowledge their responsibility for the Association's systems of internal control and risk management and recognise that such a system is designed to actively manage and minimise the risk of failure to achieve the Association's objectives. The Board delegates some appropriate financial powers to the Finance and Audit Committee as detailed in the Scheme of Delegation. The Association has a cautious risk appetite across all its principal risks. The trustees review the key risk indicators for each principal risk area on a regular basis through the delegated Committees of Finance and Audit, Governance, Care and Engagement. Trustees monitor that appropriate action is being taken where risk does not align with appetite.

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

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

## Reputational risk

Retaining the Association's reputation is paramount. Due to the diverse nature of our activities this risk relates to several areas including our extensive research programme (for example our policies on the use of animals and embryonic stem cells in research), the provision of care through our MND Care Centres and Networks, the support provided by our Association visitor network, and the extensive activities of our 2,400 volunteers across England, Wales and Northern Ireland. Controls and policies relating to all our activities focus on reputational impacts and these are monitored regularly for compliance.

## Financial risk

Whilst the Association has had a strong year in 2021, we remain very aware of the risk to future income as household incomes are impacted by significant increases in the costs of utilities, high inflation, increasing interest rates, and the economy potentially moving into a recession later in 2022. The impact on the Association could lead to reduced income generation at the same time as need for further financial support grows from our community. To mitigate this risk, the Association undertakes weekly income and core expenditure reporting so that we can identify, and react to, any financial pressures which we will manage tightly using our reserves.

While we remain cautious about the financial position in 2022, the robust performance in 2021 has significantly reduced our financial risk and means that the Association will begin the year in a much stronger position than anticipated. The strong financial position has enabled the auditors to confirm that the Association remains a going concern.

## External environment risk

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

## Compliance risk

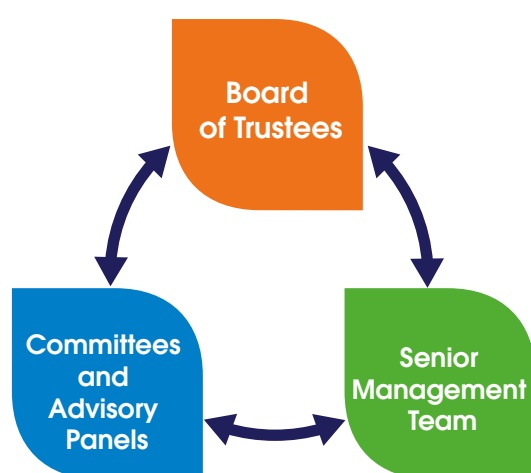
The Association must comply with a range of legal and regulatory requirements including charity law, data protection, fundraising standards, health and safety and safeguarding. To mitigate these risks the Association has robust and embedded processes and policies, which are complemented by regular and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

# Structure, Governance and Management

## Structure

The Association was originally formed on 6 October 1979 and was incorporated as a company limited by membership guarantee in 1986. The Association is governed by its *Articles of Association* and in the event of it being wound up, every member is liable for an amount not exceeding £1 to facilitate the payment of the debts and liabilities of the Association. At 31 December 2021, there were 10,984 members.

## Governance



Our governance structure is designed to ensure that:

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

## The Board of Trustees

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

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

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

## Committees of the Board

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

### Care Committee

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

### Engagement Committee

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

### Finance and Audit Committee

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



## Governance Committee

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

## Remuneration Committee

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

## Biomedical and Healthcare Research Advisory Panels

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

## Branches, groups and affiliates

At 31 December 2021, the Association had 90 branches and groups and two affiliates (based in Jersey and the Isle of Man). Each branch and group sign a charter annually called *Agreement for working together*, which sets out the parameters of the powers delegated to them by the Board. Branches and groups, whose financial results are included in these statements, are governed by the Board. The two affiliates are excluded from the consolidation as they are not part of the Association.

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

## Environmental impact

The Association initiates and monitors changes to process and practice that reduce its environmental impact. We moved to our new national office at Francis Crick House in January 2020 and this gave us an opportunity to adopt more sustainable practices. These included reducing in-house printing resources to encourage teams to work more digitally. The need for most staff to work from home has seen significant reductions in travel, printing and facilities' expenditure. We will learn from the new digital and homeworking approaches and ensure that we continue to incorporate these methods in our ways of working post-pandemic. Money saved through environmental efficiencies is diverted into achieving the charity's strategic objectives.

## Management

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

## Safeguarding

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

## Whistleblowing

We take any evidence of malpractice very seriously and support anyone who is raising genuinely held concerns. We reviewed these policies in detail in 2021 and they are backed up by mandatory staff and volunteer training.

## Grants

Grants are awarded for both research projects and care services:

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

**Care** – We provide grants to existing specialist MND Care Centres and Networks. At 31 December 2021 the Association was providing financial support to 22 such centres and networks. Performance is monitored annually for existing Care Centres, with a full grant renewal process every four years.

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

## Investment policy

Investments are held to cover reserves for the management of risk and for future investment opportunities. The investment objective is to provide resources to cover short term demands arising from sudden or unexpected events that could influence fundraising income. The trustees take a prudent approach to risk, holding the Association's investments in cash deposits, near cash and general recognised cash equivalents (including but not limited to Certificates of Deposit and other short-term investments). Counter party limits and acceptable credit ratings are set by the Finance and Audit Committee. Any investment donated to the Association will ordinarily be sold at the earliest opportunity, unless there is a specific request from the donor for the shares to be held as fixed asset investments. During the year, the low interest rate environment meant that returns on deposit investments remained low earning just £69,000 in 2021 versus £121,000 in 2020.

## Group reserves policy

The trustees have adopted a robust and flexible reserves policy to meet the changing needs of the charity. This states that the general reserve should be in the range of three to five months' general expenditure represented in cash and readily realisable investments, held centrally and within branches. This is a target range of between £5 million and £8.4 million. As at the year end, the unrestricted/undesignated reserves balance sat at £8.5 million. Trustees believe that this remains a prudent level given the continuing uncertainty associated with the future economic outlook which could have a detrimental impact on our ability to raise funds.

# Statement of Trustees' Responsibilities and Corporate Governance

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

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

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

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

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

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

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

This Trustees' Report, prepared in accordance with the Charities Act 2011 and the Companies Act 2006 was approved by the Board of Trustees on 28 May 2022 including in their capacity as company directors, the strategic report contained therein, and signed on its behalf by:



**Richard Coleman**

Chair, Board of Trustees

28 May 2022

# Organisational information and financial statements

## Board of Trustees

Chair: Richard Coleman

Chair-elect: Dr Usman Khan (*from May 2021*)

Vice Chair: Jan Warren

Honorary Treasurer:

Tim Kidd (*until July 2021*)

James Marshall (*from July 2021*)

Andy Cawdell

Elizabeth Ellis (*from July 2021*)

Alan Graham MBE (*until July 2021*)

Devia Gurjar (*until March 2022*)

Dr Usman Khan (*from May 2021*)

Tim Kidd (*until July 2021*)

Catherine Knights

James Marshall (*from March 2021*)

Debra Martin (*from July 2021*)

Dr Shaun McGee

Vicky Paeschel

Siobhán Rooney

Dr Nik Sharma

Dr Heather Smith

Katy Styles

## Senior management team

Sally Light, Chief Executive

Linda Allen, Director of Fundraising

Mark Chapman, Director of Finance

Dr Brian Dickie, Director of Research Development

Nick Goldup, Director of Care Improvement

Chris James, Director of External Affairs

Chris Wade, Director of Engagement

## Company secretary

Mark Chapman

## Registered office

Francis Crick House  
6 Summerhouse Road  
Northampton  
NN3 6BJ

## Professional advisers

### Statutory auditors

Haysmacintyre LLP  
10 Queen Street Place  
London  
EC4R 1AG

### Solicitors

Bates Wells  
2-6 Cannon Street  
London  
EC4M 6YH

### Bankers

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

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



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

## Opinion

We have audited the financial statements of Motor Neurone Disease Association for the year ended 31 December 2021 which comprise the Consolidated Statement of Financial Activities, The Group and Charity Balance Sheets, the Statement of Cash Flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 December 2021 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

## Basis for opinion

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

## Conclusions relating to going concern

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

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

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

## Other information

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

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

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

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

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

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

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

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

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

## Responsibilities of trustees for the financial statements

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

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

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

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

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

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

financial statements such as the Companies Act 2006, Charities Act 2011, Charity SORP and payroll taxes.

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

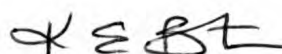
- inspecting correspondence with regulators and tax authorities;
- discussions with management including consideration of known or suspected instances of non-compliance with laws and regulation and fraud;
- evaluating management's controls designed to prevent and detect irregularities;
- identifying and testing journals, in particular journal entries posted with unusual descriptions or significant values; and
- challenging assumptions and judgements made by management in their critical accounting estimates.

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

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

## Use of our report

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



Kathryn Burton (Senior Statutory Auditor)

**21 June 2022**

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

# Consolidated Statement of Financial Activities

(incorporating an income and expenditure account)

For the year ended 31 December 2021

	Notes	Unrestricted funds £000	Restricted funds £000	Total Funds 2021 £000	Total funds 2020 £000
<b>Income and endowments from:</b>					
Donations and legacies:	1a				
Donations		12,817	6,735	<b>19,552</b>	12,708
Legacies		8,523		<b>8,523</b>	6,012
Charitable activities					
Other trading activities	1b	743	-	<b>743</b>	705
Investments		69	-	<b>69</b>	121
Other	1c	56	-	<b>56</b>	365
<b>Total income</b>		<b>22,208</b>	<b>6,735</b>	<b>28,943</b>	19,911
<b>Expenditure on:</b>					
Raising funds		4,037	-	<b>4,037</b>	3,686
Charitable activities:					
Care		6,545	372	<b>6,917</b>	6,867
Research		1,257	3,548	<b>4,805</b>	2,799
Campaigning and raising awareness		1,666	136	<b>1,802</b>	1,724
Volunteer development		502	-	<b>502</b>	507
<b>Total expenditure</b>	4	<b>14,007</b>	<b>4,056</b>	<b>18,063</b>	15,583
<b>Net income/ (expenditure)</b>	3	<b>8,201</b>	<b>2,679</b>	<b>10,880</b>	4,328
<b>Other recognised gains/ (losses):</b>					
Other gains/ (losses)		(38)		<b>(38)</b>	40
<b>Net movement in funds</b>		<b>8,163</b>	<b>2,679</b>	<b>10,842</b>	4,368
<b>Reconciliation of funds:</b>					
Total funds brought forward		12,772	2,360	<b>15,132</b>	10,764
<b>Total funds carried forward</b>	18a, 19	<b>20,935</b>	<b>5,039</b>	<b>25,974</b>	15,132

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

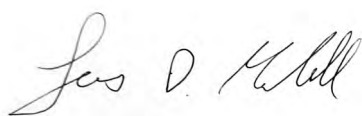
The movement on restricted funds is shown in note 18a.

# Balance Sheet

For the year ended 31 December 2021

		Group		Charity	
	Notes	2021 £000	2020 £000	2021 £000	2020 £000
<b>Fixed assets</b>					
Tangible assets	11	581	835	581	835
<b>Total Tangible Assets</b>		<b>581</b>	<b>835</b>	<b>581</b>	<b>835</b>
<b>Current assets</b>					
Stocks	13	22	31	-	-
Debtors	14	7,900	5,544	8,035	5,631
Investments	15	17,238	9,200	17,238	9,200
Cash at bank and in hand		15,434	12,619	15,352	12,447
		<b>40,594</b>	<b>27,394</b>	<b>40,625</b>	<b>27,278</b>
<b>Creditors: amounts falling due within one year</b>	16a	<b>9,794</b>	<b>9,993</b>	<b>9,913</b>	<b>10,004</b>
<b>Net current assets</b>		<b>30,800</b>	<b>17,401</b>	<b>30,712</b>	<b>17,274</b>
<b>Total assets less current liabilities</b>		<b>31,381</b>	<b>18,236</b>	<b>31,293</b>	<b>18,109</b>
<b>Creditors: amounts falling due after more than one year</b>	17	<b>5,407</b>	<b>3,104</b>	<b>5,407</b>	<b>3,104</b>
<b>Net assets</b>	19	<b>25,974</b>	<b>15,132</b>	<b>25,886</b>	<b>15,005</b>
<b>Accumulated funds</b>					
Restricted funds	18a	5,039	2,360	5,039	2,360
Designated funds	18a, 18b	12,656	4,295	12,656	4,295
Unrestricted funds:					
Unrestricted funds	18a	8,191	8,350	8,191	8,350
Funds retained in subsidiary	12a	88	127		
Retained Earnings					
		<b>25,974</b>	<b>15,132</b>	<b>25,886</b>	<b>15,005</b>

The financial statements on pages 19 to 43 were approved and authorised for issue by the Board of Trustees on 28 May 2022, and were signed on its behalf by:



**James Marshall**  
Treasurer



**Richard Coleman**  
Chair

The net movement in funds for the Association for the year ending 31 December 2021 was £10,842,000 (2020 : £4,368,000).

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



# Statement of Cash Flows

For the year ended 31 December 2021

	Notes	2021 £000	2020 £000
<b>Cash flows from operating activities:</b>			
Net income/ (expenditure) for the reporting year		10,842	4,368
<b>Adjustments for:</b>			
Depreciation and amortisation charges	11	326	345
Dividends and interest from investments		(69)	(121)
Gain on disposal of fixed assets	11	-	13
(Increase) / decrease in stock	13	9	(2)
(Increase) / decrease in debtors	14	(2,356)	(775)
Increase / (decrease) in creditors	16a,17	2,104	(1,424)
<b>Net cash generated from operating activities</b>		<b>10,856</b>	<b>2,404</b>
<b>Cash flows from investing activities:</b>			
Movement in cash held as investment			-
Dividends and interest from investments		69	121
Purchase of fixed assets	11	(72)	(473)
<b>Net cash used in investing activities</b>		<b>(3)</b>	<b>(352)</b>
<b>Increase in cash and cash equivalents in the reporting year</b>		<b>10,853</b>	<b>2,052</b>
<b>Cash and cash equivalents at the start of the year</b>		<b>21,819</b>	<b>19,767</b>
<b>Cash and cash equivalents at the end of the year</b>		<b>32,672</b>	<b>21,819</b>

## Analysis of cash and cash equivalents

Group	Balance 1 January 2020 £000	Cash flow changes £000	Balance 1 January 2021 £000	Cash flow changes £000	Balance 31 December 2021 £000
<b>Net cash</b>					
Short term deposits	9,365	(165)	9,200	8,038	17,238
Bank current accounts	10,394	2,219	12,613	2,818	15,431
Cash in hand	8	(2)	6	(3)	3
<b>Net funds</b>	<b>19,767</b>	<b>2,052</b>	<b>21,819</b>	<b>10,853</b>	<b>32,672</b>

# Statement of Accounting Policies

## Legal Status

The Association is a company limited by guarantee not having a share capital, incorporated in England and Wales (company number: 02007023) and a charity registered in England and Wales (charity number: 294354). The charity's registered office address is 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. The members undertake to contribute to the assets of the company in the event of it being wound up, either whilst members or within one year of the membership ceasing. The maximum contribution required from each member is £1. There were 10,984 members at 31 December 2021 (31 December 2020: 10,390).

## Principal accounting policies

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

### a) Basis of preparation

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

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

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

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

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

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

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

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

Despite the continuing pandemic, 2021 proved to be a very strong year for the charity with reserves increasing and the Association's financial position remaining strong. As such, the trustees consider there are no material uncertainties about the charity's ability to continue as a going concern. Trustees regularly review potential risks and make strategic changes as and when required. The review of the charity's financial position, reserves levels and future plans through to the end of December 2024 gives trustees confidence that the charity remains a going concern for the foreseeable future.

### d) Consolidated financial statements

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

In accordance with the exemption afforded by section 408 of the Companies Act 2006 a separate Statement of Financial Activities for Motor Neurone Disease Association has not been prepared. The surplus of the parent charity was £10,880,000 (2020: surplus £4,328,000).

### e) Income

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

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

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

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

# Statement of Accounting Policies (continued)

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

## f) Investment income

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

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

## g) Fund accounting

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

## h) Expenditure and irrecoverable VAT

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

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

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

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

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

## j) Operating leases

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

## k) Intangible fixed assets

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

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

Software licences	4 years
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## l) Tangible fixed assets

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

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

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

## m) Investments

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

# Statement of Accounting Policies (continued)

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

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

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

## **n) Financial instruments**

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

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

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

## **p) Debtors**

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

## **q) Stocks**

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

## **r) Creditors and provisions**

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

## **s) Long term liabilities**

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

## **t) Employee benefits**

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

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

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

## **u) Taxation**

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

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

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



# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## Income

### 1a Donations and legacies

	2021 £000	2020 £000
Individuals	7,306	3,682
Community and other fundraising	6,240	3,137
Appeals	2,076	1,914
Charitable foundations (see note 2)	1,170	1,896
Corporate donations	941	881
Tax recovered	1,819	1,198
	<b>19,552</b>	<b>12,708</b>
<b>Legacies</b>	<b>8,523</b>	<b>6,012</b>
	<b>28,075</b>	<b>18,720</b>

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

### 1b Other trading activities

	2021 £000	2020 £000
Charity-organised fundraising	418	446
Merchandise sales and advertising	39	37
Conferences and events	286	222
	<b>743</b>	<b>705</b>

### 1c Other

	2021 £000	2020 £000
Costs recovered from the International Alliance	18	11
HMRC Job Retention Grant	25	333
Other	13	21
	<b>56</b>	<b>365</b>

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 2 Grants receivable from Charitable foundations

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

	2021 £000		2021 £000
My Name's Doddie Foundation	200	The Basil Samuel Charitable Trust	8
The Betty Messenger Charitable Foundation	100	Rosybank Charitable Trust	7
Mark Armitage Charitable Trust	94	James Tudor Foundation	7
Constance Travis Charitable Trust	50	The Ofenheim Charitable Trust	7
Darby Rimmer MND Foundation	50	The Nick Smith Foundation	6
The Linbury Trust	50	Vodafone UK Foundation	5
Netherby Trust	40	The William & Mabel Morris Charitable Trust	5
Alan Davidson Foundation	38	B&Q Foundation	5
Heaton-Ellis Trust	31	Douglas Compton James Charitable Trust	5
Bruce Wake Charitable Trust	25	John James Bristol Foundation	5
The William Brake Foundation	25	M K Rose Charitable Trust	5
Ian Karten Charitable Trust	24	Pilkington Charities Fund	5
The Freshfield Foundation	24	Sir James Knott Trust	5
Malcolm Gunter Foundation	20	Sir James Reckitt Charity	5
Richard Mackay Charitable Trust	20	Sir Samuel Scott of Yews Trust	5
The Marie Helen Luen Charitable Trust	20	Stephen Hawking Foundation	5
Edith Murphy Foundation	15	The 29th May 1961 Charitable Trust	5
The Harris Family Charitable Trust	15	The Berni Charitable Trust	5
The Elizabeth and Prince Zaiger Trust	12	The Billmeir Charitable Trust	5
The Zochonis Charitable Trust	12	The Chalk Cliff Trust	5
Peacock Charitable Trust	11	The Christopher H R Reeves Charitable Trust	5
Medicash Foundation	10	The David Lister Charitable Trust	5
Fieldrose Charitable Trust	10	The Eveson Charitable Trust	5
Frank Brake Charitable Trust	10	The G C Gibson Charitable Trust	5
Margaret Giffen Charitable Trust	10	The Jones 1986 Charitable Trust	5
Payne-Gallwey Charitable Trust	10	The Kirby Laing Foundation	5
The Hornby Lonsdale Charitable Trust	10	The Oldhurst Trust	5
The Priory Foundation	10	The Simon Gibson Charitable Trust	5
Lloyds Bank Foundation for England & Wales	9		
Dere Street Barristers Charitable Trust	8	Anonymous	41
Annandale Charitable Trust	8		
The Orr Mackintosh Foundation	8	<b>TOTAL</b>	<b>1,170</b>

In 2020, grants receivable from Charitable foundations totalled £1,896,000

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 3 Net income for the year

This arises after charging:

	2021 £000	2020 £000
Auditors' remuneration:		
External audit	29	38
Other services	-	1
Operating lease rentals:		
Motor vehicles	302	221
Land and buildings	199	160
Other	14	14
Depreciation and amortisation of owned assets	326	345
Loss on disposal of fixed assets	-	(16)

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

Total expenditure incurred is further analysed as follows:

	Notes	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	Total 2021 £000	Total 2020 £000
Care and care centres		3,251	2,625	1,041	6,917	6,867
Research		536	4,078	191	4,805	2,799
Campaigning and raising awareness		1,333	-	469	1,802	1,724
Volunteering		389	-	113	502	507
<b>Costs of charitable activity</b>		5,509	6,703	1,814	14,026	11,897
Raising funds		3,131	-	906	4,037	3,686
<b>Total resources expended 2021</b>		<b>8,640</b>	<b>6,703</b>	<b>2,720</b>	<b>18,063</b>	<b>15,583</b>
Total resources expended 2020	23a	8,181	4,416	2,986		15,583

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 5 Support costs

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

	Care £000	Research £000	Campaigning and raising awareness £000	Volunteering £000	Raising funds £000	<b>Total 2021 £000</b>	Total 2020 £000
Management	171	31	77	18	149	<b>446</b>	486
Governance	24	4	11	2	20	<b>61</b>	123
Finance	161	29	72	17	140	<b>419</b>	487
Information and communications technology	289	53	130	31	251	<b>754</b>	725
Facilities	254	46	114	27	221	<b>662</b>	847
Human resources	143	26	64	16	125	<b>374</b>	238
Conferences and events	1	1	1	1	-	<b>4</b>	80
	1,043	190	469	112	906	<b>2,720</b>	2,986

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

## 6 Grants payable

Grants were awarded during the year as follows:

	Note	<b>2021 £000</b>	2020 £000
Grants to institutions	4	<b>4,989</b>	3,003
Grants to individuals		<b>1,714</b>	1,413
		<b>6,703</b>	4,416

Grants made to, and for, individuals affected by motor neurone disease are for expenses such as respite care, building adaptations and equipment rental. These grants benefited 2,479 individuals throughout the Association's network across England, Wales and Northern Ireland.

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 6 Grants payable (continued)

	2021 £000	2020 £000
Balance at start of year	9,947	11,915
Awarded in year	6,703	4,416
Paid in year	(3,663)	(6,384)
Balance at end of year	12,987	9,947
Falling due within one year (note 16a)	7,580	6,843
Falling due after more than one year (note 17)	5,407	3,104
	12,987	9,947

### Commitments

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

Group and Charity	2021 £000	2020 £000
Payable within one year	1	214
Payable in years two to five	881	911
	882	1,125



# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 6 Grants payable (continued)

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

	2021 £000	
Kings College London	1,080	Research & Care
LifeArc	800	Research
University College London	758	Research
University of Sheffield	283	Research
University of Aberdeen	248	Research
University of Sussex	223	Research & Care
University of Nottingham	215	Research
Trinity College Dublin	156	Research
Plymouth Primary Care Trust (S.West)	108	Care
University of Newcastle	94	Research
S Wales Care Network (Cardiff)	92	Care
The Register Renewal - Oxford	85	Research
Southampton Care Centre	83	Care
The James Cook Uni Hosp(M'Boro)	77	Care
Norfolk/Norwich Care Centre	70	Care
Leeds Care Centre	68	Care
Cambridge Care Centre	62	Care
Barts Care Centre	55	Care
Small Grants	51	Research
Bristol Care Centre	51	Care
University of East Anglia	51	Research
Newcastle General Hospital	48	Care
Preston Care Centre	46	Care
Nottingham University Hospital	43	Care
National Hospital for Neurology & Neurosurgery	31	Care
Manchester Care Centre	30	Care
Walton Centre for Neurology & Neurodurgery	30	Research
Sheffield Care Centre	24	Care
Liverpool Care Centre	23	Care
Manchester Metropolitan University	3	Research
University of Edinburgh	1	Care
	<b>4,989</b>	

In 2020, grants payable totalling £3,003,000 were made

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

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

The employment costs of all employees were:

	2021 £000	2020 £000
Gross wages and salaries	5,999	6,024
Social security costs	579	564
Other pension costs	430	411
Medical insurance	36	37
	<b>7,044</b>	<b>7,036</b>

The total number of employees whose emoluments for the year (not including pension contributions) exceeded £60,000 relates to all of the seven members of the senior management team across 2021. These emoluments are identified as follows:

	2021	2020
£100,000 - £109,999	1	1
£90,000 - £99,999	-	-
£80,000 - £89,999	6	3
£70,000 - £79,999	-	3
£60,000 - £69,999	-	-

Employers pension contributions for the higher paid employees above are £50,400 for the year ended 31 December 2021 (2020: £49,469).

The trustees devolved the day-to-day running of the Association to the 7 members of the senior management team, who served in the year, as identified on pages 30 and 31 of these accounts. As such, this body is identified as the key management personnel of the Association and included above are the following payments specifically to this group:

	2021 £000	2020 £000
Gross wages and salaries	604	592
Benefits-in-kind	4	4
Pension costs	50	49
Social security costs	68	66
	<b>726</b>	<b>711</b>

	2021 £000	2020 £000
<b>Trustee remuneration and expenses</b>		
Reimbursement directly to trustees	1	3
Payment to third parties in respect of trustee expenses	5	3
	<b>6</b>	<b>6</b>
<b>Number of trustees holding office during the year</b>	<b>17</b>	<b>15</b>

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

The charity trustees neither received nor waived any emoluments during the year (2020: £nil). Trustee expenses in the year include travel and subsistence expenses totalling £6,096 (2020: £5,578). These expenses were all incurred in the course of their duties and were reimbursed, or paid directly to third parties on their behalf as shown above. Trustee indemnity insurance is held at a cost of £1,573 (2020: £1,573).

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

## 8 Staff numbers

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

	2021 Headcount	2020 Headcount
Care	69	66
Research	13	13
Campaigning and raising awareness	31	32
Volunteering	7	8
Raising funds	60	59
	<b>180</b>	<b>178</b>

Staff numbers above include an appropriate apportionment of support staff.

## 9 Pension costs

The Association operates defined contribution personal pension schemes for employees. The assets of the schemes are held separately from those of the Association in funds independently administered by Standard Life. The amounts paid to the funds represent contributions from both the employer and employees. The employer's contributions in the year were £430,361 (2020: £411,500). There are no other ongoing obligations arising. Amounts outstanding at year end were £0 (2020: £0).

## 10 Taxation

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

The subsidiary company is liable for corporation tax on the profits retained. This was £nil in 2021.

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 11 Fixed assets

Group and Charity	Motor vehicles £000	Computers, fixtures, fittings and equipment £000	Total tangible fixed assets £000	Total intangible fixed assets* £000
<b>Cost</b>				
At 1 January 2021	8	1,659	1,667	46
Additions	-	72	72	-
Disposals	-	-	-	-
<b>At 31 December 2021</b>	<b>8</b>	<b>1,731</b>	<b>1,739</b>	<b>46</b>
<b>Depreciation and amortisation</b>				
At 1 January 2021	8	824	832	46
Charged in the year	-	326	326	-
Eliminated on disposal	-	-	-	-
<b>At 31 December 2021</b>	<b>8</b>	<b>1,150</b>	<b>1,158</b>	<b>46</b>
<b>Net book value</b>				
<b>At 31 December 2021</b>	<b>-</b>	<b>581</b>	<b>581</b>	<b>-</b>
At 31 December 2020	-	835	835	-

\* Intangible fixed assets comprises purchased software licences.

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 12 Fixed asset investments

### Motor Neurone Disease (Sales) Limited

The Association owns a wholly owned subsidiary company, Motor Neurone Disease (Sales) Limited, which is registered in England and Wales (Company number: 01989172) at Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ. This subsidiary operates mail order catalogues selling promotional clothing, gifts and cards and runs Challenge and other fundraising events. All taxable profits are donated to the Association each year under Gift Aid. Audited accounts are filed with the Registrar of Companies, and below is a summary of its trading results for the year ended 31 December 2021:

<b>Motor Neurone Disease (Sales) Limited</b>	<b>2021</b>	<b>2020</b>
<b>Income Statement</b>	<b>£000</b>	<b>£000</b>
Turnover	<b>144</b>	252
Cost of sales	<b>(122)</b>	(168)
Gross profit	<b>22</b>	84
Administration costs	<b>(20)</b>	(43)
Profit / (Loss) before interest and tax	<b>2</b>	41
Net interest payable	<b>(1)</b>	(1)
Profit / (Loss) on ordinary activities before tax	<b>1</b>	40
Corporation tax	<b>0</b>	0
<b>Profit / (Loss) for the financial year</b>	<b>1</b>	40

The aggregate of the assets, liabilities and funds was:

	<b>2021</b>	<b>2020</b>
	<b>£000</b>	<b>£000</b>
Assets	<b>150</b>	271
Liabilities	<b>(61)</b>	(144)
Funds (representing 2 ordinary shares of £1 each)	<b>89</b>	127

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

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

	<b>2021</b>	<b>2020</b>
	<b>£000</b>	<b>£000</b>
Gross income	<b>28,943</b>	19,911
Surplus for the year	<b>10,880</b>	4,328



# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 13 Stocks

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Purchased goods for resale	22	31	-	-

## 14 Debtors

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Loan to subsidiary company	-	-	50	51
Amounts due from subsidiary company	-	-	44	46
Legacies	6,349	4,680	6,349	4,680
Other debtors	590	270	631	267
Income tax reclaimable	774	269	774	269
Prepayments	187	325	187	318
	7,900	5,544	8,035	5,631

## 15 Current asset investments

The total of current asset investments £17,237,543 (2020: £9,200,169) is constituted by fixed term and other bank and building society deposits with maturity dates within 12 months plus other investments which will be converted to cash with 12 months of the Balance Sheet date.

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

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Accruals for grants payable	7,580	6,843	7,580	6,843
Trade creditors	995	1,022	1,142	1,022
Accruals and deferred income (note 16b)	766	1,969	766	1,966
Payroll taxation and social security	216	27	216	27
Provisions and other creditors (note 21)	237	132	209	146
	9,794	9,993	9,913	10,004

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 16b Analysis of deferred income

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Deferred income at 1 January	1	1	1	1
Released during the year	(1)	(1)	(1)	(1)
Deferred during the year	28	1	28	1
Deferred income at 31 December	28	1	28	1

## 17 Creditors: amounts falling due after one year

	Group		Charity	
	2021 £000	2020 £000	2021 £000	2020 £000
Research and Care Centre Creditors	5,407	3,104	5,407	3,104
	5,407	3,104	5,407	3,104

## 18a Statement of funds

Group and Charity	Balance at 1 January 2020			Balance at 1 January 2021			Balance at 31 December 2021
	£000	Income £000	Expenditure £000	£000	Income £000	Expenditure £000	
<b>Unrestricted funds:</b>							
General funds	6,944	10,361	(8,828)	8,477	11,154	(11,352)	8,279
Designated funds:							
Care Centre grants	1,302	1,821	(2,232)	891	2,337	(2,347)	881
Ice Bucket Challenge funded projects:							
Research	214	-	-	214	-	(213)	1
Care	115	-	-	115	-	(113)	2
Campaigning and raising awareness	55	-	-	55	-	-	55
Volunteering and new opportunities	60	-	(40)	20	-	(20)	0
Research & Strategic Investment		3,000		3,000	8,717		11,717
note 18b	1,746	4,821	(2,272)	4,295	11,054	(2,693)	12,656
<b>Total unrestricted funds</b>	<b>8,690</b>	<b>15,182</b>	<b>(11,100)</b>	<b>12,772</b>	<b>22,208</b>	<b>(14,045)</b>	<b>20,935</b>

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 18a Statement of funds (continued)

Group and Charity	Balance at 1 January 2020 £000	Income £000	Expenditure £000	Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 31 December 2021 £000
<b>Restricted funds:</b>							
Research	1,340	2,537	(2,560)	1,317	3,659	(3,548)	1,428
Care	(958)	1,527	(1,336)	(767)	2,723	(372)	1,584
Volunteering	14	-	(14)	(0)	-	-	(0)
Branches and Groups	1,658	694	(542)	1,810	345	(128)	2,027
Campaigning	20	11	(31)	(0)	8	(8)	0
Total restricted funds	2,074	4,769	(4,483)	2,360	6,735	(4,056)	5,039
<b>Total funds</b>	<b>10,764</b>	<b>19,951</b>	<b>(15,583)</b>	<b>15,132</b>	<b>28,943</b>	<b>(18,101)</b>	<b>25,974</b>

Charity		Balance at 1 January 2020 £000	Income £000	Expenditure £000	Balance at 1 January 2021 £000	Income £000	Expenditure £000	Balance at 31 December 2021 £000
Unrestricted funds:								
General funds		6,857	10,321	(8,828)	8,350	11,155	(11,314)	8,191
Designated funds	note 18b	1,746	4,821	(2,272)	4,295	11,054	(2,693)	12,656
		8,603	15,142	(11,100)	12,645	22,209	(14,007)	20,847
Restricted funds		2,074	4,769	(4,483)	2,360	6,735	(4,056)	5,039
<b>Total funds</b>		<b>10,677</b>	<b>19,911</b>	<b>(15,583)</b>	<b>15,005</b>	<b>28,944</b>	<b>(18,063)</b>	<b>25,886</b>

### Restricted Funds

Restricted funds are utilised as follows:

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

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 18b Designated funds

Designated funds represent:

	2021 £000	2020 £000
i) the amounts committed by the Association in respect of grants payable for the MND Care Centre Network not reflected in the Consolidated Statement of Financial Activities. Care Centre commitments run for up to 4 years and so the funds designated for these are required to meet future commitments on agreed contracts extending to 2024..	881	891
ii) the trustees previously also designated the IBC monies of £7.2m together with additional reserves for the following specific activities:		
Research projects	1	214
Care	2	115
Campaigning and raising awareness	55	55
Engagement of volunteers and to fund emerging new opportunities	0	20
These funds are expected to be fully utilised by the end of 2021.		
iii) Trustees agreed to designate £3m of the exceptional income in 2020 to research and strategic investment projects which will run through to the end of 2023. A further £9m of the 2021 surplus was also designated for the delivery of our new Promises.		
Board approved reallocation of reserves - 2020	2,717	3,000
Board approved reallocation of reserves - 2021	9,000	
	<b>12,656</b>	<b>4,295</b>

## 19 Analysis of net assets between funds

### 2021

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

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

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 19 Analysis of net assets between funds (continued)

### 2020

Group:	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	835
Net current assets less long-term liabilities	2,360	4,295	7,642	14,297
Total net assets	2,360	4,295	8,477	15,132

Charity:	£000	£000	£000	£000
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	835
Net current assets less long-term liabilities	2,360	4,295	7,515	14,170
Total net assets	2,360	4,295	8,350	15,005

## 20 Leasing commitments

### Operating leases

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

	2021 £000	2020 £000
Within one year	254	245
Between two to five years	752	587
Over five years	238	-
	1,244	832

The charge to the Statement of Financial Activities is £245,399 (2020: £395,000)



# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 21 Provisions for liabilities and charges

<b>Charity</b>	Leasehold dilapidations £000	Bad debts (incl Legacy) £000	Obsolete stock £000	<b>Total £000</b>
At 1 January 2021	99	72	-	<b>171</b>
Additions	-	84	-	<b>84</b>
Utilised	-	(70)	-	<b>(70)</b>
Balance at 31 December 2021	99	86	-	<b>185</b>

<b>Group</b>	Leasehold dilapidations £000	Bad debts £000	Obsolete stock £000	<b>Total £000</b>
At 1 January 2021	99	72	27	<b>198</b>
Additions	-	84	-	<b>84</b>
Utilised	-	(70)	(27)	<b>(97)</b>
Balance at 31 December 2021	99	86	-	<b>185</b>

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

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 22. Consolidated Statement of Financial Activities (incorporating an income and expenditure account) For the year ending 31 December 2020

	Unrestricted Funds £000	Restricted Funds £000	Total Funds 2020 £000
Income and endowments from:			
<b>Donations and legacies:</b>			
Donations	8,095	4,613	<b>12,708</b>
Legacies	5,856	156	<b>6,012</b>
Charitable activities			
Other trading activities	705	-	<b>705</b>
Investments	121	-	<b>121</b>
Other	365	-	<b>365</b>
Total income	15,142	4,769	<b>19,911</b>
Expenditure on:			
<b>Raising funds</b>	3,686	-	<b>3,686</b>
<b>Charitable activities:</b>			
Care	4,989	1,878	<b>6,867</b>
Research	239	2,560	<b>2,799</b>
Campaigning and raising awareness	1,692	32	<b>1,724</b>
Volunteer development	494	13	<b>507</b>
Total expenditure	11,100	4,483	<b>15,583</b>
Net gain / (loss) on investments	-	-	-
Net income for the year	4,042	286	<b>4,328</b>
<b>Transfers between funds</b>	-	-	-
<b>Other recognised gains/ (losses) :</b>			
Gains/ (losses) on revaluation of fixed assets	-	-	-
Other gains/ (losses)	40	-	<b>40</b>
<b>Net movement in funds</b>	4,082	286	<b>4,368</b>
Reconciliation of funds:			
Total funds brought forward	8,690	2,074	<b>10,764</b>
Total funds carried forward	12,772	2,360	<b>15,132</b>

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 23 Prior year figures

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

Total expenditure incurred is further analysed as follows:

	Activities undertaken directly £000	Grant funding of activities (note 6) £000	Support costs (note 5) £000	<b>Total 2020 12 months £000</b>
Care and care centres	3,270	2,504	1,093	<b>6,867</b>
Research	653	1,912	234	<b>2,799</b>
Campaigning and raising awareness	1,177	-	547	<b>1,724</b>
Volunteering	351	-	156	<b>507</b>
<b>Costs of charitable activity</b>	<b>5,451</b>	<b>4,416</b>	<b>2,030</b>	<b>11,897</b>
Raising funds	2,730	-	956	<b>3,686</b>
<b>Total resources expended 2020</b>	<b>8,181</b>	<b>4,416</b>	<b>2,986</b>	<b>15,583</b>

### 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	<b>Total 2020 12 months £000</b>
Management	179	36	88	23	160	<b>486</b>
Governance	46	9	23	5	40	<b>123</b>
Finance	180	36	88	23	160	<b>487</b>
Information and communications technology	268	53	132	34	238	<b>725</b>
Facilities	312	63	153	40	279	<b>847</b>
Human resources	88	17	43	11	79	<b>238</b>
Conferences and events	20	20	20	20	-	<b>80</b>
	<b>1,093</b>	<b>234</b>	<b>547</b>	<b>156</b>	<b>956</b>	<b>2,986</b>

# Notes to the Consolidated Financial Statements

For the year ended 31 December 2021

## 23 Prior year figures (continued)

### 23c Analysis of net assets between funds

	Restricted funds £000	Designated funds £000	General funds £000	Total funds £000
<b>Group:</b>				
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	<b>835</b>
Net current assets less long-term liabilities	2,360	4,295	7,642	<b>14,298</b>
Total net assets	2,360	4,295	8,477	<b>15,132</b>

	£000	£000	£000	£000
<b>Charity:</b>				
Fund balances at 31 December 2020 are represented by:				
Fixed assets	-	-	835	<b>835</b>
Net current assets less long-term liabilities	2,360	4,295	7,515	<b>14,170</b>
Total net assets	2,360	4,295	8,350	<b>15,005</b>

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Royal Patron: HRH The Princess Royal

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