

Muscular Dystrophy UK

Fighting muscle-wasting conditions



Annual Report and Financial Statements Year ended 31 March 2022

www.musculardystrophyuk.org

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Report of the Board of Trustees 2021/22

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What Muscular Dystrophy UK does – core purpose and activities

Our vision

A world with effective treatments and cures for all muscle-wasting conditions and no limits in life for individuals and families affected.

Our mission

We are the UK charity for individuals and families living with muscle-wasting conditions.

- We support research to drive the development of effective treatments and cures.
- We ensure access to specialist NHS care and support.
- We provide services and promote opportunities to enable individuals and their families to live as independently as possible.

We know we can beat muscle-wasting conditions more quickly if we work together. We are uniting skills, knowledge and resources in the UK and working with others around the world so we can improve the quality of life for those affected, and bring treatments and cures closer to reality.

Our values

- **We care:** we care about everyone affected by muscle-wasting conditions.
- **We are inclusive:** we are working to ensure there is support and treatment for everyone living with muscle-wasting conditions in the UK.
- **We are collaborative:** we work in partnership across the UK, and internationally, to maximise our impact.
- **We are focused on results:** everything we do is designed to improve the quality of life for individuals and families; we won't stop until treatments and cures are found for all muscle-wasting conditions.
- **We are determined:** we have been leading the fight against muscle-wasting conditions for 60 years and are unwavering in our commitment to unite resources and achieve our vision.

Objects of Muscular Dystrophy UK for the Public Benefit

The Charity is established

- to promote research into muscular dystrophy and allied neuromuscular conditions
- to promote the provision of care and treatment and other relief to those affected by muscular dystrophy and allied neuromuscular conditions
- to assist those who care for persons affected by muscular dystrophy and allied neuromuscular conditions
- to provide education and training to persons affected by muscular dystrophy and allied neuromuscular conditions
- to raise the awareness of the public on any matter relating to the Charity's objects.

Public Benefit

The charity Trustees consider that they have complied with their duty in section 17 of the Charities Act 2011 to have due regard to Public Benefit guidance published by the Charity Commission and that the benefits that the charity provides are not unreasonably restricted.

The work of Muscular Dystrophy UK

Muscular Dystrophy UK (MDUK) works to improve the lives of more than 110,000 people living with a muscular dystrophy and associated condition today. We believe this as passionately now as we did when we were over 60 years ago years ago. It drives everything we do.

It is this vision that unites us all – from the researchers we support to the health professionals that we train; from the people we help through our information and advocacy services to our supporters who inform, guide and campaign with us to make change happen.

We:

- fund pioneering research for better treatments that will improve people's lives today and transform those of future generations
- drive change so that people can access treatments faster and the best NHS care and support
- ensure that we are here for all people and their families affected by a muscle-wasting condition whether awaiting a diagnosis, recently diagnosed or living with a condition.

Over the years, the charity has made important contributions in funding research and developing clinical support, which have led to vital progress such as an early and accurate diagnosis, access to steroid treatments, spinal surgery and respiratory support, which, with improved care, enhance quality of life and life expectancy. Additionally, in 2021/22 we worked on access to seven different treatments for people living with muscle wasting conditions in the UK.

With advances in technology, there are now opportunities to achieve a great deal more through identifying and developing promising research, helping to get clinical trials underway and developing a critical mass of scientists and clinicians working together to tackle the challenge of muscle-wasting conditions.

Muscle-wasting conditions are a group of rare and very rare conditions. Compared with the more common acute conditions, they do not receive the same priority in research funding or investment in clinical care.

Achievements and performance against objectives for 2021/22

Overview

Performance Indicators	Progress during the year
To support research with the goal of effective treatments and cures being identified for all conditions	We funded eight innovative projects and a Four-Year PhD studentship as part of our SMA PhD Partnership with Spinal Muscular Atrophy UK (SMA UK). We launched our 2022 grant call and awarded £1.3m in new and research grants.
To ensure access to specialist NHS care from a multidisciplinary team	We successfully secured NHS funding for two new neuromuscular specialist posts, supported neuromuscular clinical networks and provided training to more than 1,600 health and care professionals through online training modules. 40 specialist neuromuscular care advisors attended our in-person conference
To provide services and promote opportunities to enable each affected individual to live as independent a life as they wish	We responded to more than 2,000 phone and email requests for support from people affected by muscle-wasting conditions; an 8 percent increase on non-Coronavirus queries compared to the year before. More than 86,000 people visited our website's care and support areas, an almost 4 percent increase on the total 2020/21 figure. 9,354 people used our online forum to share experiences and support each other – over three times more than last year.
Income generation	<p>We ended the year bringing in a net income including legacies of nearly £4.3M. We saw a return to a sell-out portfolio of live events that were produced to comply with COVID-19 safety regulations. We concluded the £1.2M appeal for the MDUK Oxford Neuromuscular Centre and Trust fundraising brought in over £1M gross for the first time. Individual Giving continued to see loyalty from supporters. Regional Development saw the positive impact of the roll out of new strategy, with supporters across the country taking on activities and corporates choosing us as their charity of the year.</p> <p>Previous investment in legacy income came to fruition with a near doubling of our legacies from £874k in 2020/21 to £1.65M 2021/22.</p>

Improving lives today and transforming those of the future: accelerating research to develop effective treatments and cures.

MDUK works to improve the lives of people living with a neuromuscular condition. High-quality research plays a key role in our ambition, helping us to better understand these conditions and maximise treatment improvements.

Our three-year research strategy, 'Transforming lives through research', provides the guiding force for our research support. We have continued to support high-quality research that deepens our understanding of neuromuscular conditions and to support studies into ultra-rare conditions. We have the journey to encourage new researchers to join the field.

To help manage the long-term financial impact of the pandemic, we limited the scope of the call for our grant round in 2021/22 and asked researchers for proposals of up to 12 months' duration. Despite working to a different timetable from previous years with the applications arriving in early June and final decisions being made in the winter, we have funded eight innovative projects. These grants cover a range of conditions, namely collagen VI-related disorders, Duchenne muscular dystrophy, facioscapulohumeral muscular dystrophy (FSHD), myotonic dystrophy and congenital myotonic dystrophy. In addition to the project grants, we were delighted to continue our partnership with Spinal Muscular Atrophy UK (SMAUK) to support one four-year PhD studentship in spinal muscular atrophy (SMA) research. Following a series of no-cost extensions

to facilitate different working patterns and furlough during the pandemic, several of our pre-existing grants reached their natural end during 2021/22 and, at the end of the year, the charity was funding 31 projects in the UK and through international partnerships.

MDUK remains an executive member of the European Neuromuscular Centre (ENMC). The ENMC is a network of neuromuscular research charities from across Europe that bring experts together to tackle challenges in the field of neuromuscular research. The ENMC supported development work of workshops by introducing pre-meetings via Zoom and hosting some workshops either remotely or in a hybrid model. As in previous years, many of these workshops included UK clinicians, researchers and patient representatives. This could not have happened without MDUK's support.

Despite reduced capacity within the research team, we have continued to ensure that patients and families can find out about new studies, treatments and clinical trials through the 'MDUK Research Line'.

Driving change for access to specialist care and support

2021/22 saw MDUK secure national attention on the impact of the COVID-19 pandemic on people living with muscle-wasting conditions and the services they use through the publication of our series of 'Shining a Light' reports. Our central UK-wide report was followed by three reports specific to Northern Ireland, Scotland and Wales; all four reports made recommendations for overcoming the challenges people face when seeking to access neuromuscular specialist care and support - recommendations that guided much of our work in this area throughout the year and that were used in our responses to major health policy consultations such as the UK Rare Disease Framework.

We continued in our role as a member of the National Institute of Health and Care Excellence (NICE) Managed Access Oversight Group (MAOG) for Duchenne muscular dystrophy treatment, Translarna, which has been available in England (mirrored in Wales and Northern Ireland) through a Managed Access Agreement (MAA) since we first successfully secured access in 2016. During 2021/22 we helped to ensure that the Duchenne community was informed of the extension of the MAA from July 2021 to January 2023 and began our engagement with the new NICE appraisal of the treatment, leading to a joint-submission with Action Duchenne to the first stage of the process and hosting a virtual discussion between NICE and affected families.

MDUK played a key role in securing access to the spinal muscular atrophy (SMA) treatment risdiplam through engagement with both NICE and the Scottish Medicines Consortium (SMC). We worked in partnership with SMA UK as we engaged in the NICE appraisal process to help ensure the treatment became available through an MAA event after publication of a first draft of guidance by NICE that did not recommend the treatment for use on the NHS in England, with MDUK becoming

a member of the MAOG. In Scotland we worked with SMA UK to gather the views of the SMA community and represented the patient voice through our joint submission to the SMC. MDUK's Director of Research & Innovation and the Chair of our Scottish Council then gave evidence together to the Patient and Clinical Engagement (PACE) meeting, which helped to secure access to the treatment in Scotland.

We engaged in the final stages of NICE's appraisal of SMA treatment, Zolgensma and welcomed its recommendation for use by the NHS in England, which followed a positive SMC recommendation the previous year. We continued to monitor the roll-out of access to a third SMA treatment, Spinraza, through our role on its MAOG and communicated news to the SMA community of an extension to the treatment's eligibility criteria. We worked in partnership with SMA UK, individuals and families to address specific issues around access in some local areas – particularly affecting adults.

Having played a prominent role in the NICE appraisal of mexiletine for myotonia in adults with non-dystrophic myotonic disorders in 2020/21, we warmly welcomed

publication of NICE's Final Appraisal Document in 2021/22 recommending the use of the treatment by the NHS. MDUK also engaged in the early stages of the NICE appraisal process for Pompe disease treatment cipaglucosidase alfa with miglustat and we continue to await developments around the appraisal of a second Pompe disease treatment, avalglucosidase alfa. As 2021/22 came to an end we began engaging in the NICE appraisal processes for efgartigimod for treating generalised myasthenia gravis and ravulizumab for treating refractory antibody positive generalised myasthenia gravis.

Our work around access to treatments also encompassed activity around securing newborn screening for SMA and we further developed our work as joint secretariat of the UK SMA Newborn Screening Alliance. The Alliance is led by Professor Laurent Servais, Professor of Paediatric Neuromuscular Diseases at the MDUK Oxford Neuromuscular Centre.

We aim to ensure that people with any type of neuromuscular condition receive the best possible care and support, from the point of diagnosis and throughout their lives. This involves many different professional roles to identify and meet people's needs. Over the past year, we have secured NHS funding for two new specialist neuromuscular roles; an additional nurse and physiotherapist. We completed specific work on the standards of care for adults with Duchenne muscular dystrophy, which were published in the Journal of Neuromuscular Diseases and launched on World Duchenne Awareness Day. We

formed a working group of adults living with Duchenne muscular dystrophy and leading clinicians to convert the standards of care into patient friendly resources, which will be launched in 2022/23.

During 2021/22 we delivered many well-attended virtual meetings for our regional and national neuromuscular networks and over 1600 healthcare professionals accessed our suite of online training modules. We also held our neuromuscular care advisor conference in December 2021 which was attended by over 40 care advisors and provided them with a forum to discuss lessons learnt during the pandemic and new ways of working.

MDUK's audit of neuromuscular services and resulting Centres of Excellence awards are important tools in our work to identify best practice and drive up service standards. This work had been delayed as a result of the COVID-19 pandemic, but in 2021/22 we were able to successfully recruit the sub-committee of our Services Development Committee that will steer this work in 2022/23.

We continue to provide support for the cross-party groups on muscular dystrophy in the Houses of Parliament, Scottish Parliament, Welsh Parliament and Northern Ireland Assembly, ensuring that issues affecting people with muscle-wasting conditions receive political attention across the UK. In 2021/22 we delivered a number of virtual meetings across these groups, including the launches of the four 'Shining a Light' reports.

Living well with muscle-wasting conditions: improving quality of life by enabling independent living

Being diagnosed with a muscle-wasting condition means adjusting to a new and unexpected reality. We believe that it is vital that people have easy access to the information and support they need throughout their experience of their condition. That is why we provide personal, free, expert information resources and confidential support. We cover every topic from the latest research and money worries to physical symptoms and emotional well-being.

Our helpline team continues to provide practical advice and support and listen to people's concerns. In 2021/22 the three topics that people most contacted us about were welfare information requests; access to our care plans and alert cards; and housing and adaptation queries. In total we responded to 2,078 phone and email requests for support from people with muscle-wasting conditions. The volume of queries we supported relating to Coronavirus fell from 236 in 2020/21 to just 36 in 2021/22, meaning that we saw an 8 percent increase in non-Coronavirus queries.

More than 86,000 people visited our website's care and support areas. This is a growth of 3.7 percent on 2020/21, despite the fact that in that year 40,000 people turned to us for information and advice specific to COVID-19. In addition, 9,354 people used our online forum to share experiences and support each other during 2021/22 – over three times more than last year. Our new website went live in mid-July 2021 and delivered a considerable improvement to people's engagement with it; our bounce rate* reduced by 26% percent as visitors had more meaningful interactions with our website and successfully found other relevant information on it.

Our advocacy service supports people who may be struggling to get the care and services to which they are entitled. We help by providing advice or intervening on their behalf. In 2021/22 we supported 274 people through this service; a 10 percent increase on 2020/21.

As well as supporting people to access financial support, we provide grants to help people living with muscle-wasting conditions meet the costs of powered mobility equipment through our grant-giving arm, the Joseph Patrick Trust (JPT). In 2021/22 we provided 24 grants through the programme and began planning how to increase this number in 2022/23.

We continued to bring our community together through our virtual Muscle Group sessions and our online seminar series 'Muscles Matter 2021'. The programme of 20 seminars covered a range of specific muscle-wasting conditions and a number of more general topics relating to living well with a muscle-wasting condition. We received 1,152 bookings for the live virtual sessions, the recordings of which were viewed 8,113 views across YouTube and IGTV.

During 2021/22 our Moving Up programme supported 10 young disabled people through work experience placements, paid internships and employability support. Participants are supported to develop plans to help aid their long term development and achieve their goals. In addition, they are taught how to best maximise their chances at landing a suitable role, whilst making sure that they are looking after their mental health. They are also informed of their legal rights in regards to disability employment law, so that they are aware of what they are entitled to and eligible for, either at interview stage, or when they have gained employment. Of the 10

*A high bounce rate means that a visitor's overall session duration is short; they visit a page on your site and leave. A low bounce rate means that visitors are spending time on a page and clicking on available links.

participants, nine have successfully found work, or have gone into the next stage of their education.

Coronavirus continues to be a significant concern to our community. We continued to work as part of the Shielding and High Risk Coalition, meeting regularly with the Vaccines Minister to ensure that people with muscle-wasting conditions were appropriately prioritised for access to vaccines and had accurate information about the programme roll-out. We continued to access Government briefings so that we could relay the latest information to our community and so that we could raise concerns when necessary about issues such as the lack of clarity around access to Coronavirus treatments.

Changing Places toilets

MDUK is proud to co-chair the Changing Places Consortium, which is the home of the Changing Places toilets campaign in the UK. The campaign seeks to ensure that people who need them, including many people affected by muscle-wasting conditions, are able to use highly accessible toilet and changing facilities in public places, and promotes their use.

Our Changing Places toilets work during 2021/22 has been largely driven by our work connected to the Government programmes that we support delivery of. We continued to administer a £2m grant programme in partnership with the Department for Transport (DfT) to ensure there is increased provision of Changing Places toilets in motorway service areas across England.

This project has been impacted by the COVID-19 pandemic with installations being delayed by lockdowns and a temporary hold put on capital projects across the Motorway Service Area network. However, we continue to work with the partners and rollout has now re-commenced with a programme completion deadline of 30 June 2023. We agreed a new partnership with the DfT

to increase provision of these facilities across other areas of the transport network and are currently in discussions with Network Rail, following our insight work highlighting the need for more Changing Places toilets on the rail network.

We launched a new partnership with the Department of Levelling Up, Housing and Communities (DLUHC) to provide insight to help shape a scheme for the distribution of £30m of government funding to install Changing Places toilets in existing buildings in England, and to provide advice and support to Local Authorities in receipt of this funding from 2021/22. We were delighted to end 2021/22 with the announcement that £23.5m of the funding has been allocated across 191 Local Authorities and will see up to 513 new Changing Places toilets installed in public places and tourist attractions across England. This will vastly improve accessibility for those who need Changing Places toilets. A second round of funding applications for the balance of the £30m fund totalling £6.5m has now also been approved for 2022/23 that will prioritise Local Authorities that did not apply during the first round of funding or where provision is poor.

Thanks to funding from True Colours Trust, we have been able to update the Changing Places toilets website. Phase one saw the creation of a new look with improved functionality. Further developments will include improvements to the Changing Places toilet map and registration process, which will benefit users and venues alike.

We have also added two new social media channels to our communications stream; LinkedIn, which is useful for professional connections with suppliers, venues and stakeholders; and Instagram, which broadens our reach in the community of those who use Changing Places toilets. Both channels will allow us to explore new communications ideas and ensure we continue to build a strong Changing Places toilets community.

Scotland

MDUK works in each of the four countries of the UK. We are required to provide a report on our activities in Scotland by the Office of the Scottish Charity Regulator.

In 2021/22, we continued our support of research in Scotland. We supported two on-going research grants at the University of St Andrews and the University of Edinburgh. In addition, we awarded a new four-year PhD Studentship in partnership with Spinal Atrophy UK to Dr Lyndsay Murray of the University of Edinburgh.

We responded to 213 requests for support in Scotland; 57 of these were advocacy cases. We continued to work closely with the Scottish Muscle Network. We launched a new support group for young adults living with a muscle-wasting condition in Scotland. We continued to focus our influencing work in Scotland around our role as secretariat of the Cross Party Group on Muscular Dystrophy in the Scottish Parliament. This centred around access to treatments and on key issues affecting people living with a muscle-wasting condition. As part of this, we produced a Manifesto for Muscles to ensure that candidates in the 2021 Scottish Parliament elections were briefed on the issues relevant to people with muscle-wasting conditions.

In January 2022, we launched our Scotland specific version of the 'Shining a Light' report, putting forward key recommendations to improve neuromuscular services in the country. We discussed our findings at a Scottish Cross Party Group meeting and with our Scotland Muscle Group and the report publication secured strong media coverage. We used the report's findings and recommendations to feed into the Scottish Cross Party Group on Mental Health's review into mental

health inequalities and wrote to Scottish health ministers on the urgent need to improve mental health provision for people with a muscle-wasting condition in Scotland; this has led to dialogue with the neurological conditions' clinical priorities team within the Scottish Government.

In February the Scottish Medicines Consortium (SMC) announced that the SMA treatment risdiplam would be available in Scotland to everyone with SMA Types 1 to 3 or who have between 1 to 4 copies through the ultra-orphan pathway. MDUK played a significant role in securing this outcome, working closely with SMA UK, appearing in the Patient and Clinical Expert meeting which was a key part of the process.

Our Scottish Council supported and advised us throughout the year and we held four virtual meetings.

We continue to work with PAMIS in Scotland as Co-Chairs of the Changing Places Consortium to improve access to specialist facilities.

Our Regional Development team has continued with their one-to-one relationship building of supporters in the community but this is now done primarily in a digital rather than a physical way. This is undoubtedly set to continue as the team find that in many instances, this virtual form of supporter and volunteer engagement is easier and for some communications is a better use of resources than physical face to face fundraising, with less time spent on the road and more time to work with our supporters.

Our six Scottish Family Funds raised over £10,000 with Georgie's Genes raising an incredible £2,500 taking on the Seven Hills of Edinburgh challenge.

Sadly, due to COVID-19 restrictions in early 2022 we took the decision to postpone our annual Question of Support event. However, plans for 2023 are already underway.

In February 2022, Natalie Flemming and her partner Sean, from Wishaw, were chosen to take part in a 'win your wedding' competition through Go Radio, and in the course of two weeks the couple raised £12,000 for MDUK from hosting bake sales and raffles.

Despite the ongoing restrictions, we have raised a fantastic £110,000 this year across Scotland.

Due to pandemic restrictions we had to postpone some skydives, but the schedule of challenge activities in Scotland is now back on track and we have restarted the campaign to recruit skydivers for Summer 2022.

We have identified that outdoor events are starting to grow in popularity in Scotland and have concentrated our efforts on recruiting people to take part in the Edinburgh Marathon, kiltwalk and other events with over 21 people signed up so far.

Plans for 2022/23

The charity sector is estimating a loss of over £12bn from the impact of COVID-19, with both the business and household purse affected. At the same time, the Consumer Prices Index (CPI) rose by 9.0% in the 12 months to April 2022, and is anticipated to continue to rise, increases in electricity, gas and other fuels, and owner occupiers' housing costs and transport costs are adding to the continued financial challenges forecast for the sector and our community from the cost-of-living crisis.

The COVID-19 pandemic enabled us to see what priorities our community had during this period; during which we saw an increase in people contacting the helpline for guidance and support, including care plans/alert cards. Our marketing strategy insight work has enabled us to clarify and start addressing gaps in our reach, whilst early work on our new strategy helped us to focus on four clearly-defined audiences.

We have made internal structural changes and shared our priorities. Understandably our external voice initially focussed on what had happened, what was changing, what we were focusing on and how. As we progress in 2022/23, we need to continue to have a strong core, whilst adapting to the most pressing needs of our community. Continuing to build the community of volunteers and partnerships will be essential to our ability to grow our reach and impact.

Our 2021 'Shining a Light' report has shown how the pandemic has exacerbated the already poor level of local specialist care and support services to individuals and families.

The findings of the epidemiology study presented in 2022 deduced that the number of people living with muscular dystrophies and associated conditions in the UK exceeds 110,000; this is a significant increase of 40,000 from the 2010 study. The vast majority of people have no access to any treatments for their conditions. People are living longer today, because of a better understanding about their conditions and, therefore, better specialist care and opportunities to live well for longer continue to be essential.

The pandemic has enabled us to drive our collaborative spirit further with charities in the neuromuscular sector in the UK as we delivered guidance at pace, this collaboration continues to grow with a focus on access to treatments.

Akin to many sectors, the impact of the pandemic has been felt at MDUK; recruitment, retention, staff wellbeing and EDI (Equality, Diversity and Inclusion) are priorities to maintaining the positive culture and mentality that enables us to work as a high performing team to continue to support our community's needs.

In 2018, when we agreed our three-year strategy, Making Every Day Count 2019-2022, we said that the important progress already achieved over 60 years was heartening, but there was still so much more to do. Our commitment to finding treatments and ultimately cures through research, and to drive improvements in care and quality of life, remains as strong today as ever.

Alongside our core mission, we committed ourselves to work for change in four key areas that people with muscle-wasting conditions and their families told us were

particularly important to them:

- fast track to treatments
- mental health advocacy
- advances in technology
- sport, leisure and exercise.

We focussed on why this work mattered, what we would be investing in, and our objectives for:

- transforming lives through research
- driving change
- living well with muscle-wasting conditions.

In 2022/23, we will:

Accelerate Research

The theme of innovation and partnership underpins all that we do and enables research to be given every chance to succeed.

MDUK will:

- Continue to invest money to deliver high-quality research to understand the underlying causes of muscle-wasting conditions, always making sure our investment has maximum impact. In 2022/23 our grant round is open to proposals covering all conditions and for up to three years' duration for project grants.
- Encourage scientists with new ideas and technologies to come into this area of research. In 2021/22 we saw that this activity pays off because we funded researchers never-before supported by MDUK. We continue to encourage new ideas and collaborations in the field.
- Continue to drive innovation and influence our partners and others to do the same. We hope to continue our partnership with Healx to deliver treatment for FSHD using AI technology. Additionally, we will work in partnership with LifeArc to support a

£1m call for translational research into congenital muscular dystrophies.

- Due to the pandemic, many non-COVID-19 related clinical trials have been stalled. By maintaining our investment in the MDUK Oxford Neuromuscular Centre and clinical trial coordinators in Newcastle and London, we have been able to support access to clinical trials.
- Harness the power of genetics for example through our support of fundamental research grants, such as the recent grant to Professor Jennifer Morgan at University College London, who is investigating whether collagen VI genes are important for the proper function of muscle stem cells.
- Continue to facilitate drug development by providing crucial information, through natural history case studies on how a condition progresses with time and how it affects people through our ongoing support of the world's largest natural history study in Duchenne muscular dystrophy known as the NorthStar programme. In addition, we will launch a call for support of a natural history study for nemaline myopathy during 2022/23.
- Increase our understanding of the disease mechanism through our continued support of research projects funded through our annual grant rounds.
- Improving the quality of life by developing evidence-based interventions that improve the quality of life of people affected by a muscle-wasting condition.

Driving Change for Access to Specialist Care and Support and Improving Quality of Life by Enabling Independent Living

MDUK is here for all people and their families affected by a muscle-wasting condition, no matter where you are on your journey. Together we are making change happen, through our

Care, Campaigns and Support work, both nationally and locally, and galvanising those who are passionate about driving change for people living with a muscle wasting condition to join us.

MDUK will:

- Fast track access to treatments, by engaging in the scheduled NICE appraisal processes for the Duchenne muscular dystrophy treatment Translarna and for the Pompe disease treatments avalglucosidase Alfa and cipaglucosidase alfa (with miglustat) and others as they become scheduled throughout the year.
- We will monitor the ongoing roll-out of the spinal muscular atrophy treatments risdiplam and Spinraza and represent the SMA community through our formal roles on the two National Institute of Health and Care Excellence (NICE) Managed Access Oversight Groups for the treatments. We will also monitor the roll-out of a third SMA treatment, zolgensma, and will seek early access to all three treatments through our role as joint-secretariat of the SMA Newborn Screening Alliance.
- We will continue to track the development of potential new treatments across all conditions we cover through horizon scanning and dialogue with a range of stakeholders including NICE, the Scottish Medicines Consortium (SMC), the Medicines and Healthcare products Regulatory Agency (MHRA) and individual pharmaceutical and biotechnology companies.
- Our work will continue to support professionals so that better trained and supported staff will provide improved care and ensure that more people affected by muscle-wasting conditions receive the support they need. We will seek to both grow and develop the NHS neuromuscular specialist workforce through our engagement in both national and regional professional networks; our provision of professional development resources; and the continuation of our unique professional conferences for health professionals engaged in the support of people affected by muscle-wasting conditions.
- This activity and our work to improve access to NHS specialist support will centre on the return of MDUK's audit of NHS neuromuscular services across the UK. The audit process will be used to identify the challenges faced by neuromuscular services as they seek to provide comprehensive multi-disciplinary care and support to people living with muscle-wasting conditions. It will also allow us to work in partnership with services to address these challenges ahead of the awarding of MDUK Centre of Excellence status in 2023/24.
- We will continue to seek to improve NHS psychology services for people living with muscle-wasting conditions and will strengthen and build partnerships to further develop our mental health matters activity. Our work on standards of care for adults living with Duchenne muscular dystrophy will continue.
- We will influence policy and commissioning decisions around the provision of specialist neuromuscular services across the UK, using the recommendations from our suite of 'Shining a Light' reports and engaging in key processes such as the development and implementation of Rare Disease Framework action plans and the introduction of the Integrated Care System model in England.

- We will support independent living by helping people to live well with their condition by providing information, practical advice, advocacy and support on the phone, online, through specialist information and advocacy roles in the devolved nations, through our local Muscle Groups and through connected people to our Peer Support volunteers. We will continue to deliver our virtual Muscles Matters series while beginning to bring our community back together with face-to-face events. We will help people access essential mobility equipment through the JPT programme.
- We are changing communities by supporting those who want to take action to change the communities they live in; we will complete delivery of our Moving Up project, supporting young disabled people to gain access to employment; and we will continue to co-chair the Changing Places Consortium with PAMIS in Scotland.
- We continue to work to remove the barriers that people face to access sport and leisure activities, so they can enjoy the activities that they love and that help them live healthier and more independent lives; in 22/23 we will complete the distribution of over £2m in partnership with the Department for Transport to provide access to motorway service station and key transport hub Changing Places toilets in England, as well as continuing to support the delivery of the £30m Department for Levelling Up, Housing and Communities project to increase the provision of Changing Places toilets in existing buildings via Local Authorities.

Fundraising

MDUK will:

- Deliver a £5.7m gross budget; £4.4m in active fundraising and £1.3m in legacy, which will result in a net figure of £3.9m. Across the board the team have built on the successes they've seen during 21/22 moving from a period of consolidation to ambitious but realistic targets.
- Review the fundraising portfolio to ensure we have the right activities for our audiences to engage and support wherever they are in their relationship with MDUK, maximising potential and spreading risk, making events COVID-secure where possible and being agile in response to the changing fundraising landscape because of the ongoing effects of the pandemic, the impact of the cost of living crisis and the Russian invasion of Ukraine.
- Maximise the return on investment through effective deployment of our resources and continued monitoring and improvement where possible of return on investment.
- Ensure that fundraising successfully raises awareness of the charity's work and is integrated into our charity communications activities.
- Monitor, evaluate and develop our unrestricted fundraising policy to be integral to our fundraising strategy.

Fundraising statement

Our supporters are key to our advancements in the fight to beat muscle-wasting conditions, and to observe and promote a consistently high standard of fundraising, we will regularly monitor our practices to identify any necessary training and set policy priorities for our fundraising. We will ensure a culture of honesty, integrity and respect with the public, as well as transparency of process to our donors about our cause or the way their donation will be used.

We also recognise how important it is to manage the data of our supporters compliantly, and with care and integrity. Our statement of fundraising best practice, which underlies MDUK's commitment to the following personal information practices, is:

- to deliver best practice rather than solely compliance
- to adhere to the guidelines of the Data Protection Act 2018 and GDPR
- to never seek to sell supporter data
- to always inform individuals if we are conducting research that impinges on their privacy, to apply the principle of data minimisation and only capture in our research the minimum amount of personal data required
- to enable our audiences to choose which communications they receive and how.

These actions enable us to protect vulnerable people and all other members of the public from any behaviour that could be deemed:

- an unreasonable intrusion into a person's privacy
- unreasonably persistent
- placing undue pressure on a person to give.

We know we can beat muscle-wasting conditions more quickly and reach more people with these conditions, by working together.

We offer many different opportunities for our fundraisers and donors to engage with us to enable MDUK to fulfil our charitable objectives.

These include: special and challenge events; corporate partnerships; trusts and foundations; regional and community fundraising activity including Family Funds, Fundraising Groups, Branches and events; individual giving, which includes regular giving, major gifts, appeals, raffles and a weekly lottery, membership scheme, Christmas cards and online shop sales; Legacy and In-Memory programmes.

We conduct our Payroll giving, our gaming programme, legacy administration, the shop fulfilment, print- and mailing-houses for external mailings, and the majority of our regional and national challenge events through commercial participation agreements. We monitor our third-party providers and operate due diligence checks to ensure best practice as well as carry out internal analysis to ensure the work delivered by the agencies provides best value to the charity, its supporters and users.

We are paid-up members of the Fundraising Regulator and subscribe to the Fundraising Codes of Practice. We have ensured staff remain up-to-date in all areas of fundraising governance and training through mandatory online training as well as seminars and events by relevant providers.

The number of complaints received in 2021/22 was a total of eight, which derived from the following: Nought from 15,484 mailings about our raffles to warm supporters; Nought from 335 HQ Challenge Eventers, Nought from six special events (2,348 guests); six complaints from 3,033 participants in response to our Town & Gown challenge events; one from 377 volunteer fundraising events; one from 44,254 pieces of direct mail sent out. We learn from the complaints received, investigating them to see what improvements can be put in place for future activity.

Financial review and policies

The total income for 2021/22 was £6,669k (2021: £5,544k). The increase in total income demonstrates a recovery from the pandemic in the previous financial year. Income from donations, gifts, grants and fundraising activities totalled £4,464k (2021: £3,051k). Legacies income for 2021/22 was £1,648k (2021: £874k). Investment income was £151k (2021: £158k). Other income amounted to £284k (2021: £157k). In addition, £604k (2021: £1,304k) was received in Government Grants, including £301k (2021: £null) of UK Government COVID-19 Medical Research Charity Support Fund Grant and £273k (2021: £799k) Changing Places Project grants from the Ministry of Housing, Communities and Local Government.

Expenditure on charitable activities was in respect of medical research, access to specialist NHS care and support, and provision of information, support, and opportunities to enable independent living. The total charitable expenditure has increased compared to the previous year to £3,781k (2021: £2,371k), because of the charity returning to pre-COVID-19 operational levels.

Medical research in the search for effective treatments and eventual cures for muscle-wasting conditions comprised 51 percent (2021: 28 percent) of the total expenditure on charitable activities. Access to specialist NHS care and support comprised 25 percent (2021: 53 percent), and provision of information, support and opportunities to enable independent living comprised 24 percent (2021: 19 percent) of our charitable activity.

The charity ended 2021/22 with a net surplus of £1,107k (2021: £2,681). The largest contribution to the surplus was the 9 percent (£526k) higher than forecasted income due to some grants for future work received before the year end. This included a £300k grant from the Garfield Weston Foundation for a 2-year project starting April 2022. The reduction in expenditure by 4 percent (£264k) against the reforecast representing mainly phasing of some grants payable to the next financial year. An unrestricted surplus of £409k (2021: £2,537) for the year will continue to allow the charity to recover from the COVID-19 pandemic and other challenges such as growing inflation and price increases over the coming years. The restricted surplus of £698k (2021: £144k) was mainly from a grant from the Garfield Weston Foundation and receipt of further Changing Places grants, which are budgeted to be expended in the future years.

Reserves policy

Free reserves available to the charity exclude restricted, endowment and designated funds, and the tangible fixed assets held as unrestricted funds. It is considered that the charity should hold free reserves to provide sufficient protection to cover core costs, including salaries and central overheads, to meet its forward unrestricted commitments should it suffer an immediate or unforeseen drop in income.

The recommended free reserves level is revised annually as part of the budget process on the basis of the financial impact of the current risks facing the charity. The reserves policy is reviewed annually by the Trustees. The charity seeks to maintain free reserves to manage the risks to which the charity is exposed in the course of its business, including but not limited to safeguarding against volatile voluntary income. As there were no major changes to the

risks facing the charity since March 2021, the Trustees consider that in order to meet these needs, and to operate effectively, the charity needs reserves of around £1.5-£2m, based on the current analysis of risk. This has been reviewed in line with 2022/23 budget.

The 2021/22 financial year was a recovery year for the charity following COVID-19 impact in 2020/21. The changes implemented in 2020/21, to cut costs and protect reserves, were fully embedded and through prudent financial management MDUK remains in a strong financial position supported by the reserves to underwrite any future risks to secure post-pandemic continuation of charitable activities in the 2022/23 financial year. The risk to fundraising remains a key focus due to new risks from the cost of living crisis as we plan our future strategy to deliver our charitable objectives for a community which has grown in numbers and are impacted by this new crisis.

The charity's free unrestricted reserves were £4,530k at 31 March 2021 (excluding tangible assets and designated funds). In the 2021/22 financial year, the charity did not use its free reserves and continued prudent operations. This created a further increase, resulting in total unrestricted funds of £4,959k on 31 March 2022.

The unrestricted funds balance continues to be substantially higher than the target level agreed by the Trustees. However, in March 2021, the Trustees approved that any surplus in the reserves should be used to underwrite operations and delivery in the 2021/22 and 2022/23 financial years, when the impact of the COVID-19 pandemic is likely to continue and risks to any live fundraising events remain high. We had no need to do so in 2021/22 and we will continue to monitor our recovery in 2022/23. If the surplus balance is not needed then, it will support a development of the new strategic plan, when the current strategy comes to an end in 2022.

The designated funds balance represents the remaining balance on the IT investment fund, which will be reallocated to fixed assets once the customer relationship management (CRM) and IT project are finished in the first quarter of 2022/23 financial year.

Having reviewed the strategic risks facing the charity and 2022/23 budget projections, the Board of Trustees considers that there are sufficient reserves held at 31 March 2022 to manage those risks effectively. Accordingly, they continue to adopt the 'going concern' basis in preparing the Annual Report and Accounts.

Investment policy

The overall objectives are to create sufficient income and capital growth to enable the charity to carry out its purposes consistently year by year with due and proper consideration for future needs and the maintenance of and, if possible, the enhancement of the value of the invested funds while they are retained. Both capital and income may be used at any time for the furtherance of the charity's aims. The objectives are to be achieved by investing prudently in a broad range of fixed interest securities and equities, which are quoted on a Recognised Investment Exchange and Unit Trusts and OEICs (open-ended investment companies), which are authorised under the Financial Services and Markets Act 2000. There should be no direct investment in the following: derivative contracts, including futures and options; commodities

and derivatives thereof, contracts for differences or structured products. The investment policy is reviewed by the Finance Committee on an annual basis.

Ethical considerations

It has been decided not to invest directly in tobacco manufacture and distribution, this is defined as companies with more than 20 percent of their turnover in this activity. In 2020/21, Trustees reviewed the approach of the fund manager towards avoiding offenders in greenhouse gas emissions and it was felt that their approach is sufficient. Trustees reserve the right to exclude companies or industry sectors that carry out activities contrary to the aims of the charity, or from holding particular investments that damage the charity's reputation. Trustees expect the fund manager to have considered the suitability of investments of the same kind as any particular investment proposed or retained. In 2021/22, Trustees and SLT confirmed that the fund manager was not investing in Russian businesses following the Russian invasion of Ukraine.

Remuneration policy

Salaries of the Chief Executive and the Senior Leadership Team (SLT) are set by the Board's Appointments and Remuneration Committee, taking into account the performance of the charity overall, external comparisons, and the needs of the charity in the longer term. The Board's Appointments and Remunerations Committee reviews the performance of the CEO and the SLT annually. In 2021/22 the CEO froze her salary in agreement with the Trustees, following a year where a pay cut was taken to support the charity through this challenging period.

The charity pays above the London Living Wage for all posts. We advertise vacant posts on our website and seek applicants from both our current staff and externally.

No member of the SLT has a car supplied by the charity, and all staff members (and Trustees) travel on standard fares on charity business.

None of the Trustees is paid any remuneration or receives any other benefits from their work for the charity. Details of reimbursed expenses to Trustees can be found in Note 18.

Risk management

The Trustees continue to support formal risk management procedures, to assess business risks and implement strategies to minimise risk. Risks have been identified and classified in terms of their potential impact and likelihood, as well as the processes in place to manage them. The comprehensive risk management strategy is based upon a detailed risk register, which is subject to regular scrutiny and review. Risks are reviewed against the strategic aims of the charity and are evaluated against controls in place. Action plans to minimise or remove risk where possible are in place and kept under review.

The following risks have been identified as the most significant for the charity's financial sustainability:

- a. maintaining income levels is essential to the charity's financial sustainability – the charity continues to monitor the risks associated with its diverse voluntary income

- streams using close budget control, clear marketing plans and regular review
- b. needing to hold a sufficient level of unrestricted funds to provide protection against loss of income or unplanned expenditure – during the COVID-19 pandemic, the charity has reviewed these fortnightly, then monthly, and by the end of 20/21 returned to keeping these funds under quarterly review when appropriate
 - c. the impact of a stock market crash on the value of the investment portfolio, mitigated by taking the advice of professional investment managers
 - d. data protection: given GDPR, fines and attacks on data, this is a very real risk to the charity; leading experts in the field have been advising us and we continue to work proactively to address this issue
 - e. providing information that meets the needs of our users is essential for their continued support of the charity – the charity is reviewing all communications, publications and the website to ensure they meet the needs of all of our audiences
 - f. staff recruitment and retention: akin to most sectors the third sector is encountering a challenging period for staff turnover – the charity is engaging with team members on Wellbeing, Sustainability and Equality, Diversity and Inclusion to build a workplace staff are proud to be.

Our risk management policy proved effective during the initial year of the COVID-19 pandemic when the charity reacted to the potential impact of the pandemic in March 2020 by forming a special Board Emergency Sub-committee, who worked with the SLT on reducing the impact of the pandemic, this committee met again in 2021/22 to refresh members and the criteria for which it may be called upon again.

Grant-making policies

MDUK makes grants for research. We carry out grant calls to attract grant applications. These are peer-reviewed, and then recommended to the Trustees by the Medical Research Committee and members of the Lay Research Panel. Once a grant is approved, it is monitored annually to ensure that objectives are being met.

MDUK also makes grants for equipment. The JPT committee considers the applications against approved criteria before approving the grants.

Reference and administrative details

Muscular Dystrophy UK is a charitable company limited by guarantee. It is registered as a charity (Number 205395) in England and Wales and (Number SCO39445) in Scotland. The details of the Patron, the President, Honorary Life Presidents, Vice Presidents, Committees, SLT and advisors are set out on pages 50 to 55.

Structure, governance and management

Governing document

The Muscular Dystrophy Group of Great Britain and Northern Ireland, operating as Muscular Dystrophy UK, is a company limited by guarantee governed by its Memorandum and Articles of Association, dated 2 September 1961 and as amended on 24 October 2007, to allow for current arrangements and charity law best practice. Muscular Dystrophy UK is registered as a charity with the Charity Commission and the Office of the Scottish Charity Regulator. Anybody over the age of 18-years-old who supports and promotes the objectives of the charity can become a member excluding current staff. Muscular Dystrophy UK has a wholly-owned trading subsidiary, Muscular Dystrophy Group (Trading) Ltd.

Appointment of Trustees

MDUK has between seven and 17 elected Trustees. The selection, appointment, retirement and duties of Trustees are described in detail in the Memorandum and Articles of Association (article 29-44 et al).

Trustee induction and training

New Trustees receive an induction pack of documents and attend briefing that cover MDUK's operating plans, recent financial performance and organisational structure. During the induction, and over time, they meet and form working relationships with staff. Development opportunities include ongoing training, briefings and the annual Board Away Day.

Organisation

The Board of Trustees is ultimately responsible for the management of MDUK. The Board meets quarterly, and there are standing committees covering key areas of activity: research (Medical Research Committee, MRC) and Lay Research Panel (LRP), care (Services Development Committee, SDC), finance (Finance Committee), fundraising (Appeals Board), volunteers (Volunteering Steering Group, VSG), Marketing (Content Advisory Group, CAG) and appointments (Appointments and Remuneration Committee). A Chief Executive, with delegated authority, is appointed by and is accountable to the Trustees for managing the day-to-day operations of MDUK and the delivery of operational plans.

Members

MDUK has a body of around 200 Members, who carefully monitor the charity's progress. They are volunteers drawn from the various stakeholder groups that the charity represents: individuals, family members, scientists, doctors, MPs, Lords and others. Trustees are Members. If you are keen on following the charity's work and would be interested in becoming a Member, please contact the charity.

Volunteers

Volunteers are central to the work of MDUK. We rely on voluntary help in all aspects of the work of the charity. Volunteers work in the office, get involved in fundraising, provide their advice and guidance on many committees, provide support to individuals and families with muscle-wasting conditions, and get involved with campaigning and media work. All these efforts help the charity achieve its aims and objectives and we would wish to thank them all for their hard work and support.

Charity Governance Code

This code is a practical tool to help charities and their trustees develop high standards of governance. In 2018/19, the Board reviewed the code (which was refreshed in 2020, with reference to Equality, Diversity and Inclusion principle and Integrity principle). We continually work together on how these principles and practices should be applied at MDUK. In 2021/22 the Trustees engaged in workshops about the organisational purpose, vision and values, were regularly updated on the culture of the organisation, risk management and engage in committees. These committees and the Board of Trustees are annually reviewed and updated to ensure that they are an effective team with a balance of skills, experience and backgrounds to make informed decisions, and to ensure that no one individual has undue power or influence.

Related parties

The Joseph Patrick Trust (JPT), an unincorporated charity, (registered charity number 294475), is the welfare arm of MDUK, which is its sole corporate Trustee. Constituted on 30 April 1986, it provides direct financial assistance in the form of welfare grants to individuals and families living with muscle-wasting conditions, throughout the UK. The JPT receives most of its income from MDUK and from its own investments.

The consolidated financial statements also include the Trading subsidiary, Muscular Dystrophy Group (Trading) Limited of the Muscular Dystrophy Group of Great Britain and Northern Ireland.

MDUK maintains extremely close working relationships with partner charities that also assist those living with muscle-wasting conditions.

Statement of Trustees' responsibilities

The Trustees, who are also directors of the charitable company, are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and regulations.

Company law requires the directors to prepare financial statements for each financial year. Under company law, the directors have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law, the directors 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 company and the group and the profit or loss of the group for that period. In preparing these financial statements, the directors 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 company will continue in operation.

The directors are responsible for keeping adequate accounting records that are sufficient to show and explain the charitable company's transactions and disclose with reasonable accuracy at any time the financial position of the charity and group enabling them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the company and group and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Provision of information to auditors

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

- there is no relevant audit information of which the company's auditors are unaware; and
- the directors 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 report, incorporating the Strategic Report, is approved by the Board and signed on its behalf by:



Professor M Hanna

Chairman

12 July 2022

INDEPENDENT AUDITOR'S REPORT TO THE TRUSTEES AND MEMBERS OF MUSCULAR DYSTROPHY GROUP OF GREAT BRITAIN AND NORTHERN IRELAND

Opinion

We have audited the financial statements of Muscular Dystrophy Group of Great Britain and Northern Ireland (the 'parent charitable company') and its subsidiaries (the 'group') for the year ended 31 March 2022 which comprise the Consolidated Statement of Financial Activities (incorporating an Income and Expenditure Account), the Group and Parent Charitable Company Balance Sheets, the Statement of Group Cash Flows and notes to the financial statements, including 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 the parent charitable company's affairs as at 31 March 2022 and of the group's incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 (as amended) and regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

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 charitable company 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 and parent charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

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

Other information

The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained in the 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.

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 course of 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 themselves. 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) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- trustees' annual report (which includes the strategic report) has 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 parent charitable company and their environment obtained in the course of the audit, we have not identified material misstatements in the trustees' annual report (which includes the strategic report).

We have nothing to report in respect of the following matters where the Companies Act 2006 or the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- the parent charitable company has not kept adequate and sufficient accounting records, or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company's 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

As explained more fully in the trustees' responsibilities statement set out on page 24, 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 and 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 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

We have been appointed as auditor under Section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report to you in accordance with regulations made under those Acts.

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 aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

As part of an audit in accordance with ISAs (UK) we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purposes of expressing an opinion on the effectiveness of the group and parent charitable company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty

exists related to events or conditions that may cast significant doubt on the group and parent charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the group or parent charitable company to cease to continue as a going concern.

- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.
- Obtain sufficient appropriate audit evidence regarding the financial information of the entities or business activities within the group to express an opinion on the consolidated financial statements. We are responsible for the direction, supervision and performance of the group audit. We remain solely responsible for our audit report.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Explanation as to what extent the audit was considered capable of detecting irregularities, including fraud

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.

The objectives of our audit in respect of fraud, are; to identify and assess the risks of material misstatement of the financial statements due to fraud; to obtain sufficient appropriate audit evidence regarding the assessed risks of material misstatement due to fraud, through designing and implementing appropriate responses to those assessed risks; and to respond appropriately to instances of fraud or suspected fraud identified during the audit. However, the primary responsibility for the prevention and detection of fraud rests with both management and those charged with governance of the charitable company.

Our approach was as follows:

- We obtained an understanding of the legal and regulatory requirements applicable to the charitable company and considered that the most significant are the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 (as amended), regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charity SORP, and UK financial reporting standards as issued by the Financial Reporting Council
- We obtained an understanding of how the charitable company complies with these requirements by discussions with management and those charged with governance.
- We assessed the risk of material misstatement of the financial statements, including

the risk of material misstatement due to fraud and how it might occur, by holding discussions with management and those charged with governance.

- We inquired of management and those charged with governance as to any known instances of non-compliance or suspected non-compliance with laws and regulations.
- Based on this understanding, we designed specific appropriate audit procedures to identify instances of non-compliance with laws and regulations. This included making enquiries of management and those charged with governance and obtaining additional corroborative evidence as required.

There are inherent limitations in the audit procedures described above. We are less likely to become aware of instances of non-compliance with laws and regulations that are not closely related to events and transactions reflected in the financial statements. Also, the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery or intentional misrepresentations, or through collusion.

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 and to the charitable company's trustees, as a body, in accordance with Section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charitable company's members and trustees those matters which we are required to state to them in an auditor's report addressed to them and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to any party other than the charitable company and charitable company's members as a body, and the charity's trustees, as a body, for our audit work, for this report, or for the opinions we have formed.



Andrew Stickland (Senior Statutory Auditor)
for and on behalf of Moore Kingston Smith LLP, Statutory Auditor
9 Appold Street, London EC2A 2AP

Moore Kingston Smith LLP is eligible to act as auditor in terms of Section 1212 of the Companies Act 2006.

Date: 28 July 2022

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 MARCH 2022

	Notes	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2022 £000	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2021 £000
Income							
Income from charitable activities							
Donations, gifts and grants	2	2,565	1,316	3,881	2,199	751	2,950
Government grants	2	-	604	604	505	799	1,304
Legacies	2	1,172	476	1,648	874	-	874
Income from other trading activities	11	101	-	101	93	8	101
Investment income	2, 10	151	-	151	158	-	158
Other income	2	243	41	284	142	15	157
Total income		4,232	2,437	6,669	3,971	1,573	5,544
Expenditure							
Expenditure on raising funds	3	1,748	-	1,748	1,136	-	1,136
Costs from other trading activities	3	80	-	80	67	-	67
		1,828	-	1,828	1,203	-	1,203
Charitable activities							
Medical research	3, 5	932	998	1,930	-33	700	667
Access to specialist care and support	3	815	117	932	965	299	1,264
Independent living	3	293	626	919	253	187	440
Total – charitable activities		2,040	1,741	3,781	1,185	1,186	2,371
Total expenditure		3,868	1,741	5,609	2,388	1,186	3,574
Net gain/(loss) on investment assets	9	46	1	47	659	52	711
Transfer between funds		-	-	-	295	(295)	-
Net movement in funds		409	698	1,107	2,537	144	2,681
Reconciliation of funds							
Total funds brought forward	15	4,969	4,753	9,722	2,432	4,609	7,041
Total funds carried forward	15	5,378	5,451	10,829	4,969	4,753	9,722

There are no recognised gains or losses other than those disclosed above. All results are derived from continuing activities. The accompanying notes on pages 33 to 49 form an integral part of the financial statements.

BALANCE SHEETS AS AT 31 MARCH 2022

COMPANY REGISTRATION NUMBER 705357

CHARITY REGISTRATION NUMBER 205395/SC039445

	Note	Group 2022 £000	Group 2021 £000	Charity 2022 £000	Charity 2021 £000
Fixed Assets					
Tangible Assets	8	323	189	322	188
Investments	9	5,781	5,628	5,387	5,258
Total Fixed Assets		6,104	5,817	5,709	5,446
Current Assets					
Stock	12	13	11	-	-
Debtors	13	881	373	923	405
Cash at Bank		7,507	7,194	7,442	7,189
Total Current Assets		8,401	7,578	8,365	7,594
Creditors falling due within one year	14	(3,676)	(3,673)	(3,380)	(3,387)
Net Current Assets		4,725	3,905	4,984	4,207
Total Assets less current liabilities		10,829	9,722	10,693	9,653
Net Assets		10,829	9,722	10,693	9,653
The funds of the Charity					
Unrestricted					
- Designated	15	419	439	322	438
- General	15	4,959	4,530	4,970	4,492
		5,378	4,969	5,292	4,930
Restricted	15	5,044	4,348	4,994	4,318
Endowment	15	407	405	407	405
Total Charity Funds		10,829	9,722	10,693	9,653

The Statement of Financial Activities for the year ended 31 March 2022 for the parent charitable company only was a surplus of £1,041k (2020: surplus of £2,569k).

The accompanying notes on pages 33 to 49 form an integral part of the financial statements. Approved and authorised for issue by the Board of Trustees on 12 July 2022 and signed on its behalf by:



Prof M Hanna
Chairman



M Brown
Treasurer

STATEMENT OF GROUP CASHFLOWS – FOR THE YEAR-ENDED 31 MARCH 2022

		2022 £000	2021 £000
Net cash inflow/(outflow) from operating activities (note a)		479	152
Net Cash flow from investing activities			
Dividends from investments		151	158
Purchase of Tangible Fixed Assets		(211)	(58)
Proceeds of sale of Investments		2,821	1,171
Purchase of Investment		(2,927)	(1,269)
Net Cash provided by investing activities		(166)	2
Increase/(decrease) in cash and cash equivalents in the year		313	154
Reconciliation of net cash inflow to movement in net funds			
Increase/(decrease) in cash and cash equivalents in the year (note b)		313	154
Cash and cash equivalents at the beginning of the year		7,194	7,040
Cash and cash equivalents at the end of the year		7,507	7,194
Notes to cash flow statement			
(a) Reconciliation of net movement in funds to net cash flow from operating activities:			
		2022 £000	2021 £000
Net movement in funds		1,107	2,681
Dividends from investments		(151)	(158)
Investment (gains) / losses		(47)	(711)
Depreciation		77	58
Decrease / (Increase) in debtors / stock		(511)	73
Increase / (Decrease) in all creditors		3	(1,791)
Net cash provided by/(used in) operating activities		479	152
(b) Analysis of changes in net cash funds			
	1-Apr-21 £000	Cashflows £000	31-Mar-22 £000
Cash and cash equivalents	7,194	313	7,507
Total cash and cash equivalents	7,194	313	7,507

The accompanying notes on pages 33 to 49 form an integral part of the financial statements.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

1. ACCOUNTING POLICIES

ACCOUNTING CONVENTION

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice for Charities (SORP 2015) (Second Edition, effective 1 January 2019) applicable to charities preparing accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) and the Companies Act 2006. The financial statements have been prepared under the historical cost convention unless otherwise stated in the relevant accounting policy note(s). Muscular Dystrophy UK meets the definition of a public benefit entity under FRS102.

The principal accounting policies adopted in the preparation of the financial statements are set out below.

GOING CONCERN ACCOUNTING POLICIES

The charitable company's level of free reserves available at the year end, were considered adequate resources to continue in operational existence for the foreseeable future, even with continuous impact of the Covid-19 pandemic. The pandemic caused the Trustees to review the positions of the Charity and its subsidiaries in 2020/21 financial year, but there was no need for further reviews in 2021/22. The budgets and cash flows for 2022/23 were reviewed in July 2022 and the Trustees have considered cash forecasts covering twelve months period until July 2023. Accordingly, the financial statements have been prepared on a going concern basis and the trustees do not anticipate any material uncertainties.

BASIS OF CONSOLIDATION

Subsidiary undertakings are fully consolidated and hence these financial statements are referred to as 'consolidated financial statements'. Non-autonomous branches are treated as part of the parent charity and are referred to as 'charity' financial statements. A separate Statement of Financial Activities (SOFA) for the parent charity is not presented because Muscular Dystrophy UK has taken advantage of the exemption afforded by section 408 of Companies Act 2006.

The subsidiary undertakings included in this consolidated accounts include:

- Muscular Dystrophy Group (Trading) Limited (registered company number 00893086);
- The Joseph Patrick Trust (JPT), an unincorporated charity, (registered charity number 294475).

Consolidation has been done on a line-by-line basis, with all inter-company transactions eliminated. The accounting dates and policies are the same.

1. ACCOUNTING POLICIES (cont.)

INCOME

Income is recognised in the SOFA when the effect of the transaction results in an increase in the charity's assets. This will be dependent on three factors:

- i. Entitlement – when Muscular Dystrophy UK has control over the rights to the resource, enabling it to receive the economic benefit
- ii. Probability – when it is probable, more likely than not that the economic benefit will be received
- iii. Measurement – when the monetary value can be measured with sufficient reliability.

Income received for a specific purpose is treated as restricted funds. Where income is received subject to donor-imposed conditions that specify a future time period in which the expenditure should take place, such income is deferred and recognised as a liability. It is released as income in the accounting period in which Muscular Dystrophy UK is allowed to expend the resource.

Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably through estate accounts (or cash receipt) 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 not recognised in the accounts.

Government grant income paid under the Coronavirus Job Retention Scheme (CJRS) has been recognised in the Statement of Financial Activities in the period to which the underlying furloughed staff costs relate to.

Services in kind are valued at the lower of their market value and equivalent market cost were these to be purchased directly by the charity. The Trustees consider that all services in kind received in 2021/22 do not meet recognition criteria outlined in module 6 of the charity SORP 2019. Therefore, no estimates for this services were included in this set of accounts.

EXPENDITURE

All expenditure is recognised on an accruals basis and includes irrecoverable VAT where appropriate. Grants awarded are recognised as a liability when Muscular Dystrophy UK is under a legal or constructive obligation to a third party. Expenditure on raising funds includes all expenditure incurred in pursuance of Muscular Dystrophy UK's fundraising activities.

Charitable expenditure includes all expenditure incurred in pursuance of Muscular Dystrophy UK's objectives. The costs of these activities are divided between grants and other direct costs. Support costs including governance costs have been allocated to each activity on the basis of expenditure incurred.

1. ACCOUNTING POLICIES (cont.)

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include audit fees and costs linked to the strategic management of the charity.

Muscular Dystrophy UK awards three types of grant:

1. Grants to fund medical research.
2. Grants for the installation of Changing Places toilets.
3. Grants to specific beneficiaries to enable them to purchase equipment to alleviate their muscle-wasting condition, and other small welfare grants dispensed by Branches to individual beneficiaries.

TAXATION

Muscular Dystrophy Group of Great Britain and Northern Ireland and the Joseph Patrick Trust are registered charities with the meaning of para 1 schedule 6 Finance Act 2010. Accordingly, they are exempt from taxation in respect of income or capital gains within categories covered by Chapter 3 of Part 11 of the Corporation Tax Act 2010 or section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes. No tax charge arose in the period.

Muscular Dystrophy Group (Trading) Limited donates by way of Gift Aid all taxable profits to the parent charity.

LISTED INVESTMENTS

Listed investments are shown at the bid-market value ruling at the date of the Balance Sheet and after taking into account any subsequent impairment in value. Muscular Dystrophy UK has full discretion in its investment policy.

The Statement of Financial Activities includes the aggregate of realised and unrealised gains and losses during the year.

UNLISTED INVESTMENTS

Unlisted investments are shown at cost unless there is reason to believe that there has been a significant reduction in their value.

FINANCIAL INSTRUMENTS

Basic financial instruments are initially recognised at transaction value and subsequently measured at amortised cost with the exception of investments which are held at fair value. Financial assets held at amortised cost comprise cash at bank and in hand, together with trade and other debtors. A specific provision is made for debts for which recoverability is in doubt. Cash at bank and in hand is defined as all cash held in instant access bank accounts and used as working capital. Financial liabilities held at amortised cost comprise all creditors except social security and other taxes.

1. ACCOUNTING POLICIES (cont.)

INTANGIBLE AND TANGIBLE FIXED ASSETS AND DEPRECIATION

Items or projects with a value exceeding £500, and which have a life exceeding one year, are capitalised. Improvements to leasehold property are depreciated over the full length of the lease. Depreciation is provided on all other tangible fixed assets on a straight-line basis to write off the cost as follows:

Leasehold premises:	over length of lease
Motor Vehicles:	over three years
All other assets:	over four years.

OPERATING LEASES

The charity provides for operating leases on property on an actual cost basis. Rent-free periods on property are apportioned over the life of the lease, or to the first break clause if earlier. Any rent-free period is to offset the additional costs incurred by moving into new premises and reflects the inducement offered in that period by the landlord to let the property.

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.

CASH AT BANK AND IN HAND

Cash at bank and cash 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 or matures within three months of the date of the balance sheet.

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 after allowing for any trade discounts due.

EMPLOYEE BENEFITS

Short term benefits including holiday pay are recognised as an expense in the period in which the service is received. Employee termination benefits are accounted for on an accrual basis and in line with FRS 102.

PENSIONS

Muscular Dystrophy UK offers defined contributions to employees' pension arrangements. The amount charged to the SOFA in respect of pensions costs is the contributions payable within the year. Differences between contributions payable and contributions actually paid are shown as accruals in the Balance Sheet.

1. ACCOUNTING POLICIES (cont.)

ACCOUNTING ESTIMATES AND AREAS OF SIGNIFICANT JUDGMENT

In preparing the financial statements, Trustees are required to make estimates, judgements and assumptions that affect the application of the charity's accounting policies and the reported assets, liabilities, income and expenditure and the disclosures made in the financial statements. Estimates and judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances. Actual results may differ from these estimates.

Judgement and estimates have been applied in the accounts in the following key areas:

- Estimating the useful economic life of tangible fixed assets
- Estimating the probability of the receipt of legacy income and the amount to be received
- Valuation of services received in kind
- Estimating the costs of dilapidation at the end of the current lease

STOCK

Stock is included at the lower of cost or net realisable value. Donated items of stock are recognised at fair value, which is the amount the charity would have been willing to pay for the items on the open market.

FUND ACCOUNTING POLICIES

Unrestricted funds are funds received and applied to achieve the general objectives of the MDUK.

Designated funds are unrestricted funds earmarked by the Trustees for particular purposes. Endowment funds are represented by capital assets held as investments which generate income which in turn is applied to specific objectives of the MDUK as laid down by the donor.

Restricted funds are to be used for specified purposes as laid down by the donor. Expenditure which meets these criteria is identified to the fund, together with a fair allocation of support costs where applicable.

2. INCOME

	2022			2021		
	Unrestricted Funds	Restricted Funds	Total 2022	Unrestricted Funds	Restricted Funds	Total 2021
	£000			£000		
Events and promotions	1,034	131	1,165	332	80	412
Direct marketing	850	16	866	837	13	850
Major Donors and Corporate	247	236	483	460	73	533
Trusts	130	1,019	1,149	185	403	588
Regional development	556	245	801	477	191	668
Legacy	1,172	476	1,648	874	-	874
Other income	243	314	557	806	813	1,619
Total income*	4,232	2,437	6,669	3,971	1,573	5,544

* Of this income £604k comes from Government Grants (2020/21 £1,304). The government grants included £331k from UK Government Covid Medical Research Charity Support Fund included in Trust income above and £273k from the Ministry of Housing, Communities and Local Government included in Other income figure.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

3. EXPENDITURE

	Direct Costs		Support	
	Grants £000	Other £000	Costs £000	2022 £000
Raising Funds				
Expenditure on raising funds	-	1,558	190	1,748
Costs from other Trading Activities	-	63	17	80
Total	-	1,621	207	1,828
Charitable Expenditure				
Access to care and independent living				
Access to care	-	756	176	932
Independent living	37	709	173	919
Total	37	1,465	349	1,851
Pursuit of Knowledge				
Medical research	1,236	330	364	1,930
Total Charitable Expenditure	1,273	1,795	713	3,781
Total Expenditure	1,273	3,416	920	5,609

2020/21 Comparatives	Direct Costs		Support	
	Grants £000	Other £000	Costs £000	2021 £000
Raising Funds				
Expenditure on raising funds	-	973	163	1,136
Costs from other Trading Activities	-	49	18	67
Total	-	1,022	181	1,203
Charitable Expenditure				
Access to care and independent living				
Access to care	-	962	302	1,264
Independent living	(25)	360	105	440
Total	(25)	1,322	407	1,704
Pursuit of Knowledge				
Medical research	192	316	159	667
Total Charitable Expenditure	167	1,638	566	2,371
Total Expenditure	167	2,660	747	3,574

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

3. EXPENDITURE (cont.)

'Direct Costs' include all costs incurred in delivering the relevant activity.

'Support Costs' comprise of the following :

	2022 £000	2021 £000
Chief Executive and Human Resources	103	96
Finance and insurance	207	238
Office costs	454	270
Information Technology	129	121
Governance	27	22
Total	920	747

These costs have been allocated across the activities on the basis of expenditure incurred for each of the activities.

§ 'Access to care' includes Policy, Communications and training activities. 'Independent living' includes advocacy, care, equipment grants and Changing Places.

§ 'Research' includes the research grants and departmental running costs

§ 'Governance' includes the annual audit fee and Trustees expenses.

4. STAFF COSTS

	2022 £000	2021 £000
Remuneration of Staff		
Wages and Salaries	1,928	1,934
Social Security Costs	187	183
Pensions	110	107
Total	2,225	2,224

11 redundancies were made in the year (2020/21: 17). The cost of the redundancy payments was £24k (2020/21: £24k).

The monthly average number of employees during the period was 57 (2020/21: 59), of whom there were the following higher paid employees as detailed below.

Details of the Key Management Personnel, which consists of the Senior Management Team, can be found on page 54. Their total aggregate employment benefits were £444k (2020/21: £447k).

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

4. STAFF COSTS (cont.)

	2022 No	2021 No
Earned between the ranges		
£60,000 to £70,000	1	2
£70,000 to £80,000	2	-
£100,000 to £110,000	1	1
	2022 No	2021 No
Number of staff by activity		
Direct Charitable Expenditure	18	18
Fundraising and Publicity	33	35
Management and Administration	6	6
Total	57	59

Pension Schemes

There were no outstanding contributions (2019/20: £0) at the Balance Sheet date.

5. GRANT EXPENDITURE

	Research Grants £000	Welfare Grants £000	Total 2022 £000	Total 2021 £000
Grants awarded in the year	1,326	67	1,393	1,070
Grants cancelled in the year	(90)	(30)	(120)	(903)
Total	1,236	37	1,273	167
	Research Grants £000	Welfare Grants £000	Total 2021 £000	
Grants awarded in the year	1,067	3	1,070	
Grants cancelled in the year	(875)	(28)	(903)	
Total	192	(25)	167	

With the exception of some welfare grants that are paid to individuals, all grants are paid to institutions. A list of grants to institutions is available from the registered office. The Welfare grants include Changing Places grants.

Apart from the two strategic grants at University of Oxford (MDUK Oxford Neuromuscular Centre), there were no institutions in receipt of material grants (over £80k pa) in 2021/22.

At the balance sheet date, the charity had conditional grant commitments that had not been accrued in the accounts as all the criteria relating to payment in subsequent years had not been met, as follows:

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

5. GRANT EXPENDITURE (cont.)

			2022 £000	2021 £000
Payable between one and five years			2,371	3,311
Reconciliation of grant funding commitments :				
		Research 2022 £000	Welfare 2022 £000	Total 2022 £000
Carrying amount at start of year		2,940	272	3,212
Additions		1,326	67	1,394
Amounts charged and cancelled in year		(1,592)	(126)	(1,718)
Carrying amount at end of year		2,674	214	2,888

6. OPERATING LEASE COMMITMENTS

Muscular Dystrophy UK is committed to the following minimum lease commitments under a non-cancellable operating lease on its headquarters and office equipment.

	2022 £000	2021 £000
Expiring up to one year	257	257
Expiring between one and five years	-	257

7. NET INCOME

Net Income is stated after charging

	2022 £000	2021 £000
Auditor's remuneration	25	21
Auditor's remuneration - non audit services	3	10
Depreciation	77	58
Operating lease rentals	232	232

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

8. TANGIBLE FIXED ASSETS

Group	Leasehold premises £000	Computer equip- ment £000	Motor cars £000	Other assets £000	Other equip- ment £000	Total £000
Cost at 1 Apr 2021	201	515	100	15	48	879
Disposal	-	(131)	(76)	-	(1)	(208)
Additions	12	197	-	--	2	211
At 31 Mar 2022	213	582	24	15	48	883
Depreciation 1 Apr 2021	157	385	100	-	48	690
Disposal	-	(131)	(76)	-	(1)	(208)
Provided for year	20	57	-	-	-	77
At 31 Mar 2022	177	311	24	-	47	560
Net Book Value						
At 31 Mar 2022	36	271	-	15	1	323
At 31 Mar 2021	44	130	-	15	-	189

All tangible fixed assets are used in the promotion of Muscular Dystrophy UK's work; none is held for investment. Included in Other Assets are three portraits especially commissioned by the charity; they are held at a cost of £15k. In the opinion of the Trustees, they are worth not less than this valuation and as such no depreciation is charged.

9. INVESTMENTS

	Group 2022 £000	Group 2021 £000	Charity 2022 £000	Charity 2021 £000
Market Value at beginning of year	5,628	4,820	5,258	4,503
Acquisitions	2,927	1,268	2,732	1,180
Sales proceeds	(2,821)	(1,171)	(2,625)	(1,081)
	5,734	4,917	5,366	4,602
Realised (loss)/gain on disposals	28	(83)	(2)	(85)
Unrealised gain / (loss) on revaluation of Investments	19	794	23	741
Market value at end of year	5,781	5,628	5,387	5,258
Historical Cost at end of year	4,983	4,353	4,644	4,042

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

9. INVESTMENTS (cont.)

Spread of Investments

The investments of Muscular Dystrophy UK are held as follows:

Investments listed on a recognised Stock Exchange and Unit Trusts	Group 2022 £000	Group 2021 £000	Charity 2022 £000	Charity 2021 £000
- UK and Overseas equities	4,234	3,510	4,063	3,234
- UK and Overseas fixed interest	496	1,375	323	1,342
- Property funds	375	341	341	311
- Hedge funds	357	220	342	205
	5,462	5,446	5,069	5,092
Cash on Deposit awaiting investment	257	120	256	104
Unlisted equities	62	62	62	62
Total	5,781	5,628	5,387	5,258

Investment management costs for the year were £30k (2021/22: £28k).

There was no individual investment that constituted more than five percent of the total investment portfolio (at market value) as at the year end. (2020/21 : £nil)

10. INCOME FROM INVESTMENTS

	Group 2022 £000	Group 2021 £000	Charity 2022 £000	Charity 2021 £000
UK Equities, UK fixed interest and other	140	143	133	134
Short term Deposit and Bank interest	11	15	10	15
	151	158	143	149

11. INVESTMENTS IN SUBSIDIARY UNDERTAKINGS

The accounts of Muscular Dystrophy UK (i.e. 'charity' accounts) incorporate the results of the following entity on a line-by-line basis:

- Joseph Patrick Trust, a separately registered charity, 294475, which makes grants towards welfare equipment. Muscular Dystrophy UK is the sole corporate Trustee.
- Muscular Dystrophy Group (Trading) Limited, 893086, which undertakes trading activities on behalf of the charity and covenants all profits to the charity. Muscular Dystrophy UK is the sole shareholder.
- They are both registered at 61A Great Suffolk Street, London, SE1 0BU.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

11. INVESTMENTS IN SUBSIDIARY UNDERTAKINGS (cont.)

Their net assets and results for the year ended 31 March 2022 are summarised below:

	Muscular Dystrophy Group (Trading) Ltd £000	Joseph Patrick Trust £000
Fixed Assets	1	394
Current Assets	126	5
Current Liabilities	(124)	(266)
Total Net Assets	3	133
Represented by:		
Total Funds	3	133
Total income	101	19
Total expenditure*	(80)	1
Investment gains/losses and other B/S movements	-	46
Surplus for the year	22	65
Country of Registration	England	England
Number of fully paid £1 ordinary shares	100	-
Voting rights owned by Muscular Dystrophy UK	100%	100%

* The positive figure in JPT expenditure line is due cancellation of grants expired and unclaimed, which was larger than grants awarded in the year.

12. STOCK

The stock held in Muscular Dystrophy Group (Trading) Ltd represents new goods available for sale valued at £13k (2020/21 : £11k).

13. DEBTORS

	Group 2022 £000	Group 2021 £000	Charity 2022 £000	Charity 2021 £000
Trade debtors	50	40	-	4
Amount due from subsidiary undertakings	-	-	92	71
Prepayments and accrued income	833	320	831	317
Other debtors	(2)	13	-	13
	881	373	923	405

All amounts are due within one year, and all intra group balances are unsecured and do not bear interest.

14. CREDITORS FALLING DUE WITHIN ONE YEAR

	Group 2022 £000	Group 2021 £000	Charity 2022 £000	Charity 2021 £000
Accruals for grant commitments	2,888	3,212	2,674	2,940
Accruals and Deferred Income	368	128	296	123
Taxation and Social Security	51	58	45	50
Other Creditors	369	275	365	274
	3,676	3,673	3,380	3,387

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

15. FUNDS

	April 2021 £000	Income £000	Expendi- ture £000	Movement between funds £000	Investment gains £000	March 2022 £000
<i>Endowment Fund</i>						
Orchid Ball	405	-	-	-	1	406
<i>Restricted Funds</i>						
Provision of care						
City Bridge Trust / Work experience	75	60	(53)	-	-	82
Scotland	28	30	(39)	-	-	19
Psychological support	28	-	-	-	-	28
Volunteering	138	-	(78)	-	-	60
Joseph Patrick Trust – Assistive Technology	30	20	-	-	-	50
Changing Places	2,580	297	(421)	-	-	2,456
The Garfield Weston CCS Fund	-	300	-	-	-	300
Other care	59	99	(152)	-	-	6
Research						
The Patrick Research Fund	298	-	-	-	-	298
Congenital Muscular Dystrophy	-	465	-	-	-	465
Oxford Neuromuscular Centre	374	118	(273)	-	-	219
Q Trust Fellowship	3	1	-	-	-	4
FSHD Research	114	31	(82)	-	-	62
Duchenne Research	38	199	(133)	-	-	104
Ullrich Research	129	28	(139)	-	-	18
Nemaline Research	154	134	-	-	-	288
Congenital MD	(5)	36	-	-	-	31
Becker Research Fund	84	49	-	-	-	133
SMA Research	68	14	(41)	-	-	41
Limb Girdle research	44	1	-	-	-	45
Other research	110	582	(357)	-	-	335
Total Restricted Funds	4,753	2,437	(1,741)	-	1	5,451
<i>Designated Funds</i>						
IT Investment Fund	251		(155)			96
Tangible Assets for Charity Use	189	211	(77)	-	-	323
Total Designated Funds	440	211	(232)	-	-	419
General Fund	4,529	4,020	(3,636)	-	46	4,959
Total Unrestricted Funds	4,969	4,231	(3,868)	-	46	5,378
Total Funds	9,722	6,669	(5,609)	-	47	10,829

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

15. FUNDS (cont.)

2020/21 Comparatives	April 2020 £000	Income £000	Expendi- ture £000	Movement between funds £000	Investment gains £000	March 2021 £000
<i>Endowment Fund</i>						
Orchid Ball	353	-	-	-	52	405
<i>Restricted Funds</i>						
Provision of care						
City Bridge Trust / Work experience	52	57	(34)	-	-	75
Comic relief	24	-	-	(24)	-	-
Psychological support	117	-	(1)	(88)	-	28
Powerchair football	19	(19)	-	-	-	-
Joseph Patrick Trust - Assistive Technology	30	-	-	-	-	30
Changing Places	1,961	881	(262)	-	-	2,580
Other care	212	267	(190)	(64)	-	225
Research						
The Patrick Research Fund	307	-	(8)	-	-	299
Attenborough Fellowship	-	-	-	-	-	-
Oxford Neuromuscular Centre	328	54	(8)	-	-	374
Q Trust Fellowship	250	3	(250)	-	-	3
Walton Fund	119	-	-	(119)	-	-
Duchenne Research	297	100	(359)	-	-	38
Ullrich Research	106	24	-	-	-	130
Nemaline Research	145	9	-	-	-	154
Congenital MD	(35)	30	-	-	-	(5)
Becker Research Fund	72	11	-	-	-	83
Other research	252	157	(75)	-	-	334
Total Restricted Funds	4,609	1,574	(1,187)	(295)	52	4,753
<i>Designated Funds</i>						
Research	1,172	-	-	(1,172)	-	-
Clinical	229	-	-	(229)	-	-
IT Investment Fund	-	-	-	250	-	250
Tangible Assets for Charity Use	190	58	(58)	-	-	189
Total Designated Funds	1,591	58	(58)	(1,151)	-	439
General Fund	841	3,912	(2,329)	1,446	659	4,529
Total Unrestricted Funds	2,432	3,970	(2,387)	295	659	4,969
Total Funds	7,041	5,544	(3,574)	-	711	9,722

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

15. FUNDS (cont.)

ENDOWMENT FUND

The Orchid Ball Fund is an endowed fund, the income from which (shown separately) is restricted in the first instance to research and welfare in Scotland. Any unused income in a financial period is then directed to funding research.

RESTRICTED FUNDS

- City Bridge Trust / Work experience - this is funding received from the City Bridge Trust to support young disabled people in the London area to access work experience and develop their employability skills.
- Scotland – this is used for activities in Scotland
- Psychological Support - This is used to support our Mental Health Matters work, identifying how MDUK can best improve the mental health and wellbeing support available for people affected by muscle-wasting conditions.
- Volunteering - this is funding to support our work to identify a more strategic and sustainable approach to working with volunteers to help support our community.
- The Joseph Patrick Trust is a restricted trust within Muscular Dystrophy UK as explained in Note 11. Its assets are restricted to 'provide welfare, relief and support to those living with muscle-wasting conditions'.

MDUK currently holds seven restricted funds related to our role as co-chair of the Changing Places consortium. These seven funds are for;

- The provision of grants to motorway service areas in England to install Changing Places toilets
- The scoping of priorities for further provision of Changing Places toilets elsewhere on the transport network in England
- The provision of grants for the installation of Changing Places toilets based on this scoping
- The scoping of priorities for the installation of Changing Places toilets in existing buildings in England
- The provision of information and advice to Local Authorities in England as they utilise £30m of government funding to install Changing Places toilets in existing buildings
- Improvements to the Changing Places website and digital map
- Support to cover the general costs associated with MDUK's role as co-chair of the Changing Places Consortium

The Garfield Weston CCS Fund - Two year project funded by the Garfield Weston Trust to improve the reach of our support and increase our policy capacity to support NHS neuromuscular services.

- Other Care - this includes funding for our Muscle Group activity and work to connect families from South Asian backgrounds affected by muscle-wasting conditions with each other.
- The Patrick Research Fund - this is a donation from the Patrick family. It is to be held for research activities relating to Duchenne muscular dystrophy.
- Congenital Muscular Dystrophy - this is used to support research related to the condition congenital muscular dystrophy.
- Oxford Neuromuscular Centre - this is used to support the funding of the MDUK Oxford Neuromuscular Centre - much of the fund has come from the Q Trust.
- Q Trust Fellowship - This funding comes from the Q Trust. In 2021/22 these funds went to support the MDUK Oxford Neuromuscular Centre at request of the Trust.
- FSHD Research - this is used to support research related to the condition FSHD (facioscapulohumeral muscular dystrophy)
- Duchenne Research - this is used to support research related to the condition Duchenne muscular dystrophy.
- Ullrich Research - this is used to support research related to the condition Ullrich congenital muscular dystrophy and other collagen-VI-related muscular dystrophies.
- Nemaline Research - this is used to support research related to the condition nemaline myopathy. A significant proportion of these funds came via the MAP Nemaline family fund.
- Congenital MD - this is used to support research related to the condition LMNA congenital muscular dystrophy

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2022

15. FUNDS (cont.)

- Becker Research Fund - this is used to support research related to the condition Becker muscular dystrophy.
- SMA Research - this is used to support research related to the condition spinal muscular atrophy.
- Limb Girdle research - this is used to support research related into limb girdle muscular dystrophies.
- Other research – this is used to support research grants for which there are no condition restrictions.

UNRESTRICTED FUNDS

Muscular Dystrophy UK's reserves policy is reviewed regularly to ensure that the charity has sufficient cash and other reserves to meet its present and future commitments in an orderly and sustainable manner.

The designation of balances is as follows:

- 'tangible assets for charity use' represent the amount of unrestricted funds represented by these assets
- the General Fund is available for the ongoing operations of the charity.
- Designated Fund represents IT investment in CRM and Cloud migration projects.

Represented by: 2022	Fixed Assets £000	Investments £000	Net Current Assets £000	Total £000
Endowment Funds	-	407	-	407
Restricted Funds	-	1,830	3,214	5,044
Designated Funds	323	96	-	419
Unrestricted Funds	-	3,448	1,511	4,959
Total Funds	323	5,781	4,725	10,829

Represented by: 2021	Fixed Assets £000	Investments £000	Net Current Assets £000	Total £000
Endowment Funds	-	405	-	405
Restricted Funds	-	1,957	2,391	4,348
Designated Funds	189	-	250	439
Unrestricted Funds	-	3,266	1,264	4,530
Total Funds	189	5,628	3,905	9,722

16. LEGACIES

The charity is entitled to a share in a number of estates which it monitors closely. The following sums have not been reflected in these financial statements in accordance with the accounting policies set out in Note 1. The potential values of these estates to the charity at the balance sheet date are as follows:

	2022 £000	2021 £000
Residuary	1,138	1,310
Reversionary	247	250
	1,385	1,560

All sums are due to Muscular Dystrophy UK.

17. STATUS OF CHARITY

Muscular Dystrophy Group of Great Britain and Northern Ireland, operating as Muscular Dystrophy UK, is a registered charity and a company limited by guarantee. In the event of a winding up, Members are required to contribute an amount not exceeding £1. By virtue of s.30 of the Companies Act 2006, the charity does not use 'limited' in its name.

18. RELATED PARTY TRANSACTIONS

During the year Trustees of Muscular Dystrophy UK made donations and received reimbursement of their expenses incurred in travelling to attend Muscular Dystrophy UK's business, as follows

	2022 £000	2021 £000
Donations	21	18
Expenses	-	-

No Trustee received any remuneration during the year (2020/21: £nil).

There were no other related parties transactions.

Presidents, Board of Trustees and Committees

President

Gabby Logan MBE

Honorary Life Presidents

Professor George Dickson

Professor Martin Bobrow

Baroness Celia Thomas of Winchester MBE

Sue Barker CBE

Patrons

Michael J Attenborough

Karen E Lewis-Attenborough

Ian Corner

Alan Emery

Bill Ronald

Keith Rushton

Sir Sydney Samuelson CBE

Vice Presidents

Simon Knights

Andy Martin

Matthew Kelly

Jeremy Champion

Sebastian Crewe

Candida Crewe

Sir Guy Weston

Nicola Manby

Jeremy D Pelczer

Sir Alex Ferguson CBE

Sarah E Kelly

Anil Ahir

Michael A Thirkettle

Charity Crewe

Sophia Bergqvist

Julian Pritchard

Andrew J Weir

Andrew Graham

Charles Manby MBE

Frances Carey

Ann McNeil

Alexandra Wellesley Wesley

Victoria Elliston

Ian Mathieson

Louisa Hill

Our Research Vice Presidents

Professor Kate Bushby M.D.
Professor Patrick Chinnery FRCP FMedSci
Professor Dame Kay Davies DBE FRS FMed Sci
Dr David Hilton-Jones MA MD FRCP FRCPE
Professor Darren Monckton PhD
Professor Francesco Muntoni FRCPCH FMed Sci
Professor Mary Reilly MD FRCP FRCPI FMedSci
Professor Volker Straub MD PhD
Professor Douglas M Turnbull MBBS (Hons), MD, PhD, FRCP
Professor Matthew Wood MBChB MA DPhil FMedSci

Joseph Patrick Trust Grants Panel

Robert Warner (Chair)
Karen Duckmanton
Jane Field
Jane Freebody
James Lee
Patricia Lock
Julian Pritchard (Vice-Chair)
Kirsty Read
Jo Becker

Joseph Patrick Trust Management Committee

Julian Pritchard (Chair)
Ian Gordon
Robert Warner

Finance Committee

Marcus Brown (Chair)
Ian T Gordon (stepped down Jun 2022)
Hélène Crutzen PhD
Ian Mathieson
Charles Scott
Joseph Gordon
Brigid Sutcliffe
Michael Armstrong

Appointments and Remuneration Committee

Professor Mike Hanna FRCP MD MRCP BM BCh FMedSci (Chair)
Ian Gordon
Baroness Celia Thomas of Winchester MBE
Charles Scott

Medical Research Committee

Professor Patrick Chinnery FRCP FRCPath FMedSci (Chair)
Dr Gillian Butler-Browne PhD (Vice-Chair)
Professor Grainne Gorman MRCP, PhD
Dr Anna Mayhew PhD (stepped down July 2022)
Dr Jasper Morrow MBChB, PhD, FRACP
Professor Olivier Pourquie PhD
Professor Mary Reilly MD, FRCP, FRCPI (stepped down July 2022)
Professor Ketan Patel PhD
Professor Tracey Willis MBChB MRCPI MD
Professor Linda Popplewell PhD
Professor Heidi Fuller PhD
Professor Frédéric Relaix PhD
Dr Stefan Winblad PhD

Lay Research Committee

Richard Davenport (Chair)
Peter Ashley (Vice- Chair)
Corinthia Joseph
Alison Kay PhD
Hilary Rattue
Roli Roberts (Scientific advisor)
Andy Rose
Helen Stockdale (stepped down July 2022)
Manoj Thakrar
Alex Williamson (stepped down July 2022)
Natalie Woodcock
Graham Gornall
Victoria Houghton
David Towler
Alexa Gummow
Hannah Langford
Giovanna de Kock (invited)

Services Development Committee

Baroness Celia Thomas of Winchester MBE (Chair)
Dr Chiara Marini-Bettolo
Phillippa Farrant
Sheila Hawkins
Professor Deirdre Kelly CBE
Dr Fiona Norwood
Professor Francesco Muntoni
Professor Ros Quinlivan
Carolyn Young
Tanvi Vyas
Phillip Anderson
Lloyd Tingley

Appeal Board

The Appeal Board is a group of senior volunteers, who meet quarterly to help raise funds and awareness through their extended networks. The work of this group of committee volunteers was paused in February 2022.

Martin Cardoe (Chair)

Michelle Anthony

Alex Elberg

Joseph Gordon

Martin Hywood

Tim Lumsdon

Charles Scott

Northern Ireland Council

Claire O'Hanlon (Chair)

Claire Boylan (Secretary)

Jim McKeogh

Lucy Hare

Anne Hughes

Catherine Taggart

Suzanne Glover

Ruth Henry

Jaci McFetridge

Frances Ashe

Dave McClean

Phil Ellis

Hayley Ellis

Conor O'Kane

Houston Watson

Kerry McStravog

Niamh Mullan

Conor O'Kane

Mairead Scott

Catherine Taggart

Scottish Council

Dr Sheonad Macfarlane BSc Med Sci, MB ChB (Chair)

Lindsey Armstrong

Michael Armstrong

Connor Colhoun

David Davidson

Claire Eadie

David Gale

Catherine Gillies

Mairi Leitch

Scott McIntyre

Gill Mitan

Allyson Townhill

Stuart Townhill

Board of Trustees

Professor Michael Hanna FRCP MD MRCP BM BCh FMedSci (Chair)

Marcus Brown (Treasurer)

Michelle Anthony

Michael Armstrong

Martin Cardoe

Ian T Gordon

Joseph Gordon

Sheila Hawkins (until October 2021)

Louisa Hill (until July 2021)

Claire O'Hanlon MBE

Professor Deirdre Kelly CBE (from October 2021)

Scott Keown

Charles Scott

Baroness Celia Thomas of Winchester MBE

Tanvi Vyas

Robert Warner

Senior Leadership Team

Catherine Woodhead, Chief Executive Officer

Dr Kate Adcock, Director of Research and Innovation

Rob Burley, Director of Care, Communications and Support

Emma Jones-Parry, Associate Director of Development

Wojtek B Trzcinski, Director of Finance and Resources

We are hugely grateful to our enthusiastic and generous committee members, whose support and tireless commitment meant that this year they worked with us on developing fundraising events within the limitations of the new world that we live in. Ensuring that with live events going ahead guests, participants and volunteers remained safe but that ambitious targets were smashed. Thank you to the Microscope Ball Committee, Sports Quiz Committee, The Q Trust, The Clay Pigeon Shoot Committee and the Appeal Board.

We also value the dedication and commitment of those who fundraise for us through our Branches, Groups and Family Funds, as well as the individuals who raise funds for us as their chosen charity. Thank you – your efforts make a huge difference in the fight against muscle-wasting conditions, especially this year when once again, many of you took on those extraordinary challenges, when we've needed it most.

MDUK relies almost entirely on voluntary donations and legacies to fund our core work. This year, because of the pandemic, we received £331k as part of the government's emergency funding for medical research charities (5% of our fundraising income).

As part of our role as co-chair of the Changing Places Consortium, our Campaigns, Care and Support team has received grant funding from the Department for Transport (DfT) and Department for Levelling Up, Housing & Communities (DLUHC) to support projects that will see significant increased provision of Changing Places toilets in England. Our DfT partnership involves the distribution of grants for installations in motorway service areas and across the transport network; and our partnership with DLUHC involves our providing information and advice to Local Authorities that are in receipt of funding to increase provision in existing buildings. These partnerships as co-chair of the Changing Places Consortium represent £2,457k (45%) of the restricted funds in our 2021/22 accounts (2021: £2,580/54%).

We are sincerely grateful to everyone who has donated to and fundraised for our work over the past year.