

Muscular Dystrophy UK

Fighting muscle-wasting conditions



Annual Report and Financial Statements Year ended 31 March 2021

www.muscular dystrophyuk.org

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Report of the Board of Trustees 2020/21

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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 muscle-wasting conditions; to promote the provision of care and treatments to those affected; to assist those who care for individuals affected by such conditions; to promote education and training for affected individuals and 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 an estimated 70,000 people living with a neuromuscular condition today. We believe this as passionately now as we did when we were established 60 years ago. It drives everything we do.

It is this vision that unites us all – from 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.

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 2020/21

Overview

Performance Indicators	Progress during the year
To support research with the goal of effective treatments and cures being identified for all conditions	Owing to the pandemic and resultant impact on our financial situation, we cancelled our grant round in 2021. We also withdrew a small number of grants. Our priority was to continue support for as many of our ongoing research investments as possible.
To ensure access to specialist NHS care from a multidisciplinary team	We successfully secured NHS funding for seven new neuromuscular specialist posts, meaning we have secured and saved in the NHS up to a total NHS investment of £7.5m per year in specialist services; we supported clinical networks and provided training to more than 2,000 health and care professionals through online training modules, to better equip them to meet the needs of people affected by muscle-wasting conditions.
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 2,100 requests for information or support over the phone and by email, and 22,000 info factsheets were downloaded from our website. We saw a 46 percent increase on the previous year in the number of visits to the care and support section of our website.
Income generation	<p>We realised the impact that the pandemic was going to have on the original budgets we set back in January 2020 (totalled £6.2m, including legacies), with the immediate impact felt in February and March 2020; we initially estimated a drop in fundraising and legacy income of £2.8m. Our final reforecast figures, in line with the restrictions on our activity, moved to £3.9m.</p> <p>Our core supporter base has shown huge loyalty, donating to our emergency appeal, unrestricted grants and taking on virtual events, which helped us to reduce the initial funding gap we forecast. The fundraising landscape continued to change with the impact of the pandemic and we remained versatile in adapting activities and creating virtual models, agile with our activities and pivoting our strategy to work within the confines of the pandemic. We re-evaluated Return on Investment across the teams and restructured accordingly to ensure that we were investing in the fundraising methods that had proven to perform well during the first year of the pandemic.</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 begun the journey to encourage new researchers to join the field.

Owing to the impact of the COVID-19 pandemic, we cancelled our annual grant round in 2020. This meant that we made no new grants. Instead, we focused on providing support to as many of our ongoing research investments as possible. Three of our projects had been paused in 2019/20 because of changes in the personnel employed on the grant. We made the difficult decision to terminate these grants in order to protect as much of our grant portfolio as possible. We understand that this is disappointing. We continue to support a wide range of research projects into muscle-wasting conditions.

Like nearly all places of work, laboratories and research institutes were affected by the COVID-19 pandemic. Many staff employed on grants were furloughed. Staff have now returned, although many are working part-time or different hours, with social distancing measures in place.

To help off-set the delays imposed by the pandemic, we offered no-cost extensions to all our grant-holders and over half of our ongoing grant-holders took advantage of this. This means that while we are not granting any additional funds, we have extended the grant end dates to allow for more time to complete the work – or as much work as possible – with the budget. Despite the difficulties experienced by scientists, research is moving forward.

A number of grants reached their natural end during 2020/21 and, at the end of the year, the charity was funding approximately 40 projects in the UK and through international partnerships.

Until the end of April 2020, MDUK was funding the clinical work in the UK of the UNITE-DMD study. Genethon and their partners, Sarepta Therapeutics, have taken over the financial support for this work and are working with clinical research teams in France, in the UK, and at other international sites to take the trial forward.

MDUK is an executive member of the European Neuromuscular Centre (ENMC). This organisation was set up over 25 years ago to "encourage and facilitate communication and collaboration in the field of neuromuscular research with the aim of improving diagnosis and prognosis, finding effective treatments and

optimising standards of care to improve the quality of life of people affected by neuromuscular disorders". Members of the ENMC are national neuromuscular research charities from across Europe. The ENMC supported seven workshops in 2020/21, although the format of these was impacted heavily by the COVID-19 pandemic. The workshop organisers worked with the ENMC team to arrange virtual meetings, with face-to-face meetings to be held later. Many of these workshops included UK clinicians, researchers and patient representatives. This could not have happened without MDUK's support.

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

What we'll do next

We will continue to Invest to **deliver high-quality research** to understand the underlying causes of muscle-wasting conditions, always making sure our investment aligns with our research strategy and has maximum impact. In 2021/22, we will continue supporting

research, including our PhDs, to whom we are already committed to realise the potential of the initial investment. We will also complete a smaller than usual Grant Round that will focus on a limited number of conditions. The Grant Round will also feature the return of our partnership with Spinal Muscular Atrophy UK to support a four-year PhD studentship in SMA research.

We will continue to **encourage scientists** with new ideas and technologies to come into this area of research, building on existing scientific study to develop a new generation of therapies, with the ultimate goal of being able to treat all people, whatever their muscle-wasting condition.

We continue to help meet growing demand by **facilitating access to clinical trials** through our investment in the MDUK Oxford Neuromuscular Centre, which promotes the translation of scientific research into clinical trials. We will also continue our support for registries in 2021/22.

Driving change for access to specialist care and support

The COVID-19 pandemic had a huge impact not only on the specialist neuromuscular services that people living with a muscle-wasting condition rely upon, but also on their ability to access them. We had to put on hold our usual provision of professional development opportunities for health and other professionals involved in providing care and support for people affected by muscle-wasting conditions, as well as forums and events where they can share best practice. This was because we had to adjust our activity to direct our reduced capacity to where it was most needed. We maintained our commitment to securing access to the latest treatments for people living with muscle-wasting conditions, working in partnership with individuals, families, clinicians and other patient groups across the assessment and approval processes of seven treatments for muscle-wasting conditions.

Spinraza, the first treatment for spinal muscular atrophy (SMA) is now available, with some exclusions, for people with SMA types 1, 2 and 3 in England through a Managed Access Agreement (MAA). It's also available in Wales, Northern Ireland and Scotland. We continued in our role on the Spinraza Managed Access Oversight Committee (MAOC), helping to ensure that data being collected during the five-year MAA period can be used to secure permanent access in future. With other patient groups and clinical experts, we pushed for the eligibility criteria of the MAA to be extended so that everyone who could benefit from it would be able to receive it. Roll-out of the treatment to eligible adults has been a particular challenge, and we have engaged with individual Trusts and Health Boards to help address this.

We have been active in the appraisal processes for two other SMA treatments – Risdiplam and the gene therapy, Zolgensma. During 2020/21, Risdiplam became available to eligible patients across the United Kingdom – first through a Compassionate Use Programme and then through an Early Access to Medicines Scheme (EAMS) – ahead of the full assessment

process for NHS access taking place in 2021/22. We worked in partnership with patients and other charities to successfully challenge some Trusts and Health Boards that weren't implementing the EAMS.

We made a joint submission to the Scottish Medicines Consortium (SMC) for its review of Zolgensma, representing patients at the Patient and Clinician Engagement (PACE) meeting stage of the assessment process and at the New Drugs Committee. The SMC approved the treatment for NHS use and we published communications to explain who would be eligible and the next steps in the rollout. We actively engaged in the NICE assessment of the treatment, which also led to approval for NHS access in England.

In 2020/21, we continued our role on the MAOC for the Duchenne muscular dystrophy treatment, Translarna, by:

- helping to navigate the impact of COVID-19 on essential data collection in what was due to be the final year of the MAA
- calling for an extension to the MAA
- ensuring that families were kept informed of developments.

As 2020/21 came to a close, we welcomed confirmation that NICE, NHS England and NHS Improvement and PTC Therapeutics (the company) were exploring options to extend the MAA. In Scotland, we led a joint submission by six charities to the SMC and spoke on behalf of patients in the committee meeting, which resulted in the treatment being made available through the 'ultra-orphan pathway'.

In 2020/21, access to a second Duchenne muscular dystrophy treatment, Idebenone, through an EAMS was halted and plans to assess the treatment through NICE withdrawn. This was a result of questions about its efficacy, following an interim review of clinical trial findings commissioned by the treatment's manufacturer. We worked in partnership with clinicians and other charities to provide information and support to those affected by this decision.

We represented patients during the SMC and NICE assessments of Mexiletine, a treatment for myotonia in adults with non-dystrophic myotonic disorders. This led to approval of the treatment for use on the NHS in Scotland, with the assessment process in England continuing into 2021/22.

We also engaged in the early stages of the potential treatment for Pompe disease, *avalglucosidase alfa*, by representing patients at the NICE Scoping Workshop for the therapy.

We are passionate about securing swift access to the latest treatments for people with muscle-wasting conditions. As well as engaging in the approval processes for individual treatments, we have also engaged in the NICE methods review.

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 secured NHS funding for seven new specialist neuromuscular roles, including consultants, nurses and physiotherapists. This means that since 2013, we have helped secure 109 new specialist neuromuscular roles in the NHS and saved a further 16 from being lost. This represents a total NHS investment of £7.5m per year in specialist services – to help people live well with their condition – that would not otherwise be available to them.

Helping specialist neuromuscular health professionals develop their skills and share best practice is a key way in which we ensure that people living with muscle-wasting conditions receive the best possible care. During 2020/21, we adapted and ran many well-attended virtual meetings for our regional and national neuromuscular networks. We also launched a new online professional development module for palliative care specialists and more than 2,000 professionals took our other online training modules.

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 2020/21, we successfully adjusted to the impact of the COVID-19 pandemic and delivered a number of virtual meetings of these key groups.

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, money worries, physical symptoms and emotional well-being. And in 2020/21, we had to rapidly adapt our activity in order to support our community in the face of the COVID-19 pandemic, while navigating the impact of the pandemic on our capacity to deliver those services.

At the start of the COVID-19 pandemic, we recognised that we were uniquely placed to provide a trusted source of information and advice for people with muscle-wasting conditions. We created an online resource to collate and interpret guidance and information about COVID-19 and the available support, so that it was clear to see how this applied to people living with muscle-wasting conditions. We put this guidance on our website, and it was viewed 45,000 times in 2020/21. In order to ensure the accuracy of our information, we established a group of four leading neuromuscular consultants who edited and approved our guidance before we published it, and we led a collaboration between nine neuromuscular charities to co-ordinate dialogue between patient groups and clinicians. This had the added benefit of releasing pressure on specialist NHS staff, who could direct patients to our website and team for support.

As well as providing information and advice to our community, we also ensured that the voice of people with muscle-wasting conditions was heard on key issues, such as treatment decisions, shielding policy and vaccine prioritisation. Again, working in partnership was crucial to this

activity. We worked as part of a number of informal and formal collaborations, such as National Voices and the charity sector Shielding and High Risk Coalition. We also joined the cross-government Shielding Working Group, led by the Department for Health and Social Care.

We raised concerns about the potential impact of the Coronavirus Bill on people with muscle-wasting conditions and, along with other charities, successfully challenged NICE guidance that initially suggested people with underlying conditions such as muscle-wasting ones might be prevented from receiving acute treatment for Coronavirus. We were also vocal about BMA guidelines that caused similar concern. We helped ensure that people classed as Clinically Extremely Vulnerable, which included many people living with a muscle-wasting condition, were placed in priority group four for COVID-19 vaccination. And we helped ensure that guidance around who was classed as Clinically Vulnerable, and therefore placed in priority group six, specifically referenced people living with muscle-wasting conditions.

Our helpline team continues to provide practical advice and support and listen to

people's concerns. Despite our reduced resources because of the impact of COVID-19, we responded to 2,126 phone and email requests for support from people with muscle-wasting conditions. More than 83,000 people visited our website's care and support areas (a 46 percent increase on the 2020/21 figure) and downloaded 22,000 info factsheets. In addition, 3,200 people used our online forum to share experiences and support each other – a 7 percent increase on the year before. Our Research Line helped 168 people find out more about the latest developments and clinical trials.

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. For much of the year, we were able to offer only a reduced service, focusing primarily on supporting people to secure Personal Independence Payments (PIP). This was because we redirected our reduced resources to supporting our community through the COVID-19 pandemic. But in January, we were able to resume the full service and by the end of 2020/21, we had supported 250 people through our advocacy service.

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). We weren't able to make any grants in 2020/21 owing to COVID-19, but in February we were delighted to re-open the scheme for applications for a grant round taking place in April 2021.

In addition to providing information and support through our helpline and advocacy

services, we had planned to bring people together throughout the year through our normal programme of information and support events, local Muscle Groups and our National Conference. None of these activities was possible because of the impact of COVID-19, but we brought our community together by delivering 'Muscles Matter 2020', our first-ever programme of virtual information and support events. The programme of 14 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 1,487 bookings from 854 individuals, with a combined 2,388 views on YouTube. We will deliver a 2021 Muscles Matter programme, and establish a virtual model for the first round of Muscle Groups.

We continued to co-chair the Changing Places consortium, which ensures that people are able to access toilet and changing facilities in public places, and promotes their use. We continued to administer a £2m grant programme in partnership with the Department for Transport (DfT) to ensure there is adequate provision of Changing Places toilets in motorway service areas in England. This project has been impacted by the COVID-19 pandemic, but we continue to work with the partners to ensure rollout continues as soon as possible. We agreed a new partnership with the DfT to increase provision of these facilities across other areas of the transport network. We also finalised a new partnership with the Ministry of Housing, Communities and Local Government (MHCLG) 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.

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 2020/21, we continued our support of research in Scotland. We supported three research projects at three universities: St Andrews, Edinburgh and Glasgow. Work on the project at the University of Glasgow has been on hold because it requires individuals with Duchenne muscular dystrophy to visit the hospital to take part in the study. Naturally, the measures in place to deal with the pandemic have affected this work.

We supported 38 advocacy cases in Scotland and responded to 104 requests for support, and we continued to work closely with the Scottish Muscle Network. We continued to focus our influencing work in Scotland – on access to treatments and on key issues affecting people living with a muscle-wasting condition – around our role as secretariat of the Cross Party Group on Muscular Dystrophy in the Scottish Parliament. We also engaged in the SMC assessment processes for the treatments, Translarna and Mexiletine, and worked with individual Health Boards in Scotland to seek improved access for eligible patients to the SMA treatments, Spinraza and Risdiplam. Our Scottish Council supported and advised us throughout the year, and we held three virtual meetings.

Inspired by those who took on the 2.6 challenge, long-term supporter and Scottish Council member, Dave Gayle, set a challenge at the end of April to walk 500 miles. David's fundraising efforts moved many – leading to others joining in and racking up the miles to help reach the

500-mile goal. On 27 May 2020, Dave was delighted to announce the challenge was complete, with a total of 501 miles walked and an incredible £950 raised.

On 25 July 2020, young Alfie Hadden took to the local streets in East Kilbride to complete a personal 5k challenge. His inspiration comes from his Auntie Emma, who has limb girdle muscular dystrophy and blogs, as Simply Emma, about accessible travel and live music events from a wheelchair user's perspective. Alfie was thrilled when a couple of Rangers FC players visited him ahead of his fundraising challenge, which led to a number of press stories. Alfie, aged just four, completed the 5k challenge with his dad and helped raise an incredible £4,570.

Between 17 and 25 October, a team from Green Investment Group took on a virtual race from their Edinburgh office to their London office – a total of 376 miles. The team took to the challenge as a work colleague, Kay Riley, has muscular dystrophy. Thanks to the efforts of those involved, and funds matched by way of the Foundation Week at Macquarie, the team raised a fantastic £2,865.

The Big Give at the end of November saw donations from the Perth Branch, Scottish Council, Leo's Pride, Josephine Lobban, Cayley Timber, Angela Ross and Lisa Dick, to name a few. Combined donations saw an incredible £11,265 donated, which was then topped up further – a great result for Scotland.

December saw another Big 60 challenge, this time by Leo's Pride. The Family Fund held the event in memory of Leo, who would have turned six in December 2020. An array of supporters took on a mixture of challenges, including running 6km a day for six consecutive days, 60 burpees per day for six consecutive days, and covering 60 miles for the month of December. Everyone's determined efforts saw a staggering £6,466 raised, bringing the Family Fund's total since launch to over £60,000.

Sadly, in January 2021, Eoghan Warner, son of MDUK Trustee Robbie Warner and Eileen Warner, passed away. Well known to many, and loved by all that knew him for his kind and funny nature, Eoghan's loss was felt by all. Donations in memory of Eoghan were made to MDUK, with over £10,000 pledged – illustrating just how much Eoghan meant to all that knew him.

In February 2021, Laura Stokes decided to donate her commission from sales made throughout the month via her Body Shop business to MDUK. This great fundraising idea was a brilliant success, seeing a fantastic £1,003 raised.

A special thanks to everyone who has supported fundraising in Scotland during this extraordinary year – you helped to contribute a phenomenal £108,763, despite the ongoing impact that the pandemic had on face-to-face fundraising.

Plans for 2021/22

We regularly review the external environment and, before the potential effects of the pandemic were realised, we were already concerned about the potential consequences of Brexit on the research and care sector. Statistics for the impact of the pandemic are stark:

- Pro Bono Economics estimates the funding gap between income and expenditure across the charitable sector could reach £10 billion, with the business and household purse affected, and demand for charitable activities increasing
- the Association for Medical Research Charities (AMRC), of which we are a member, estimates medical research charities have lost at least £292m in income, forcing them to cut £270m of their research spend.

The COVID-19 pandemic has pushed us to drive our collaborative spirit further, working with charities in the neuromuscular sector to deliver guidance at pace, and to see what priorities our community had during this period. We saw an increase in the number of people contacting the helpline for guidance and support, including care plans/alert cards.

In 2019/20, our advocacy service secured over £1.5m of financial support for people with muscle-wasting conditions; the first time that this figure has exceeded £1m in a financial year. In 2020/21, we had to limit the scope of this service in order to manage our reduced capacity. After we fully reopened it in January 2021, demand was as high as before the pandemic, highlighting our continued concerns about the challenges individuals face in gaining access to the support they are entitled to, such as PIP, and the vital role that MDUK plays in helping people to overcome these challenges.

There are over 70,000 people living in the UK with over 60 rare and ultra-rare muscle-wasting conditions. The vast majority 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.

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.

Our core work is to:

- support research to drive the development of effective treatments and cures
- ensure access to specialist NHS care and support
- provide services and promote opportunities to enable individuals and their families to live as independently as possible.
- In addition, 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 matters
 - 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 2021/22, we will:

Accelerate research to develop effective treatments and cures:

- **Invest money to deliver high-quality research** to understand the underlying causes of muscle-wasting conditions, always making sure our investment has maximum impact; we will continue to support research that we are already funding to realise the potential of the initial investment; we will hold a focussed grant call, matched to the restricted funds we are holding; in 2022/23, we aim to hold a grant round with a remit that includes a wider range of neuromuscular conditions.
- **Encourage scientists with new ideas and technologies** to come into this area of research, building on existing scientific study to develop a new generation of therapies, with the ultimate goal of being able to treat all people, whatever their muscle-wasting condition; support for PhDs will continue to be a priority.
- **Use seed funding to drive innovation** and influence our partners and others to do the same; using core costs only, we will continue to pursue our partnership with Healx.
- Help meet growing demand by increasing access to clinical trials through our investment in the MDUK Oxford Neuromuscular Centre, which promotes the translation of scientific research into clinical trials.
- **Harness the power of genetics** by continuing to support the UK clinicians involved in the Genethon Duchenne muscular dystrophy gene therapy clinical trial (previously UNITE-DMD) to dose boys in the UK; through our continued support of research projects funded through our annual grant rounds.
- **Facilitate drug development** by providing crucial information, through natural history case studies on how a condition progresses with time and how it affects people; continuing with funding the world's largest natural history study in Duchenne muscular dystrophy, known as the NorthStar programme.
- **Increase our understanding of the disease mechanism** through our continued support of research projects our annual grant rounds fund.
- **Improving the quality of life** by developing evidence-based interventions that improve the quality of life of people with muscle-wasting conditions, through our partnership with Healx.

Drive change for access to specialist NHS care:

- **Fast track access to treatments**, to get drugs from the lab bench to people with muscle-wasting conditions more quickly, by working with the National Institute for Health Research to improve access to clinical trials across neuromuscular centres in the UK and ensure clinical trials are designed robustly. We will continue to engage in the approval processes for relevant treatments.
- **Support professionals** so that better-trained and supported staff provide improved care and ensure that more people with muscle-wasting conditions receive the support they need. We know a late diagnosis has implications, so a more formal diagnosis of a condition must be delivered more quickly; in 2021/22 and 2022/23, we will work in partnership to ensure that health professionals better understand muscle-wasting conditions and their impact on people's lives; we will hold a virtual conference/series for health professionals.

- **Improve access to NHS specialist support**, driving improvements in specialist neuromuscular care across the UK, identifying the challenges faced by neuromuscular services as a result of the Coronavirus pandemic, and working in partnership with services to overcome them. We will provide professional development to health and care professionals through regional neuromuscular networks, online modules and virtual events.
- **We will use our influence to improve NHS psychology services** for people with muscle-wasting conditions, by working in partnership.

Improving quality of life by enabling independent living:

- **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 officers in the devolved nations, and through our local Muscle Groups. We will continue to deliver our high-quality, accessible support for everyone on the phone, online and, when possible, face to face. We will deliver our virtual Muscles Matter series and resume our Muscle Group meetings – initially virtually.
- **Change communities** by supporting those who want to take action to change the communities they live in; through our Moving Up project we will continue to support young people to gain access to employment, and by working with our co-chair of the Changing Places consortium Pamis in Scotland, we will improve access to Changing Place toilets.
- **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; we will continue our role as co-chair of the Changing Places consortium and deliver projects with the DfT and MHCLG to help increase the provision of Changing Places toilets in sports and leisure facilities in England; and we will continue to sponsor the Powerchair football leagues with the Wheelchair Football Association and the Scottish Powerchair Football Association.

Fundraising:

- **Deliver a £5m gross budget; £4.2m in active fundraising and £930k in legacy, which will result in a net figure of £3.1m.** Budget figures reflect a period of cautious consolidation, where an assumption that live events and face-to-face activities will return, producing a growth in income, but caution in that the effects of the pandemic will continue to be felt on the household and corporate purse.
- **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 pandemic.
- **Maximise the return on investment** through effective deployment of our resources.
- **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 in order 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 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 compliance
- to never sell or swap donor data
- to never rank donors based on wealth
- not to share data with external agencies for the purposes of wealth screening or finding data you haven't provided to us before
- 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 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, mailing campaigns, 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, printer and mailing houses for external mailings, and the majority of our regional and national challenge events through commercial participation agreements. We 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 (formally Fundraising Standards Board) and subscribe to the fundraising codes of practice. This year, we have attended online virtual webinars where reputable companies have offered free training to those in need, which has allowed staff to remain up-to-date in all areas of fundraising governance and training.

The number of complaints received in 2020/21 was a total of 10, which derived from the following: 0 from 15,215 mailings about our raffles to warm supporters; 0 from 691 participants at our own virtual fundraising events; 0 from 1,314 participants at our own virtual challenge events; 8 complaints from 2,363 entrants to one challenge event that was cancelled owing to the pandemic and, in accordance with the terms and conditions, didn't offer refunds; 1 from 204 volunteer fundraising events; 0 from 52,106 pieces of direct mail sent out; 1 from 2,627 people who received an email from us advising them of a data breach affecting our fundraising software provider, Blackbaud (which, they later informed us, had not been breached).

Financial review

The total income for 2020/21 was £5,544k (2020: £6,201k). Income from donations, gifts, grants and fundraising activities totalled £3,051k (2020: £4,880k), a substantial reduction owing to COVID-19 pandemic restrictions impacting MDUK fundraising events. Legacies income for 2020/21 was £874k (2020: £979k). Investment income was £158K (2020: £211k). Other income amounted to £157k (2018: £131k). In addition, £1,304k was received in Government Grants, including £505k of Furlough grant and £799k Changing Places Project grants to be used in the future (2020: no government income was received).

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. With COVID-19 impacting the charity's operations and delivery, as explained earlier in this report, the charitable expenditure for the year was reduced by 40% to £2,371k compared to the previous financial year (2020: £4,018k). MDUK has preserved any unspent funds as part of its reserves, and will use them to support future charitable activities.

Medical research in the search for effective treatments and eventual cures for muscle-wasting conditions comprised 28% (2020: 30%) of the total expenditure on charitable activities. Access to specialist NHS care and support comprised 53% (2020: 41%), and provision of information, support and opportunities to enable independent living comprised 19% (2020: 29%) of our charitable activity. A number of research grant provisions and commitments were reviewed during 2020/21. Because of the changing circumstances of the grantees and altered timing of need, it was revised down by £875k.

The charity had a challenging year financially, but ended 2020/21 with a net surplus of £2,681 (2020: deficit of £622k). The largest contributor to the surplus was net recovery on investments of £711k (2020: loss on of £473k caused by the start of the COVID-19 pandemic). MDUK also suspended some activities in the first six months of 2020/21 while using the furlough scheme, and its ability to organise any fundraising events was largely affected for the full 12 months of the year. Moreover, as explained in the research section of this report, the new research grant call was withheld. All these factors resulted in savings that contributed to the surplus. An unrestricted surplus of £2,537 (2020: deficit of £431k) for the year will allow the charity to recover and face any future impacts of the COVID-19 pandemic, which in the view of Trustees and management is going to affect the sector for at least the next two financial years. The restricted surplus of £144k (2020: deficit of £191) was mainly from receipt of further Changing Places grants, which are budgeted to be expended as the project continues over the next few financial years.

Reserves policy

Free reserves available to the charity exclude restricted and endowment 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 calculated annually in advance 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. The Trustees consider that in order to meet these needs, and to operate effectively, the charity needs reserves of around £1.5-£2.0m, based on the current analysis of risk. This has been reviewed in line with 2021/22 budget review.

The 2020/21 financial year provided a challenging environment for the sector with reduced income as a result of the COVID-19 pandemic and restrictions on service delivery because of lockdowns across the country. MDUK responded to these challenges quickly by reducing costs and reviewing its long-term liabilities. This resulted in the charity being able to survive the pandemic without using the reserves. The Trustees and Senior Leadership Team (SLT) view was that the impact of the pandemic would be felt for much longer than one year and there would be substantial risks to delivery and income generation for at least the next two financial years. Therefore, it was agreed that the charity manage an emergency budget until the end of August followed by a new budget from September to end March to protect reserves where possible in the 2020/21 financial year, delivering essential charitable activities during an unknown period of adjustment to the pandemic. We aimed to raise funds as much from emergency funding appeals and pivoted fundraising projects to sustain the charitable activities during 2020/21 and if possible to maintain or even (as we did) build up the reserve to secure post-pandemic continuation of charitable activities in the 2021/22 and 2022/23 financial years.

The charity's free unrestricted reserves were £2,243k at 31 March 2020 (excluding tangible assets). This included a free reserve of £841k and designated reserves of £1,401k. To allow more flexibility when operating under pandemic conditions, the designations were lifted by the Trustees in November 2020. Through the investment portfolio value recovery, review of the liabilities and cost savings, MDUK managed to increase its unrestricted reserves by £2,537k in 2020/21, resulting in total unrestricted funds of £4,969k at 31 March 2021. This was mainly due to unrealised gains on the investments and major reduction in expenditure due to reduced activities, both fundraising and charitable activities. The level of activities is expected to go back to normal from 2021/22 financial year and these funds will support delivery at pre-pandemic level in still challenging fundraising environment with UK economy adjusting to the 'new norms'.

The unrestricted funds balance is 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. It will also support a development of the new strategic plan, when they current strategy comes to an end in 2022.

In addition, the Trustees agreed to invest £250k of the general funds to allow MDUK to update

our IT and CRM (database) systems to minimise risks to the data system, lower longer-term costs, and mobilise the staff to work in the new post-COVID-19 environment. This would enable the charity to review in a year's time its premises' needs, which would lead to a long-term cost reduction when our contract with the landlord comes to an end.

The higher level of total reserves (free and designated) than outlined in the policy played a substantial role in providing the charity with additional security when faced with the COVID-19 pandemic.

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.

Remuneration policy

Salaries of the Chief Executive and the 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.

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 17.

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.

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 a buffer against loss of income or unplanned expenditure – during the COVID-19 pandemic, the charity has reviewed these fortnightly, then monthly, and the charity will return 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.

Our risk management policy proved effective during the COVID-19 pandemic. 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, including an initially estimated £2.8m income drop against the original budget. Together, they:

- minimised the net effect on the charity reserves by prompt reduction of expenditure and full review of the budget to adapt to the new landscape
- delivered virtual fundraising and information/support programmes
- in May 2020, completed a restructure to transition into the new financial model with a reduction in staff from 85 to 55 to ensure long-term sustainability.

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. 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.

Going concern

Having reviewed the strategic risks facing the charity and the five-year financial projections, the Board of Trustees considers that there are sufficient reserves held at 31 March 2021 to manage those risks effectively. The Trustees consider that there is a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Accordingly, they continue to adopt the 'going concern' basis in preparing the Annual Report and Accounts.

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, senior leadership team and advisors are set out on pages 49 to 53.

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 and anybody over the age of 18 who supports and promotes the objects of the charity can become a Member. 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 a briefing that covers 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), care (Services Development Committee, SDC), finance (Finance Committee), fundraising (Appeals Board) 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 continue to work together on how these principles and practices should be applied at MDUK.

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.

Provision of information to auditors

Each person who is a director at the date of approval of this report confirms that:

So far as the director is aware, there is no relevant audit information of which the company's auditors are unaware, and the director has taken all the steps that he/she ought to have taken as a director in order to make himself/herself aware of any relevant audit information and to establish that the company's auditors are aware of that information; and this confirmation is given and should be interpreted in accordance with the provisions of Section 418 of the Companies Act 2006.

The Chief Executive, Catherine Woodhead, will continue to lead the charity to deliver the five-year financial plan to expend any additional unrestricted reserves over the period of this forecast; to ensure that at the end of the strategic projects in 2021/22, the charity ends with a break-even unrestricted budget and the minimum level of unrestricted funds needed to ensure stability in the face of operational risks. This was assessed as between £1.5m-£2.0m by the Board in 2020/21, and will be reviewed in 2021/22 in light of the ongoing effects of the COVID-19 pandemic and new reduced organisational structure.

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.

This report, incorporating the Strategic Report, is approved by the Board and signed on its behalf by:

Professor M Hanna

Chairman

20 July 2021

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 for the year ended 31 March 2021 which comprise the Consolidated Statement of Financial Activities, the group and charitable company's Balance Sheets, the Consolidated Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion, the financial statements:

- give a true and fair view of the state of the group's and of the parent charitable company's affairs as at 31 March 2021 and of the group's and parent charitable company's net movement in funds, including the income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

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

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

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

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

Auditor's responsibilities for the audit of the financial statements

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

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

Based on our understanding of the group and the environment in which it operates, we identified that the principal risks of non-compliance with laws and regulations related to the regulatory requirements of the Charity Commission and Office of Scottish Charity Regulator (OSCR), and we considered the extent to which non-compliance might have a material effect on the financial statements. We also considered those laws and regulations that have a direct impact on the preparation of the financial statements such as the Charities Act 2011, the Charity Accounts (Scotland) Regulations (as amended), Charities SORP (2019), Companies Act 2006 and payroll taxes.

We evaluated management's incentives and opportunities for fraudulent manipulation of the financial statements (including the risk of override of controls) and determined that the principal risks were related to the recognition of voluntary income and grant commitments. Audit procedures performed by the engagement team included:

- Enquiries of management regarding correspondence with regulators and tax authorities;
- Discussions with management including consideration of known or suspected

- instances of non-compliance with laws and regulation and fraud;
- Reviewing the controls and procedures of the charity, particularly in relation to the recording of income and processing of payments and payroll, to ensure these were in place throughout the year, including during the Covid-19 remote working period;
 - Evaluating management's controls designed to prevent and detect irregularities;
 - Reviewing and testing journal entries made in the year, particularly those made as part of the year end financial reporting process; and
 - Challenging assumptions and judgements made by management in their critical accounting estimates which comprise depreciation, legacy income accruals, grants payable, fund accounting and the non-recognition of services in kind.

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

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Kathryn Burton FCA (Senior Statutory Auditor)
For and on behalf of Haysmacintyre LLP, Statutory Auditors
10 Queen Street Place
London EC4R 1AG

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR ENDED 31 MARCH 2021

	Notes	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2021 £000	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2020 £000
Income							
Income from charitable activities							
Donations, gifts and grants	2	2,199	751	2,950	3,308	1,415	4,723
Government grants		505	799	1,304			
Legacies	2	874	-	874	800	179	979
					-	-	
Income from other trading activities		93	8	101	30	127	157
					-	-	
Investment income	2, 10	158	-	158	211	-	211
					-	-	
Other income	2	142	15	157	116	15	131
Total income		3,971	1,573	5,544	4,465	1,736	6,201
Expenditure							
Expenditure on raising funds	3	1,136	-	1,136	2,166	45	2,211
					-	-	
Costs from other trading activities	3	67	-	67	121	-	121
		1,203	-	1,203	2,287	45	2,332
Charitable activities							
Medical research	3,5	(33)	700	667	(96)	1,300	1,204
Access to specialist care and support	3	965	299	1,264	1,415	244	1,659
Independent living	3	253	187	440	851	304	1,155
Total – charitable activities		1,185	1,186	2,371	2,170	1,848	4,018
Total expenditure		2,388	1,186	3,574	4,457	1,893	6,350
Net gain/(loss) on investment assets	9	659	52	711	(439)	(34)	(473)
Transfer between funds		295	(295)	-	-	-	-
Net movement in funds		2,537	144	2,681	(431)	(191)	(622)
Reconciliation of funds							
Total funds brought forward	15	2,432	4,609	7,041	2,863	4,800	7,663
Total funds carried forward	15	4,969	4,753	9,722	2,432	4,609	7,041

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 48 form an integral part of the financial statements.

BALANCE SHEETS AS AT 31 MARCH 2021

COMPANY REGISTRATION NUMBER 705357

	Note	Group 2021 £000	Group 2020 £000	Charity 2021 £000	Charity 2020 £000
Fixed Assets					
Tangible Assets	8	189	190	188	188
Investments	9	5,628	4,820	5,258	4,503
Total Fixed Assets		5,817	5,010	5,446	4,691
Current Assets					
Stock	12	11	13	-	-
Debtors	13	373	443	405	467
Cash at Bank		7,194	7,040	7,189	6,988
Total Current Assets		7,578	7,496	7,594	7,455
Creditors falling due within one year	14	(3,673)	(5,465)	(3,387)	(5,100)
Net Current Assets		3,905	2,031	4,207	2,355
Total Assets less current liabilities		9,722	7,041	9,653	7,046
Net Assets		9,722	7,041	9,653	7,046
The funds of the Charity					
Unrestricted					
- Designated	15	439	1,591	438	1,591
- General	15	4,530	841	4,492	876
		4,969	2,432	4,930	2,467
Restricted					
Endowment	15	4,348	4,256	4,318	4,226
	15	405	353	405	353
Total Charity Funds		9,722	7,041	9,653	7,046

The Statement of Financial Activities for the year ended 31 March 2021 for the parent charitable company only was a surplus of £2,569k (2020: deficit of £599k).

The accompanying notes on pages 33 to 48 form an integral part of the financial statements. Approved and authorised for issue by the Board of Trustees on 20 July 2021 and signed on its behalf by:

M Hanna
Chairman

M Brown
Treasurer

STATEMENT OF GROUP CASHFLOWS – FOR THE YEAR-ENDED 31 MARCH 2021

	2021 £000	2020 £000	
Net cash inflow/(outflow) from operating activities (note a)	152	(1,584)	
Net Cash flow from investing activities			
Dividends from investments	158	211	
Purchase of Tangible Fixed Assets	(58)	(69)	
Proceeds of sale of Investments	1,171	1,295	
Purchase of Investment	(1,269)	(1,267)	
Net Cash provided by investing activities	2	170	
Increase/(decrease) in cash and cash equivalents in the year	154	(1,414)	
Reconciliation of net cash inflow to movement in net funds			
Increase/(decrease) in cash and cash equivalents in the year (note b)	154	(1,414)	
Cash and cash equivalents at the beginning of the year	7,040	8,454	
Cash and cash equivalents at the end of the year	7,194	7,040	
Notes to cash flow statement			
(a) Reconciliation of net movement in funds to net cash flow from operating activities:			
	2021 £000	2020 £000	
Net movement in funds	2,681	(622)	
Dividends from investments	(158)	(211)	
Investment (gains) / losses	(711)	473	
Depreciation	58	62	
Decrease in debtors / stock	73	290	
Decrease in all creditors	(1,791)	(1,576)	
Net cash provided by/(used in) operating activities	152	(1,584)	
(b) Analysis of changes in net cash funds			
	1-Apr-20 £000	Cashflows £000	31-Mar-21 £000
Cash and cash equivalents	7,040	154	7,194
Total cash and cash equivalents	7,040	154	7,194

The accompanying notes on pages 33 to 48 form an integral part of the financial statements.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

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 the continued 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; revised budgets were prepared in August 2020 and adopted, understandable reductions were made to the revenues, there were also reductions in costs, all of which resulted in protecting the reserves and net surplus for the year. In March 2021, new financial year budgets were prepared, taking into consideration continued Covid-19 restrictions in 2021/22, and the likely effects on some streams of fundraising. The budgets and cash flows were reviewed in July 2021 and the Trustees have considered forecasts covering twelve months period until July 2022. 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).

1. ACCOUNTING POLICIES (cont.)

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

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.

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 of 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 have been allocated to each activity on the basis of expenditure incurred.

1. ACCOUNTING POLICIES (cont.)

Governance costs have been allocated in line with cost of administration and 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 used to donate by way of Gift Aid all taxable profits to the parent charity. In November 2020 a deed of covenant was signed between the trading company and parent charity, which now guides this arrangement.

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.)

TANGIBLE FIXED ASSETS AND DEPRECIATION

Items or projects with a value exceeding £500, and which have a life exceeding one year, are likely to be 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. This is to an employee's portable scheme. 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

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 management and support costs where applicable.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

2. INCOME

	2021			2020		
	Unrestricted Funds	Restricted Funds	Total 2021	Unrestricted Funds	Restricted Funds	Total 2020
	£000			£000		
Events and promotions	717	153	870	1,450	301	1,751
Direct marketing	837	13	850	726	24	750
Corporate	75	-	75	258	133	391
Trusts	185	403	588	138	540	678
Regional development	477	191	668	766	544	1,310
Legacy	874	-	874	800	179	979
Other income *	806	813	1,619	327	15	342
Total income	3,971	1,573	5,544	4,465	1,736	6,201

* Of this income £1,304k comes from Government Grants (2019/20 £0). The government grants included the Furlough grant of £505k and Changing Places Project grants of £799k.

3. EXPENDITURE

	Direct Costs			2021 £000
	Grants £000	Other £000	Support Costs £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	567	2,371
Total Expenditure	167	2,660	748	3,574
	Direct Costs		Support	2020
	Grants £000	Other £000	Costs £000	£000
Raising Funds				
Expenditure on raising funds	-	1,981	230	2,211
Costs from other Trading Activities	-	111	10	121
Total	-	2,092	240	2,332

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

3. EXPENDITURE (cont.)

Charitable Expenditure				
Access to care and independent living				
Access to care	-	1,350	309	1,659
Independent living	223	717	215	1,155
Total	223	2,067	524	2,814
Pursuit of Knowledge				
Medical research	495	486	223	1,204
Total Charitable Expenditure	718	2,553	747	4,018
Total Expenditure	718	4,645	987	6,350
'Direct Costs' include all costs incurred in delivering the relevant activity.				
'Support Costs' comprise of the following :				
			2021	2020
			£000	£000
Chief Executive and Human Resources			96	114
Finance and insurance			238	311
Office costs			271	397
Information Technology			121	141
Governance			22	24
Total			748	987

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 Trailblazers.

§ 'Welfare Grants' includes grants made through the Joseph Patrick Trust to individuals.

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

4. STAFF COSTS (Group and Parent Charity)

	2021	2020
	£000	£000
Remuneration of Staff		
Wages and Salaries	1,934	2,746
Social Security Costs	183	261
Pensions	107	152
Total	2,224	3,159

The monthly average number of employees during the period was 59 (2019/20: 86), of whom there were the following higher paid employees as detailed below.

17 redundancies were made in the year (2019/20: 6). The cost of the redundancy payments was £24k (2019/20: £13k).

Details of the Key Management Personnel, which consists of the Senior Management Team, can be found on page 49. Their total aggregate salary was £447k (2019/20: £502k).

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

4. STAFF COSTS (Group and Parent Charity) cont.

	2021 No	2020 No
Earned between the ranges		
£60,000 to £70,000	2	-
£70,000 to £80,000	-	3
£100,000 to £110,000	1	1
	2021 No	2020 No
Number of staff by activity		
Direct Charitable Expenditure	18	41
Fundraising and Publicity	35	38
Management and Administration	6	7
Total	59	86

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 2021 £000	Total 2020 £000
Grants awarded in the year	1,067	3	1,070	2,058
Grants cancelled in the year	(875)	(28)	(903)	(1,340)
Total	192	-25	167	718
	Research Grants £000	Welfare Grants £000	Total 2020 £000	
Grants awarded in the year	1,743	315	2,058	
Grants cancelled in the year	(1,248)	(92)	(1,340)	
Total	495	223	718	

With the exception of 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.

Apart from the two strategic grants at University of Oxford (MDUK Oxford Neuromuscular Centre) and Royal Holloway University of London (UNITE-DMD), there were no institutions in receipt of material grants (over £80k pa) in 2020/21.

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 2021

5. GRANT EXPENDITURE (cont.)

		2021 £000	2020 £000
Payable between one and five years		3,311	3,066
Reconciliation of grant funding commitments :			
	Research 2021 £000	JPT 2021 £000	Total 2021 £000
Carrying amount at start of year	4,309	352	4,661
Additions	1,067	3	1,070
Amounts charged and cancelled in year	(2,436)	(83)	(2,519)
Carrying amount at end of year	2,940	272	3,212

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.

	2021 £000	2020 £000
Expiring up to one year	257	257
Expiring between one and five years	257	514

7. NET INCOME

Net Income is stated after charging

	2021 £000	2020 £000
Auditor's remuneration	21	22
Auditor's remuneration - non audit services	10	1
Depreciation	58	62
Operating lease rentals	232	232

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

8. TANGIBLE FIXED ASSETS

Group	Leasehold premises £000	Computer equipment £000	Motor cars £000	Other assets £000	Other equipment £000	Total £000
Cost at 1 Apr 2020	201	457	109	15	48	830
Disposal	-	-	-9	-	-	-9
Additions	-	58	-	-	-	58
At 31 Mar 2021	201	515	100	15	48	879
Depreciation 1 Apr 2020	137	351	105	-	48	641
Disposal	-	-	-9	-	-	-9
Provided for year	20	34	4	-	-	58
At 31 Mar 2021	157	385	100	-	48	690
Net Book Value						
At 31 Mar 2021	44	130	-	15	-	189
At 31 Mar 2020	64	107	4	15	-	190

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 2021 £000	Group 2020 £000	Charity 2021 £000	Charity 2020 £000
Market Value at beginning of year	4,820	5,321	4,503	4,961
Acquisitions	1,269	1,267	1,181	1,258
Sales proceeds	(1,171)	(1,295)	(1,081)	(1,284)
	4,918	5,293	4,603	4,935
Realised (loss)/gain on disposals	(83)	73	(85)	78
Unrealised gain / (loss) on revaluation of Investments	794	(546)	741	(510)
Market value at end of year	5,628	4,820	5,258	4,503
Historical Cost at end of year	4,353	4,282	4,042	3,972

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

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 2021 £000	Group 2020 £000	Charity 2021 £000	Charity 2020 £000
- UK and Overseas equities	3,510	2,428	3,234	2,220
- UK and Overseas fixed interest	1,375	1,306	1,342	1,282
- Property funds	341	460	311	423
- Hedge funds	220	223	205	208
	5,446	4,417	5,092	4,133
Cash on Deposit awaiting investment	120	341	104	308
Unlisted equities	62	62	62	62
Total	5,628	4,820	5,258	4,503

The unlisted equity investment has been valued at its likely realisable value.

Investment management costs for the year were £28k (2019/20: £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. (2019 : £nil)

10. INCOME FROM INVESTMENTS

	Group 2021 £000	Group 2020 £000	Charity 2021 £000	Charity 2020 £000
UK Equities, UK fixed interest and other	143	162	134	150
Short term Deposit and Bank interest	15	49	15	48
	158	211	149	198

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.

Their net assets and results for the year ended 31 March 2021 are summarised below:

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

11. INVESTMENTS IN SUBSIDIARY UNDERTAKINGS cont.

	Muscular Dystrophy Group (Trading) Ltd £000	Joseph Patrick Trust £000
Fixed Assets	2	370
Current Assets	52	4
Current Liabilities	(51)	(306)
Total Net Assets	3	68
Represented by:		
Total Funds	3	68
Total income	101	66
Total expenditure*	(64)	12
Surplus for the year	37	78
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 £11k (2019/20 : £13k).

13. DEBTORS

	Group 2021 £000	Group 2020 £000	Charity 2021 £000	Charity 2020 £000
Trade debtors	40	76	4	11
Amount due from subsidiary undertakings	-	-	71	107
Prepayments and accrued income	320	340	317	337
Other debtors	13	27	13	13
	373	443	405	468

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

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

14. CREDITORS FALLING DUE WITHIN ONE YEAR

	Group 2021 £000	Group 2020 £000	Group 2021 £000	Group 2020 £000
Accruals for grant payable	3,212	4,661	2,94	4,309
Accruals and Deferred Income	128	248	123	250
Taxation and Social Security	58	72	50	73
Other Creditors	275	484	274	468
	3,673	5,465	3,387	5,100

15. FUNDS

	April 2020 £000	Income £000	Expendi- ture £000	Movement between funds* £000	Invest- ment 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)	-	-	-	(0)
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
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 and Endowment 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

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

15. FUNDS cont.

General Fund	841	3,912	(2,329)	1,446	659	4,530
Total Unrestricted Funds	2,432	3,970	(2,387)	295	659	4,969
Total Funds	7,041	5,544	(3,574)	-	711	9,722

2019/20 Comparatives	April 2019 £000	Income £000	Expendi- ture £000	Movement between funds*	Invest- ment gains £000	March 2020 £000
<i>Endowment Fund</i>						
Orchid Ball Endowment Fund	387	-	-	-	(34)	353
<i>Restricted Funds</i>						
Provision of care						
City Bridge Trust / Work experience	54	55	(56)	-	-	53
Comic relief	-	46	(22)	-	-	24
Psychological support	41	105	(30)	-	-	116
Powerchair football	11	34	(26)	-	-	19
Other care	165	358	(311)	-	-	212
Joseph Patrick Trust - Assistive Technology	47	-	(17)	-	-	30
Changing Places	2,008	30	(77)	-	-	1,961
Research						
The Patrick Research Fund	342	-	(35)	-	-	307
Attenborough Fellowship	-	1	(1)	-	-	-
Oxford Neuromuscular Centre	215	149	(37)	-	-	327
Q Trust Fellowship	246	3	-	-	-	249
Walton Fund	27	-	-	-	-	27
Duchenne Research	417	308	(428)	-	-	297
15. FUNDS (cont.)						
Ullrich Research	139	85	(118)	-	-	106
Nemaline Research	118	40	(13)	-	-	145
Congenital MD	12	28	(75)	-	-	(35)
Becker Research Fund	42	59	(29)	-	-	72
Other research	529	435	(618)	-	-	346
Total Restricted Funds	4,800	1,736	(1,893)	-	(34)	4,609
<i>Designated Funds</i>						
Research	1,076	-	96	-	-	1,172
Clinical	447	-	(218)	-	-	229
Tangible Assets for Charity Use	183	69	(62)	-	-	190
Total Designated Funds	1,706	69	(184)	-	-	1,591
General Fund	1,157	4,396	(4,273)	-	(439)	841
Total Unrestricted Funds	2,863	4,465	(4,457)	-	(439)	2,432
Total Funds	7,663	6,201	(6,350)	-	(473)	7,041

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

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

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'.

The Trustees of the Patrick Research Fund previously converted a loan to Muscular Dystrophy UK into a fund to be applied towards research for a cure for DMD.

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

Other funds represent other restricted funds raised for specific research or projects.

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 movement of £295k from restricted to restricted funds represents 'unrestricting' of the funds with donors' permission to allow more flexibility to manage the charity finances during the Covid-19 pandemic pressure.

The designation of balances is as follows:

- 'tangible assets for charity use' represent the amount of unrestricted funds represented by these assets
- IT and CRM (database) systems' update designated fund
- the General Fund is available for the ongoing operations of the charity.

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

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2021

15. FUNDS cont.

Represented by: 2020	Fixed Assets £000	Investments £000	Net Current Assets £000	Total £000
Endowment Funds	-	353	-	353
Restricted Funds	-	2,398	1,858	4,256
Designated Funds	190	1,401	-	1,591
Unrestricted Funds	-	668	173	841
Total Funds	190	4,820	2,031	7,041

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:

	2021 £000	2020 £000
Residuary	1,310	656
Reversionary	250	250
	1,560	906

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:

	2021 £000	2020 £000
Donations	18	1
Expenses	-	2

No Trustee received any remuneration during the year (2019/20: £nil).
There were no other related party transactions (2019/20: none).

Presidents, Board of Trustees and Committees

Remembering our Royal Patron (1921-2021) HRH The Prince Philip, Duke of Edinburgh KG KT OM GBE ONZ QSO AK GCL CC CMM

We were deeply saddened to learn of the death of His Royal Highness, Prince Philip, our Royal Patron since 1966. It's hard to put into words how privileged we feel to have had his unwavering support for more than 50 years. He was deeply committed to the fight against muscle-wasting conditions and, as a result of his dedication to MDUK and the profile that he helped us to achieve, we have been able to make real progress in the fields of research and support over the years. We are grateful for his long service to the charity and send our condolences to the Queen and her family.

President

Gabby Logan MBE

Honorary Life Presidents

Professor Martin Bobrow CBE FRS FMed Sci

Sue Barker CBE

Baroness Celia Thomas of Winchester MBE

Patrons

Professor Alan Emery

Ian Corner

Bill Ronald

Sir Sydney Samuelson CBE

Keith Rushton

Vice Presidents

Anil Ahir

The Hon. Michael Attenborough CBE

Karen Attenborough

Sophia Bergqvist

Frances Carey

Jeremy Champion

Candida Crewe

Charity Crewe

Sebastian Crewe

Victoria Elliston

Sir Alex Ferguson CBE

Andrew Graham

Matthew Kelly

Sarah Kelly

Simon Knights

Charles Manby

Nicola Manby
Andrew Martin
Ian Mathieson
Ann McNeil
Jeremy Pelczer
Julian Pritchard
Michael A Thirkettle
Andrew J Weir
Guy Weston
Alex Wellesley Wesley

Our Research Vice Presidents

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

Joseph Patrick Trust Grants Panel

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

Joseph Patrick Trust Management Committee

Julian Pritchard (Chair)
Ian T Gordon
Robert Warner

Finance Committee

Marcus Brown (Chair)
Hélène Crutzen PhD
Ian T Gordon
Joseph Gordon
Ian Mathieson
Charles Scott

Appointments and Remuneration Committee

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

Ian T Gordon

Richard Price (until March 2021)

Charles Scott (from March 2021)

Baroness Celia Thomas of Winchester MBE

Medical Research Committee

Professor Hugh Willison MBBS PhD FRSE FMedSci (Chair)

Dr Gillian Butler-Browne

Professor Thomas Gillingwater MBA PhD

Dr Anna Mayhew PhD

Dr Jasper Morrow MBChB PhD FRACP

Professor Olivier Pourquie PhD

Professor Mary Reilly MD FRCP FRCPI FMedSci

Professor Frédéric Relaix

Professor Ulrike Schara MD PhD

Professor Dominic Wells MA VetMB PhD MRCVS FHEA FS (Deputy Chair)

Dr Stefan Winblad

Lay Research Committee

Alex Williamson (Chair until 31 March 2020)

Richard Davenport (Vice Chair until 31 March 2020; Chair from 1 April 2020)

Peter Ashley (Vice Chair from 1 April 2020)

Andrew Graham

Corinthia Joseph

Alison Kay PhD

Giovanna de Kock

Stephen Meech (until 31 March 2021)

Hilary Rattue

Roli Roberts PhD (Scientific advisor)

Andy Rose

Helen Stockdale

Manoj Thakrar

Natalie Woodcock

Services Development Committee

Baroness Celia Thomas of Winchester MBE (Chair)

Philip Anderson

Dr Chiara Marini-Bettolo

Phillippa Farrant

Sheila Hawkins

Dr David Hilton-Jones

Professor Deirdre Kelly

Sue Manning
Professor Francesco Muntoni FRCPCH FMedSci
Dr Fiona Norwood
Professor Ros Quinlivan FRCPCH FRCP MD
Carolyn Young
Tanvi Vyas

Appeal Board

The Appeal Board is a group of senior volunteers, who meet quarterly to help raise funds and awareness through their extended networks.

Martin Cardoe (Chair)
Alex Elberg
Joseph Gordon
Martin Hywood
Tim Lumsdon
Charles Scott

Northern Ireland Council

Claire O'Hanlon (Chair)
Clare Boylan (Secretary)
Frances Ashe
Hayley Ellis
Phil Ellis
Suzanne Glover
Lucy Hare
Ruth Henry
Anne Hughes
Dave McClean
Jaci McFetridge
Jim McKeogh
Conor O'Kane
Catherine Taggart
Houston Watson

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

Emergency Committee

Owing to the impact of the COVID-19 pandemic on the charity, an Emergency Committee was set up for a finite period, with the CEO and Finance Director.

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

Marcus Brown (Treasurer)

Ian T Gordon

Joseph Gordon

Ian Mathieson

Richard Price

Charles Scott

Board of Trustees

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

Marcus Brown (Treasurer)

Michael Armstrong

Martin Cardoe

Ian T Gordon

Joseph Gordon

Sheila Hawkins

Louisa Hill

Claire O'Hanlon

Richard Price (until March 2021)

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 Campaigns, Care and Support

Emma Jones-Parry, Associate Director of Development

Stephen Mooney, Director of Communications and Marketing

Wojtek B Trzcinski, Director of Finance and Resources

Remembering Valerie Patrick, Vice President with a lifelong commitment to MDUK, who we sadly lost in February 2021.

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 virtual campaigns, set and smashed fundraising targets despite not being able to organise and attend live events. 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 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 £106k as part of the government's emergency funding to the sector (3% 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 DfT and the MHCLG 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 MHCLG 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 £2,580k (54%) of the restricted funds in our 2020/21 accounts.

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