

Muscular Dystrophy UK

Fighting muscle-wasting conditions



Annual Report and Financial Statements Year ended 31 March 2020

www.muscular dystrophyuk.org

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Report of the Board of Trustees 2019/20

1	Report of the Board of Trustees	3-24
2	Independent Auditor's Report to the Trustees and Members of the Muscular Dystrophy Group of Great Britain and Northern Ireland	25-27
4	Consolidated Statement of Financial Activities	28
5	Balance Sheet (Group and Charity)	29
6	Consolidated Cash Flow Statement	30
7	Notes to the Financial Statements	31-47
8	Patron, President, Honorary Life Presidents, Vice Presidents, Board of Trustees and Committees	48
9	Senior management team and advisors	52
10	With gratitude	52

The Board of Trustees of Muscular Dystrophy UK (the operating name of the Muscular Dystrophy Group of Great Britain and Northern Ireland) presents its Annual Report and Financial Statements for the year ended 31 March 2020.

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 more than 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 activities and impact described in the report below all contribute to the public benefit delivered by the charity.

The work of Muscular Dystrophy UK

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.

Muscular Dystrophy UK (MDUK) works to improve the lives of an estimated 70,000 people living with a muscle-wasting or associated condition today. We believe this as passionately now as we did when we were established over 60 years ago. It drives everything we do.

It is this vision that unites us all – from researchers we fund to the health professionals that we support 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 have faster access to treatments, as well as 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 leading to vital progress such as an early and accurate diagnosis, access to steroid treatments, spinal surgery and respiratory support, which, with improved care, enhances 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.

Achievements and performance against objectives for 2019/20

Overview

Performance Indicators	Progress during the year
To support research with the goal of effective treatments and cures being identified for all conditions	In 2019/20 we continued our support for high-quality research and committed £1.2m into nine new research projects as well as £1.3m to support UK clinical trial capacity and other activities that underpin research into neuromuscular conditions. We continue to provide information on current research developments and clinical trials through our rebranded Research Line, bringing the total research commitment to over £10m.
To ensure access to specialist NHS care from a multi-disciplinary team	We successfully secured NHS funding for 11 neuromuscular specialist posts, supported clinical networks, and provided training to over 2,600 through conferences and 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 over 3,200 requests for information or support over the phone, email and face-to-face, and 22,000 info factsheets were downloaded from our website. We saw a seven percent increase on the previous year in the number of people we supported through our advocacy service, securing over £1.5m in services for them.
Income generation	We were on track to achieve the total budgeted income target for this year but owing to the impact of the COVID-19 pandemic on our work, we raised £6.2m. This was £383k below our anticipated fundraising budget. We developed a new regional strategy to focus on the audiences that have the greatest reason to support MDUK, in order to develop long-term and meaningful relationships with them. This growing of grassroots support, focussing on localised fundraising groups and Family Funds, meant we were in a good position when the impact of COVID-19 hit.

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 muscle-wasting or associated 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 invest in high-quality research to deepen our understanding of muscle-wasting conditions and support studies into ultra-rare conditions. We have begun the journey to encourage new researchers to join the field. In addition, we have continued to work to expand patient access to clinical trials.


We entered into a new funding relationship with SMA UK to jointly support PhD students in our Grant Round 2020. Unfortunately, we had to cancel the Grant Round 2020 as a result of the COVID-19 pandemic. Nevertheless, we continue to maintain relationships with funders such as the Medical Research Council, the National Institute of Health Research and others, to develop new opportunities for joint working.

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 eight workshops in 2019/20, seven of which included UK clinicians, researchers and patient representatives. This could not have happened without MDUK's support.

In 2019/20, we reviewed and streamlined our grant-making and grant scheme processes. In consultation with our Medical Research Committee, we have amended the eligibility for applicants. As of the Grant Round 2020, each applicant can submit up to one grant application per grant type; multiple grant applications for the same grant type will not be accepted. In addition, a single resubmission of a previously turned-down MDUK application is permitted.

We awarded nine new research projects and PhD studentships in 2019/20. These grants address aspects that fit with the four priority areas outlined in our research strategy, namely: harnessing the power of genetics; understanding disease mechanisms; facilitating treatment development; and improving quality of life and wellbeing. Some of these projects will investigate methods to improve the delivery of drugs, optimise the use of cough-assist devices and



find out how many people are living with muscle-wasting conditions in the UK. The charity is now funding around 50 different projects in the UK and through international partnerships.

Through our individualised service, the MDUK Research Line, we have continued to ensure that patients and families can find out about new studies and treatments and clinical trials.

Driving change for access to specialist care and support

In 2019/20, we continued our campaigning activity to secure access to the latest treatments for people living with muscle-wasting conditions, working in partnership with individuals, families, clinicians and other patient groups. We also continued to provide professional development opportunities for health and other professionals involved in providing care and support for people living with muscle-wasting conditions, as well as forums and events where they can share best practice. This a key way in which MDUK drives up the quality of the services people use and, through our successful campaigning for specialist neuromuscular NHS roles, we continued to grow the workforce across the UK.

In May 2019, NICE approved the use of Spinraza, the first-ever treatment for spinal muscular atrophy (SMA). The treatment is now available in England, with some exclusions, for people with SMA types 1, 2 and 3, through a Managed Access Agreement (MAA), which follows approval in Scotland at the end of 2018/19. During 2019/20, access also became available in Wales and Northern Ireland. We were successfully appointed to the Spinraza Managed Access Oversight Committee (MAOC), where we play a key role ensuring that data being collected during the five-year MAA period can be used to secure permanent access in future, and identifying any issues with the implementation of the MAA. We are also committed to fighting for the MAA eligibility criteria to be extended so that everyone who could benefit from it is able to receive it.

Spinraza is the second treatment that we sit on an MAOC for and, in 2019/20, we continued our role on the MAOC for the Duchenne muscular dystrophy treatment, Translarna. We also engaged in the early stages of the approval processes for non-dystrophic myotonia treatment, Mexilitine; Duchenne muscular dystrophy treatment, Idebenone; and SMA

treatments, Zolgensma and risdiplam. We are passionate about securing swift access to the latest treatments for muscle-wasting conditions. As well as engaging in the approval processes for individual treatments, we will also seek changes to the overall approval process for treatments for rare conditions by, for example, engaging in the NICE methods review.

We aim to ensure that people with any type of muscle-wasting or associated 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 11 new specialist neuromuscular roles, including consultants, nurses and physiotherapists. This means that since 2013, we have helped secure 102 new specialist neuromuscular roles in the NHS, and saved a further 16 from being lost. This is a total NHS investment of £6.9m per year in specialist services – to help people live well with their condition – that would not otherwise have been available to them.

Ensuring that specialist neuromuscular healthcare professionals are able to

develop their skills and share best practice, is a key way we ensure that people living with muscle-wasting conditions receive the best possible care. During 2019/20, 332 healthcare professionals attended our national Care Advisor Conference and Physio Conference, as well as a range of regional upskilling events. Over 2,300 professionals took our online training modules.

A muscle-wasting condition can affect every aspect of life, and we are committed to ensuring that muscle-wasting conditions, as well as the importance of access to treatments and high-quality neuromuscular specialist services, remain high on the political agenda. Ahead of the December 2019 UK General Election, we launched a Manifesto for Muscles, highlighting key areas of importance to people living with muscle-wasting conditions. Two hundred and forty-eight candidates pledged their support for the manifesto, 39 of whom were elected to the House of Commons; this provides a fantastic base of parliamentary support to help our influencing on key issues over the next few years.

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. This ensures that issues affecting people with muscle-wasting conditions receive political attention across the whole of the UK.

In our continued commitment to improving mental health support for people living with muscle-wasting conditions, we delivered mental health training to 26 neuromuscular specialist care advisors to help equip them to

support the individuals and families they work with. We also met with Minister for Mental Health Jackie Doyle-Price MP, to discuss progress against the recommendations of our major 2018 parliamentary report into access to psychological support for people with muscle-wasting conditions.

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

Being diagnosed with a muscle-wasting condition can often mean 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 online, over the phone, in communities and in hospitals. We cover every topic from the latest research, money worries, physical symptoms and emotional well-being.

Our helpline team continue to provide practical advice and support and to listen to people's concerns; we answered 1,009 calls, responded to 1,118 emails and provided face-to-face advice and support to 1,098 people in neuromuscular specialist clinics. We also provide support through our information resources and online forum. Over 57,000 people visited our website's care and support areas, and downloaded 22,000 info factsheets. In addition, 3,000 people used our online forum to share experiences, and support each other. Our Research Line helped over 470 people find out more about the latest research 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. This year the growth in demand on the service continued, as more people turned to us for help in accessing the benefits, care and services that they are

entitled to, as well as advice on housing adaptations and education support. We supported 985 people, a seven percent increase on the previous year, and secured £1.511m worth of support, more than double the total secured in 2018/19.

As well as supporting people to access financial support, we continued to provide grants to help people living with muscle-wasting conditions meet the costs of practical aids, equipment and assistive technology. Through the Joseph Patrick Trust (JPT), our grant-giving arm, we provided 234 people with grants that totalled £279k.

At the same time as providing direct support to help people with muscle-wasting conditions access the financial support they are entitled to, we campaigned for improvements to the benefits system and raised concerns about the employment experience of young disabled people. We published *Below standard: MDUK's assessment of the benefits system*, a report based on the experiences of 592 people living with a muscle-wasting condition, and launched in Parliament our Trailblazers report *Ready and able: removing the barriers that prevent young disabled people from finding employment*. We discussed the findings and recommendations of both reports with Minister for Disabled People, Justin Tomlinson MP.

In addition to providing information and support through our helpline and advocacy services, we brought people together so they could build and strengthen connections with others living with muscle-wasting conditions. As well as the 811 people who attended our range of information and support events, 3,071 people were registered to local Muscle Groups, where people can share their experiences and discuss local and national issues that affect their quality of life or prevent them from living independently. In October, a total of 312 people came together at our National Conference to reflect on 60 years of progress since the establishment of MDUK, and a further 544 people engaged with the event through our Facebook Live feeds.

We continued to co-chair the Changing Places consortium, which ensures access to more accessible toilet and changing facilities in public places, and promotes their use. There are now 1,483 registered Changing Places toilets across the UK. We continued to administer a £2m grant programme in partnership with the Department for Transport to ensure there are adequate Changing Places facilities in motorway service stations in England. We welcomed a Department of Health and Social Care announcement that 16 new Changing Places toilets are to be installed at hospitals in 10 NHS Trusts, and we continued to work with Tesco, who now have Changing Places toilets in nearly 100 stores.

We want to ensure that we properly support the people who volunteer their time and expertise to us, and to increase the reach and impact of our support through volunteering. We formed a Volunteer Steering Group,

produced a volunteer handbook, and began work on a volunteering strategy to embed a joined-up approach across the organisation. We piloted volunteer-led initiatives, including condition-specific support groups and support groups for children and young people.

Scotland

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

In 2019/20, we continued our support of research in Scotland. We supported five research projects at three universities: in St Andrews, Edinburgh and Glasgow. One of our grant-holders, Prof Eric Schirmer at the University of Edinburgh, has devised a way to pinpoint defective genes that are linked to a rare form of muscular dystrophy (Emery-Dreifuss muscular dystrophy), which causes muscle weakening and heart problems. This research could pave the way to help people to get a diagnosis earlier, thus helping them to manage their condition and provide a better quality of life.

Our influencing work in Scotland on access to treatments and on key issues affecting people living with muscle-wasting conditions continued through our role as secretariat of the Cross Party Group on Muscular Dystrophy in the Scottish Parliament. We were able to use this forum to engage directly with Prof Alison Strath, Principal Pharmaceutical Officer at the Scottish Government, on access to the SMA treatment Spinraza in Scotland. This followed our campaigning, which helped secure the drug's availability from 1 April 2019 under the Scottish Medicines Consortium ultra-orphan pathway.

We took part in a joint meeting with the Cross Party Group on Rare, Genetic and Undiagnosed Conditions on hospice provision of short-term respite breaks. We then worked with the Prince and Princess of Wales Hospice to raise the issue directly with Minister for Public Health, Sport and Wellbeing Joe FitzPatrick MSP, in a meeting alongside Convenor of the

Cross Party Group, Jackie Baillie MSP.

Our UK-wide report, *Below standard*: MDUK's assessment of the benefits system, included contributions from 40 people living with muscle-wasting conditions in Scotland. We also engaged a number of MSPs on the findings of the report, securing their support for its recommendations and calls to action. We consulted a number of MSPs who are signed up to the Disability Confident scheme to gather their views and experiences and to discuss the recommendations in our Trailblazers report, *Ready and able*: removing barriers that prevent young disabled people from finding employment.

At the start of 2019/20, we increased the level of support we were able to offer people living with muscle-wasting conditions in Scotland, by making our Information and Advocacy post full-time. Our information and advocacy service in Scotland provided 217 people with information and advice, and supported 172 people to get the benefits, care and equipment they were entitled to. We provided 23 people living in Scotland with £23,847 of grants to help meet the costs of aids and equipment. We have continued to work closely with the Scottish Muscle Network, through the clinic support provided by our Advocacy and Information Officer, and through collaboration on events and information days. We held a number of Muscle Group and other meetings in Scotland where people with muscle-wasting conditions heard more

about Self-Directed Support, support for carers, and we held a day for young people transitioning from children's to adult services.

February 2020 saw great support for our revamped Go Bright fundraising campaign: 58 people registered across Scotland and raised over £8k.

Thirty-nine people registered to Skydive for MDUK, including Muscle in with Somhairle supporters, Thomas Bradley & Co staff, a team from the Hot Tub Supercentre, a team from Applus Ltd and Leo's Pride supporters. Owing to the COVID-19 pandemic, these jumps have now been pushed back to late 2020 and 2021.

The Spirit of Christmas concerts at the Broom Parish Church in Newton Mearns in December 2019 were a great success seeing a fantastic £4,093 raised from the two nights. Children and teachers from Stagecoach Theatre Arts performed on the evening with special guest Gordon Smith also taking to the stage.

There were three collections at Glasgow Central station and Edinburgh Waverley station raising £1,986 and we had three collections at Tesco stores raising £975.

This year was great for our running portfolio, 18 people signed up to the Edinburgh Marathon Festival, raising £3,500. Scottish TV actor Jordan Young took part in the Great Scottish Run half-marathon and raised £4,331.

Our Family Funds have been successful this year in Scotland, in particular Nicola's Ninjas who held their annual charity disco event in November at the Parklands Hotel and Country Club, raising an amazing £3,778. Michael Armstrong, of Georgie's

Genes, took on an epic 35-mile ultra-marathon challenge around the island of Tiree, finishing sixth out of over 200 participants and raising over £8k.

The last-ever Pedal for Scotland cycle event took place in September. Sarah and Jane represented Muscle in with Somhairle in the 45-mile challenge from Glasgow to Edinburgh. MDUK Trustee Robbie Warner also cycled, with six-year-old Hugh Macdonald taking part for Family Fund Elliot's Fighting Fund. To date, everyone has raised a fantastic £1,375.

Also in September, Sharon and Emma took on the gruelling Loch Ness Beast Race in support of Leo's Pride, raising £1,580.

Leo Flett passed away in July, aged just four. Leo, who had congenital muscular dystrophy, touched many hearts and left a big impression on those who knew him. In celebration of his life, Leo's Pride will continue to help raise awareness and vital donations for MDUK so Leo's legacy can continue in helping make every day count for those with congenital muscular dystrophy.

Thanks to everyone who supported fundraising in Scotland this year – you helped to contribute a phenomenal £186,502 for the region.

Plans for 2020/21

We regularly review the external environment and were already concerned about the potential consequences of Brexit on the research and care sectors. The charity sector is estimating a loss of over £12bn from the impact of COVID-19, with both the business and household purse affected. The COVID-19 crisis has enabled us to drive our collective spirit further with charities in the neuromuscular sector, as we delivered guidance at pace. The COVID-19 crisis enabled us to see what priorities our community had during this period; we saw an increase in people contacting the helpline for guidance and support, including care plans/alert cards.

Prior to this, our advocacy support secured over £1.5m for the people we supported in 2019/20, exceeding £1m for the first time in a financial year. This highlighted our continued concerns about the challenges individuals face in gaining access to the support they are entitled to.

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, owing to a better understanding about their conditions and therefore better specialist care and opportunities to live well for longer.

When we agreed the three-year strategy in 2018, 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:

- 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.

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; in 2020/21 we will focus our reduced financial investment in research that we are already supporting to realise the potential of the initial investment; in 2021/22 we will hold a focussed grant call matched to the restricted funds we are holding.
- **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.
- **Use seed funding to drive innovation** and influence our partners and others to do the same; using core costs only, in 2020/21 we will launch the Healx partnership and work together to deliver the first treatments for facioscapulohumeral muscular dystrophy (FSHD), using artificial intelligence (AI) technology.
- **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 building on our long-term investment in gene therapy, started by Prof George Dickson and his team at Royal Holloway University London (RHUL); in 2020/21, we will support Linda Popplewell and her team at RHUL to complete work into the AAV vector as part of the UNITE-DMD study, and provide support to the UK teams at Newcastle and UCL as part of the UNITE-DMD study to determine the safety of gene therapy for people living with Duchenne muscular dystrophy (DMD).
- **Facilitate drug development** by providing crucial information, through natural history case studies on how a condition progresses with time and how it affects people; in 2020/21 and 2021/22, continuing with funding the world's largest natural history study in DMD, known as the NorthStar programme.
- **Increase our understanding of the disease mechanism** through our continued support of research projects funded through our annual grant rounds.
- **Improving the quality of life** by developing evidence-based interventions that improve the quality of life of people living with muscle-wasting conditions; in 2020/21, 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** by enlisting volunteers and MDUK staff on NICE approval processes for new treatments in 2020/21 and 2021/22.
- **Support professionals** so that better-trained and supported staff will provide improved care and ensure that more people living 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 2020/21 and 2021/22, we will work in partnership to ensure that healthcare professionals better understand

muscle-wasting conditions and their impact on people's lives; we will hold a virtual conference/series for healthcare professionals.

- **Improve access to NHS specialist support**, continue driving improvements in specialist neuromuscular care across the UK and press for at least one additional neuromuscular complex care centre to enable individuals and their families to access a specialist multi-disciplinary team to help manage their condition, regardless of where they live in the UK.
- **Use our influence to improve NHS psychology services** by working in partnership to improve services for people living with muscle-wasting conditions, based on the findings of the parliamentary enquiry, and to boost funding towards **mental health matters** services as part of the multi-disciplinary team.

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. In 2020/21, 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 Muscle Matters Seminar Series to help fill the void created by the COVID-19 pandemic from having to cancel Muscle Group meetings and the National and Scottish Conferences.
- **Change communities** by supporting those who want to take action to change the communities they live in; in 2020/21, through our Moving Up project, we will continue to support young people to gain access to employment; by working with our co-chair of the Changing Places consortium, Pamis in Scotland, we will improve access to Changing Places toilets.
- **Continue to work to remove the barriers that people face to access sport and leisure activities**, so they can enjoy the activities they love and that help them live healthier and more independent lives; in 2020/21 and 2021/22, we will be distributing over £2m in partnership with the DfT to provide access to motorway service station Changing Places facilities in England; in 2020/21, we will continue to sponsor the Powerchair football leagues with WFA and SPFA; leveraging our support to Powerchair football by working with Goals Beyond Grass to increase access to this sport.

Fundraising: we will

- **Having revised our budgets in response to the COVID-19 pandemic, we know we will be a sustainable £5m gross income charity in 2020/21.**
- **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, and incorporating a strong, lockdown, locally based programme.
- **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 with 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 are actions that 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 major gifts, mailing campaigns, raffles, membership scheme, Christmas cards and online shop sales; legacy and in-memory programmes. We conduct our Payroll giving, our lottery programme, legacy administration, legacy campaign, 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. We hold a number of memberships for the Institute of Fundraising to remain up-to-date in all areas of fundraising governance and training. We also attend training events with other reputable companies and institutions.

The number of complaints received in 2019/20 was a total of five, which derived from the following: zero from 57,980 mailings about our raffles and weekly lottery to both warm and cold supporters; two from 9,858 participants and guests at our own fundraising events; two from 502 volunteer fundraising events; zero from 5,755 people via our cold telemarketing campaigns; one from 51,239 pieces of direct mail sent out.

Financial review

The total income for 2019/20 was £6,201k (2019: £8,997k). Income from donations, gifts, grants and fundraising activities totalled £4,880k (2019: £4,714k). In addition, £979k was received from legacies (2019: £1,914k). Investment income was £211k (2019: £200k). Other income amounted to £131k (2019: £2,169k of which £2,000k is a Changing Places grant to be distributed on behalf of the Department for Transport).

The total expenditure, excluding losses from investments, for 2019/20 was £6,350k (2019: £8,537k). This included expenditure on charitable activities in respect to medical research, access to specialist NHS care and support, and provision of information, support and opportunities to enable independent living. Medical research in the search for effective treatments and eventual cures for muscle-wasting conditions expenditure was £1,204k (2019: £3,538). The year-on-year reduction was mainly due to the write backs of historical research balances no longer required. A number of historical research grant provisions were reviewed during 2019/20, owing to the changing circumstances of the grantees and altered timing of need. This will enable us to re-invest these funds into on-going projects and new research projects in the future. The actual research expenditure without this adjustment was £2,452k.

The charity had a stable year financially and ended the year with a net deficit of £622k (2019: Surplus £598k). The largest contributor to the deficit was net loss on investments of £473k caused by COVID-19 pandemic. The investments gains and losses do not contribute directly to the operational cash flow of the charity, but form an important part of the charity reserves. On operational level (excluding investments losses), the charity deficit was £148k. The charity continues several years' planned deficits to bring our unrestricted reserves back to the £1.6m target to maintain a sound level of reserves for development of our charitable activity in forthcoming 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 £1.6m based on the current analysis of risk.

The charity's unrestricted reserves were £2,432k at 31 March 2020 (2019: £2,863k). This included a free reserve of £841k and designated reserves of £1,591k. This is higher than the

target level agreed by the Trustees. However, in September 2016, the Trustees approved an investment in three significant new projects over the next five years. The charity has continued to support these commitments throughout 2019/20 financial year and is planning to do so in 2020/21. The designation of unrestricted funds presented in the account notes reflects this commitment. Once these investments are completed, it is anticipated that reserve levels will return to the reserves policy level, which the Trustees consider appropriate to ensure sustainability of the Charity. The higher level of reserves 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.

Remuneration policy

Salaries of the Chief Executive and the Senior Leadership Team 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 Senior Leadership Team 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 Senior Leadership Team 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 2019/20, 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 risks. 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 recent COVID-19 pandemic the charity reviewed these fortnightly, then monthly; 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 our audiences.

Our risk management policy proved effective in 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 Senior Leadership team on reducing the impact of the pandemic:

- estimated £2.8m income drop against the original budget
- 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 programme
- in May 2020, MDUK completed a restructure to transition into the new financial model with reduction in staff from 85 to 55 to ensure long-term sustainability.

Grant-making policies

Muscular Dystrophy UK 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.

Muscular Dystrophy UK also makes grants for equipment. The Joseph Patrick Trust (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 2020 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.

After being on track to achieve our income target for the year, we felt the significant and immediate impact of the pandemic: we ended the year £383k below target, with an estimated £2.8m drop in income against our 2020/21 budget. As outlined above in the Risk management section of this report, we moved quickly to adapt to the new landscape, with an effective risk management policy and a multi-pronged approach.

We reduced expenditure and overhauled the budget and, in May 2020, restructured the charity from 85 to 55 staff members. This moves us into a new financial model to ensure long-term sustainability. These steps ensured that there are no material uncertainties facing the charity in the near future.

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 48 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 12 October 2019 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

Muscular Dystrophy UK 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 Muscular Dystrophy UK's operating plans, recent financial performance and organisational structure. During the induction, and over time, they meet and form working relationships with staff.

Organisation

The Board of Trustees is ultimately responsible for the management of Muscular Dystrophy UK. 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 Muscular Dystrophy UK and the delivery of operational plans.

Members

Muscular Dystrophy UK 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 Muscular Dystrophy UK. 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 and began to work together on how these principles and practices should be applied at Muscular Dystrophy UK.

Related parties

The Joseph Patrick Trust (JPT), an unincorporated charity, (registered charity number 294475), is the welfare arm of Muscular Dystrophy UK, 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 Muscular Dystrophy UK and from its own investments.

The consolidated financial statements also include the Trading subsidiary, Muscular Dystrophy Group (Trading) Limited (registered company number 00893086).

Muscular Dystrophy UK maintains extremely close working relationships with partner charities that assist those living with muscle-wasting conditions.

STATEMENT OF TRUSTEES' RESPONSIBILITIES

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

Company law requires the directors to prepare financial statements for each financial year. Under company law, the directors have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the company and the group and the profit or loss of the group for that period. In preparing these financial statements, the directors are required to:

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

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

Provision of information to auditors

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

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

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



Professor M Hanna

Chairman

6 October 2020

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 2020 which comprise the Consolidated Statement of Financial Activities, the Group and Charitable Company's Balance Sheets, Consolidated Cash Flow Statements 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 2020 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.

Responsibilities of trustees for the financial statements

As explained more fully in the trustees' responsibilities statement p24, 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.

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.

Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the group's or the parent charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

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

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

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 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 returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

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.

Anna Bennett (Senior Statutory Auditor)
For and on behalf of Haysmacintyre LLP, Statutory Auditors
Date:

10 Queen Street Place
London
EC4R 1AG

CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES

(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT) FOR THE YEAR
ENDED 31 MARCH 2020

	Notes	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2020 £000	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2019 £000
Income							
Income from charitable activities							
Donations, gifts and grants	2	3,308	1,415	4,723	3,165	1,452	4,617
Legacies	2	800	179	979	1,861	53	1,914
Income from other trading activities		30	127	157	97	-	97
Investment income	2, 10	211	-	211	187	13	200
Other income	2	116	15	131	72	2,097	2,169
Total income		4,465	1,736	6,201	5,382	3,615	8,997
Expenditure							
Expenditure on raising funds	3	2,166	45	2,211	2,311	-	2,311
Costs from other trading activities	3	121	-	121	69	-	69
		2,287	45	2,332	2,380	-	2,380
Charitable activities							
Medical research	3,5	(96)	1,300	1,204	2,258	1,280	3,538
Access to specialist care and support	3	1,415	244	1,659	1,253	243	1,496
Independent living	3	851	304	1,155	906	217	1,123
Total – charitable activities		2,170	1,848	4,018	4,417	1,740	6,157
Total expenditure		4,457	1,893	6,350	6,797	1,740	8,537
Net gain / (loss) on investment assets	9	(439)	(34)	(473)	127	11	138
Transfer between funds		-	-	-	-	-	-
Net movement in funds		(431)	(191)	(622)	(1,288)	1,886	598
Reconciliation of funds							
Total funds brought forward	15	2,863	4,800	7,663	4,151	2,914	7,065
Total funds carried forward	15	2,432	4,609	7,041	2,863	4,800	7,663

There are no recognised gains or losses other than those disclosed above. All results are derived from continuing activities. The accompanying notes on pages 31 to 47 form an integral part of the financial statements.

BALANCE SHEETS AS AT 31 MARCH 2020

COMPANY REGISTRATION NUMBER 705357

	Notes	Group 2020	Group 2019	Charity 2020	Charity 2019
Fixed Assets					
Tangible Assets	8	190	183	188	183
Investments	9	4,820	5,321	4,503	4,961
Total Fixed Assets		5,010	5,504	4,691	5,144

Current Assets					
Stock	12	13	12	-	-
Debtors	13	443	734	467	1,152
Cash at Bank		7,040	8,454	6,988	7,929
Total Current Assets		7,496	9,200	7,455	9,081

Creditors falling due within one year	14	(5,465)	(7,041)	(5,100)	(6,580)
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Net Current Assets		2,031	2,159	2,355	2,501
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Total Assets less current liabilities		7,041	7,663	7,046	7,645
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Net Assets		7,041	7,663	7,046	7,645
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The funds of the Charity					
Unrestricted					
- Designated	15	1,591	1,706	1,591	1,706
- General	15	841	1,157	876	1,187
		2,432	2,863	2,467	2,893
Restricted	15	4,256	4,413	4,226	4,365
Endowment	15	353	387	353	387
Total Charity Funds		7,041	7,663	7,046	7,645

The Statement of Financial Activities for the year ended 31 March 2020 for the parent charitable company only was a deficit of (£599k) (2019: surplus of £693k). The accompanying notes on pages 31 to 47 form an integral part of the financial statements.

Approved and authorised for issue by the Board of Trustees on 6 October 2020 and signed on its behalf by:



M Hanna
Chairman



M Brown
Treasurer

STATEMENT OF GROUP CASHFLOWS – FOR THE YEAR-ENDED 31 MARCH 2020

	2020 £000	2019 £000
Net Cash (outflow)/inflow from operating activities (note a)	(1,584)	1,731

Net Cash flow from investing activities		
Dividends from investments	211	200
Purchase of Tangible Fixed Assets	(69)	(39)
Proceeds of sale of Investments	1,295	1,533
Purchase of Investment	(1,267)	(1,509)
Net Cash provided by investing activities	170	185
(Decrease) / Increase in Cash and Cash equivalents in the year	(1,414)	1,916

Reconciliation of net cash inflow to movement in net funds

Increase in Cash and Cash equivalents in the year	(1,414)	1,916
Cash and cash equivalents at the beginning of the year	8,454	6,538
Cash and cash equivalents at the end of the year	7,040	8,454

Notes to cash flow statement

(a) Reconciliation of net movement in funds to net cash flow from operating activities:

	2020 £000	2019 £000
Net movement in funds	(622)	598
Dividends from investments	(211)	(200)
Investment (gains) / losses	473	(138)
Depreciation	62	66
Decrease/(Increase) in Debtors / Stock	290	(82)
(Decrease)/Increase in All Creditors	(1,576)	1,487
Net Cash (used in) / provided by Operating Activities	(1,584)	1,731

The accompanying notes on pages 31 to 47 form an integral part of the financial statements.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

1. ACCOUNTING POLICIES

ACCOUNTING CONVENTION

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) – (Charities SORP 2015 (Second Edition, effective 1 January 2019), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) 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

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. However, the Covid-19 pandemic caused the Trustees to review the positions of the Charity and its subsidiaries. Revised budgets were prepared in August 2020 and adopted and although reduced revenues were expected there were also reductions in costs. Accordingly, the financial statements have been prepared on a going concern basis and the trustees do not anticipate any material uncertainties.

BASIS OF CONSOLIDATION

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

The subsidiary undertakings included in this consolidated accounts include:

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

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

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

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:

- entitlement – when Muscular Dystrophy UK has control over the rights to the resource, enabling it to receive the economic benefit
- probability – when it is probable, more likely than not that the economic benefit will be received
- 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.

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. 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:

- grants to fund medical research
- grants for clinical research
- 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.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

TAXATION

Muscular Dystrophy Group of Great Britain and Northern Ireland and the Joseph Patrick Trust are registered charities with the meaning of para 1 schedule 6 Finance Act 2010. Accordingly, they are exempt from taxation in respect of income or capital gains within categories covered by Chapter 3 of Part 11 of the Corporation Tax Act 2010 or section 256 of the

Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes. No tax charge arose in the period.

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

LISTED INVESTMENTS

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

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.

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.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

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.

CRITICAL ESTIMATES AND AREAS OF SIGNIFICANT JUDGMENT

There are no areas of critical estimate or significant judgment, except legacy recognition as referred to in Income above.

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.

2. INCOME

	2020			2019		
	Unrestricted Funds	Restricted Funds	Total 2020	Unrestricted Funds	Restricted Funds	Total 2019
	£000			£000		
Events and promotions	1,450	301	1,751	1,209	330	1,539
Direct marketing	726	24	750	713	42	755
Corporate	258	133	391	450	83	533
Trusts	138	540	678	67	408	475
Regional development	766	544	1,310	823	589	1,412
Legacy	800	179	979	1,861	53	1,914
Other income	327	15	342	259	2,110	2,369
Total income	4,465	1,736	6,201	5,382	3,615	8,997

Of this income £0 comes from Government Grants (2018/19 £2,000k).

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

3. EXPENDITURE

	Direct Costs		Support Costs	Total
	Grants £000	Other £000	£000	2020 £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

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		Support Costs	Total
	Grants £000	Other £000	£000	2019 £000
Raising Funds				
Expenditure on raising funds	-	2,129	182	2,311
Costs from other Trading Activities	-	69	-	69
Total	-	2,198	182	2,380
Charitable Expenditure				
Access to care and independent living				
Access to care	-	1,283	213	1,496
Independent living	331	633	159	1,123
Total	331	1,916	372	2,619
Pursuit of Knowledge				
Medical research	2,579	456	503	3,538
Total Charitable Expenditure	2,910	2,372	875	6,157
Total Expenditure	2,910	4,570	1,057	8,537

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

3. EXPENDITURE (continued)

'Direct Costs' include all costs incurred in delivering the relevant activity. 'Support Costs' comprise of the following:

	2020 £000	2019 £000
Chief Executive and Human Resources	114	172
Finance and insurance	311	280
Office costs	397	420
Information Technology	141	162
Governance	24	23
Total	987	1,057

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)

	2020 £000	2019 £000
Remuneration of Staff		
Wages and Salaries	2,746	2,541
Social Security Costs	261	245
Pensions	152	126
Total	3,159	2,912

The monthly average number of employees during the period was 86 (2018/19: 84), of whom there were the following higher paid employees as detailed below. Six redundancies were made in the year. The cost of the redundancy payments was £13k. No redundancies were made in the prior year.

Details of the Key Management Personnel, which consists of the Senior Management Team, can be found on page 49. Their total aggregate salary was £502k (2018/19: £375k).

	2020 No	2019 No
Earned between the ranges		
£60,001 to £70,000	-	2
£70,001 to £80,000	3	2
£90,001 to £100,000	-	1
£100,001 to £110,000	1	-

	2020 No	2019 No
Number of staff by activity		
Direct Charitable Expenditure	41	37
Fundraising and Publicity	38	41
Management and Administration	7	6
Total	86	84

Pension Schemes

There were outstanding contributions of £0 (2018/19: £16,567) at the Balance Sheet date.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

5. GRANT EXPENDITURE

	Research Grants £000	Welfare Grants £000	Total 2020 £000	Total 2019 £000
Grants awarded in the year	1,743	315	2,058	2,910
Grants cancelled in the year	(1,248)	(92)	(1,340)	-
Total	495	223	718	2,910

	Research Grants £000	Welfare Grants £000	Total 2019 £000
Grants awarded in the year	2,579	331	2,910
Grants cancelled in the year	-	-	-
Total	2,579	331	2,910

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 three strategic grants at University of Oxford, Royal Holloway, Newcastle and UCL, there were no institutions in receipt of material grants (over £80k pa) in 2019/20.

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

	2020 £000	2019 £000
Payable between one and five years	3,066	5,953

Reconciliation of grant funding commitments :			
	Research 2020 £000	JPT 2020 £000	Total 2020 £000
Carrying amount at start of year	5,572	381	5,953
Additions	1,743	315	2,058
Amounts charged and cancelled in year	(3,006)	(344)	(3,350)
Carrying amount at end of year	4,309	352	4,661

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

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

	2020 £000	2019 £000
Expiring up to one year	257	258
Expiring between one and five years	514	758
Expiring after more than five years	-	-

7. NET (EXPENDITURE) / INCOME

Net Income is stated after charging		
	2020 £000	2019 £000
Auditor's remuneration excluding VAT	22	21
Auditor's remuneration – non audit services	1	-
Depreciation	62	66
Operating lease rentals	232	233

8. TANGIBLE FIXED ASSETS

Group	Leasehold Premises £000	Computer equipment £000	Motor cars £000	Other equipment £000	Other Assets £000	Total £000
Cost at 1 April 2019	201	389	109	48	15	762
Disposal	-	-	-	-	-	-
Additions	-	69	-	-	-	69

At 31 March 2020	201	457	109	48	15	830
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Depreciation 1 April 2019	117	316	98	48	-	579
Disposal	-	-	-	-	-	-
Provided for year	20	35	7	-	-	62

At 31 March 2020	137	351	105	48	-	641
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Net Book Value						
At 31 March 2020	64	107	4	-	15	190
At 31 March 2019	84	73	10	1	15	183

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

8. TANGIBLE FIXED ASSETS (continued)

Parent Charity	Leasehold Premises £000	Computer equipment £000	Motor cars £000	Other equipment £000	Other Assets £000	Total £000
Cost at 1 April 2019	201	389	109	48	15	762
Disposal	-	-	-	-	-	-
Additions	-	66	-	-	-	66

At 31 March 2020	201	454	109	48	15	827
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Depreciation 1 April 2019	117	316	98	48	-	579
Disposal	-	-	-	-	-	-
Provided for year	20	34	7	-	-	61

At 31 March 2020	137	350	105	48	-	640
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Net Book Value						
At 31 March 2020	64	105	4	-	15	188
At 31 March 2019	84	73	10	1	15	183

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 2020 £000	Group 2019 £000	Charity 2020 £000	Charity 2019 £000
Market Value at beginning of year	5,321	5,207	4,961	4,856
Acquisitions	1,267	1,509	1,258	1,460
Sales proceeds	(1,295)	(1,533)	(1,284)	(1,482)
	5,293	5,183	4,934	4,834
Realised gain / (loss) on disposals	73	(77)	78	(80)
Unrealised gain / (loss) on revaluation of Investments	(546)	215	(510)	207
Market value at end of year	4,820	5,321	4,503	4,961
Historical Cost at end of year	4,282	4,244	3,972	3,928

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

9. INVESTMENTS (continued)

Spread of Investments

The investments of Muscular Dystrophy UK are held as follows:

Investments listed on a recognised Stock Exchange and Unit Trusts	Group 2020 £000	Group 2019 £000	Charity 2020 £000	Charity 2019 £000
- UK and Overseas equities	2,428	2,957	2,220	2,696
- UK and Overseas fixed interest	1,306	1,325	1,282	1,283
- Property funds	460	473	423	436
- Hedge funds	223	213	208	198
	4,417	4,968	4,133	4,613
Cash on Deposit awaiting investment	341	291	308	286
Unlisted equities	62	62	62	62
Total	4,820	5,321	4,503	4,961

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

Investment management costs for the year were £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 2020 £000	Group 2019 £000	Charity 2020 £000	Charity 2019 £000
UK Equities, UK fixed interest and other	162	163	150	150
Short term Deposit and Bank interest	49	37	48	37
	211	200	198	187

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 gift aids all profits to the charity. Muscular Dystrophy UK is the sole shareholder.
- They are both registered at 61A Great Suffolk Street, London, SE1 0BU.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

11. INVESTMENTS IN SUBSIDIARY UNDERTAKINGS (continued)

Their net assets and results for the year ended 31 March 2020 are summarised below:

	Muscular Dystrophy Group (Trading) Ltd £000	Joseph Patrick Trust £000
Fixed Assets	2	317
Current Assets	88	44
Current Liabilities	(84)	(372)
Total Net (Liabilities)/Assets	7	(10)
Represented by:		
Total Funds	7	(10)
Total income	157	238
Total expenditure	(120)	(296)
Surplus/(Deficit) for the year	37	(58)

Country of Registration	England	England
Number of fully paid £1 ordinary shares	100	-
Voting rights owned by Muscular Dystrophy UK	100%	100%

12. STOCK

The stock held in Muscular Dystrophy Group (Trading) Ltd represents new goods available for sale valued at £13k (2018 : £12k).

13. DEBTORS

	Group 2020 £000	Group 2019 £000	Charity 2020 £000	Charity 2019 £000
Trade debtors	76	116	11	10
Amount due from subsidiary undertakings	-	-	106	528
Prepayments and accrued income	340	579	337	575
Other debtors	27	39	13	39
	443	734	467	1,152

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 2020

14. CREDITORS FALLING DUE WITHIN ONE YEAR

	Group 2020 £000	Group 2019 £000	Charity 2020 £000	Charity 2019 £000
Accruals for grant payable	4,661	5,953	4,309	5,572
Accruals and Deferred Income	248	497	250	438
Taxation and Social Security	72	68	73	68
Other Creditors	484	523	468	502
	5,465	7,041	5,100	6,580

15. FUNDS

	April 2019 £000	Income £000	Expenditure £000	Investment (losses)/ gains £000	March 2020 £000
Endowment Fund					
Orchid Ball Endowment Fund	387	-	-	(34)	353

Restricted Funds

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
Joseph Patrick Trust Restricted Funds	47	-	(17)	-	30
Changing Places	2,008	30	(77)	-	1,961
Other care	165	358	(311)	-	212

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
Ullrich Research	139	85	(118)	-	106
Nemaline Research	118	40	(13)	-	145
Congenital MD*	12	28	(75)	-	(35)

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

15. FUNDS (continued)

	April 2019 £000	Income £000	Expenditure £000	Investment gains £000	March 2020 £000
Montague Thompson Coon Charitable Trust	42	59	(29)	-	72
Other research	529	435	(618)	-	346
Total Restricted Funds	4,800	1,736	(1,893)	(34)	4,609

Designated Funds					
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
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Total Unrestricted Funds	2,863	4,465	(4,457)	(439)	2,432
Total Funds	7,663	6,201	(6,350)	(473)	7,041

*funds received early in 2020/21, active fundraising campaign ongoing for this fund

	April 2018 £000	Income £000	Expenditure £000	Investment gains £000	March 2019 £000
2018/19 Comparatives					
Endowment Fund					
Orchid Ball Endowment Fund	387	-	-	-	387

Restricted Funds					
Provision of care					
City Bridge Trust / Work experience	29	80	(55)	-	54
Comic relief	8	4	(12)	-	0
Psychological support	54	32	(45)	-	41
Powerchair football	22	4	(15)	-	11
Other care	72	290	(197)	-	165
Joseph Patrick Trust - Assistive Technology	159	12	(135)	11	47
Changing Places	-	2,011	(3)	-	2,008

Research					
The Patrick Research Fund	363	-	(21)	-	342
Attenborough Fellowship	-	5	(5)	-	0
Oxford Neuromuscular Centre	258	164	(207)	-	215
Q Trust Fellowship	242	4	-	-	246
Walton Fund	15	12	-	-	27
Duchenne Research	209	505	(297)	-	417
Ullrich Research	240	82	(183)	-	139

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

15. FUNDS (continued)

	April 2018 £000	Income £000	Expenditure £000	Investment gains £000	March 2019 £000
Nemaline Research	104	61	(47)	-	118
Congenital MD	68	19	(75)	-	12
Montague Thompson Coon Charitable Trust	83	-	(41)	-	42
Other research	601	330	(402)	-	529
Total Restricted Funds	2,914	3,615	(1,740)	11	4,800
Designated Funds					
Research	1,939	-	(863)	-	1,076
Clinical	447	-	-	-	447
Tangible Assets for Charity Use	210	-	(27)	-	183
Total Designated Funds	2,596	0	(890)	0	1,706
General Fund	1,555	5,382	(5,907)	127	1,157
Total Unrestricted Funds	4,151	5,382	(6,797)	127	2,863
Total Funds	7,065	8,997	(8,537)	138	7,663

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.
- 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 designation of balances is as follows:

- 'tangible assets for charity use' represent the amount of unrestricted funds represented by these assets
- research and clinical designations have been identified as ongoing priority areas for spend in the next two years
- the General Fund is available for the ongoing operations of the charity.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

15. FUNDS (continued)

	Fixed Assets £000	Investments £000	Net Current Assets £000	Total £000
Represented by: 2020				
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

	Fixed Assets £000	Investments £000	Net Current Assets £000	Total £000
Represented by: 2019				
Endowment Funds	-	387	-	387
Restricted Funds	-	2,627	1,786	4,413
Designated Funds	183	1,523	-	1,706
Unrestricted Funds	-	784	373	1,157
Total Funds	183	5,321	2,159	7,663

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:

	2020 £000	2019 £000
Residuary	656	735
Reversionary	250	250
	906	985

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.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2020

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:

	2020 £000	2019 £000
Donations	1	17
Expenses (3 Trustees; 2018/19: 5 Trustees)	2	4

No Trustee received any remuneration during the year (2019: £nil).

There were no other related parties transactions.

Presidents, Board of Trustees and Committees

Patron

HRH The Prince Philip, Duke of Edinburgh KG KT OM GBE ONZ QSO AK GCL CC CMM

President

Gabby Logan MBE

Honorary Life Presidents

J Alexander Patrick CBE DL (deceased 18 April 2020)

Professor Martin Bobrow CBE FRS FMedSci

Sue Barker OBE

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

Ann McNeil

Valerie Patrick

Jeremy Pelczer

Julian Pritchard

Michael A Thirkettle

Baroness Celia Thomas of Winchester MBE
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 Sir Douglass M Turnbull MBBS (Hons), MD, PhD, FRCP FMedSci
Professor Matthew Wood MBChB MA DPhil FMedSci

Joseph Patrick Trust Grants Panel

Robert Warner (Chair)
Jo Becker
Karen Duckmanton
Jane Field
Jane Freebody
James Lee
Patricia Lock
Julian Pritchard
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
Andrew Graham (until October 2019)
Ian Mathieson
Charles Scott

Appointments and Remuneration Committee

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

Medical Research Committee

Professor Hugh Willison MBBS PhD FRSE FMedSci (Chair)
Dr Gillian Butler-Browne
Professor Frédéric Relaix
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 Ulrike Schara MD PhD
Dr Stefan Winblad
Professor Dominic Wells MA VetMB PhD MRCVS FHEA FS (Deputy Chair)

Lay Research Committee

Alex Williamson (Chair until 31 March 2020)
Richard Davenport (Vice Chair until 31 March; Chair from 1 April 2020)
Naima Ali-Khan
Peter Ashley (Vice Chair from 1 April 2020)
Andrew Graham
Corinthia Joseph
Alison Kay PhD
Giovanna de Kock
Stephen Meech
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)
Dr Chiara Marini-Bettolo
Phillippa Farrant
Sheila Hawkins
Professor Deirdre Kelly
Sue Manning
Professor Francesco Muntoni FRCPCH FMedSci

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.

Jeremy Pelczer (Chair, until December 2019)
Martin Cardoe (Chair, from December 2019)
Karen Attenborough (until December 2019)
Alex Elberg
Martin Hywood
Tim Lumsdon
Charles Scott

Northern Ireland Council

Claire O'Hanlon (Chair)
Marie Hollywood (Vice Chair)
Clare Boylan (Secretary)
Graham Cloke (Treasurer)
Art Connolly
Leona Connolly
Phillip Ellis
Hayley Ellis
Suzanne Glover
Lucy Hare
Michael Hollywood
Anne Hughes
Corman McAteer
Dave McLean
Jaci McFetridge
Jim McKeogh
Kerry McStravog
Niamh Mullan
Conor O'Kane
Mairead Scott
Catherine Taggart

Scottish Council

Dr Sheonad Macfarlane BSc Med Sci MB ChB (Chair)
Lindsey Armstrong
Michael Armstrong
Connor Colhoun
David Davidson
Claire Eadie

David Gale
Catherine Gillies
Craig Hamilton
Mairi Leitch
Scott McIntyre
Gill Mitan
Allyson Townhill
Stuart Townhill

Board of Trustees

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Senior Leadership Team

Catherine Woodhead, Chief Executive
Dr Kate Adcock, Director of Research and Innovation
Rob Burley, Director of Campaigns, Care and Support
Emma Jones-Parry, Associate Director of Development (from Apr 2020)
Stephen Mooney, Director of Marketing and Communications (from May 2020)
Wojtek B Trzcinski, Finance and Resources Director
Nikki Hill, Director of Marketing and Communications (until Apr 2020)
Alec Raven, Director of Development (until Jan 2020)

Remembering J Alexander Patrick, Honorary Life President following his lifelong support of MDUK, who we sadly lost in April 2020.

With gratitude

We are hugely grateful to our enthusiastic and generous committee members whose support and tireless commitment make our events and fundraising campaigns the success that they are: 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.

MDUK relies almost entirely on voluntary donations and legacies to fund our vital work. We received no government funding for our core charitable activities. Our Campaigns, Care and Support team is currently administering a grant provided by the Department for Transport to expand the availability of Changing Places toilets across the motorway network in England.

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