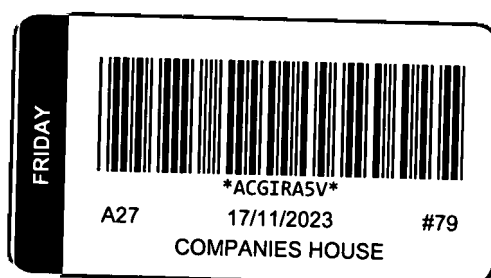


# Annual Report 2022/23

Together we are stronger





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# A message from our Chair and Chief Executive

**Welcome to our annual report and accounts.  
A year in which we have rallied our community  
so that everyone with a muscle-wasting and  
weakening condition can get the healthcare,  
support and treatments needed to feel stronger,  
both mentally and physically.**

The Covid-19 pandemic required fast paced, difficult decisions which continued into 2022/23. These hard decisions, a clear focus and the amazing support of our community have allowed us to successfully return to a full grants round for new research projects this year, bringing our total live research grants to 43 projects and our current commitments to £6m. This support also helped us to deliver more assistance to our community, with an increased demand coming through our helpline phone and email service - greater than during the initial Covid-19 period.

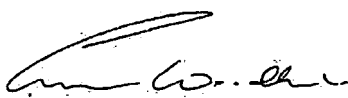
The main area for which people come to us continues to be access to welfare and financial support, particularly in navigating the PIP system. We provide information, advice, and advocacy support in this area and in the year ahead we will be increasing our policy capacity around this to tackle decision-makers about

issues that our community experience. The investment to do this will come from our unrestricted reserves, which we have built up through careful planning and the excellent delivery of activities like the Microscope Ball, along with all the collections at shops and stations, cakes sales, marathon to three-kilometre runs, people skydiving and numerous other community fundraising activities. There are also those kind enough to leave a gift in their Will, who will be able to see an ongoing legacy supporting our community both today and tomorrow.

Other planned investments for 2023/24 include an increase in research commitments; more effective communications, so we can reach a greater number of the 110,000 people who need our support; and a continued drive to collaborate with our colleagues in the NHS to provide localised specialist support and access to new treatments.

This year saw the completion of the access journey in England for the first treatment in our field, Translarna, for some people living with Duchenne muscular dystrophy, when NICE recommended it as an NHS treatment option. Since we began the push for this treatment in 2016, great strides have been made in treatment development, by the end of this reporting year we were working on access to 12 treatments for five different conditions. But more must be done, and we are pleased to be investing in further funding partnerships.

As a responsible leader we continue to evolve our work to address wider issues of climate change, racism, equality, diversity, and inclusion, so we can help create a safer, better society. This year we launched our equality, diversity and inclusion (EDI) strategy and worked closely with our EDI ambassador to give our community a voice across many platforms.



**Catherine Woodhead**  
Chief Executive

We have already made great advances that would have been unthinkable just 10 years ago, and we are determined to go even further and faster. Our community makes us stronger and that's why we worked together to refresh our organisational strategy this year. Bringing together individuals, families and carers, scientists, health professionals, supporters, volunteers, donors and everyone who is close to us across England, Scotland, Northern Ireland and Wales.

Thank you to our dedicated community for graciously giving your time and money throughout the year. And to the scientists, healthcare professionals, our dedicated President, trustees, and staff team – thank you! The support from everyone has helped us to make every day count for people living with muscle-wasting and weakening conditions. We are all unique individuals. Together we are stronger.



**Professor Michael Hanna**  
Chair



**Thank you to our dedicated community for graciously giving your time and money throughout the year. And to the scientists, healthcare professionals, our dedicated President, trustees, and staff team."**

# Tiffany's story

**Tiffany shares her journey so far, and why being an Equality, Diversity and Inclusion Ambassador is so important to her.**

"My son Roman, aged three, lives with the very rare muscle-wasting condition LMNA-CMD. He was diagnosed at the age of one. Getting the news was hard to take for myself and his dad as we didn't previously know anything about muscle-wasting conditions.

"Despite all the challenges he faces, Roman is a boy who is full of life. He doesn't let anything hold him back and amazes everyone who meets him.

"We now have a lot more knowledge and are finding our feet. But it can be a very lonely world, and none of our friends and family have been through an experience like ours. This inspired me to write a children's book to help people learn more about the support Roman needs with his condition, in a way that is easy to understand. It's also really important to have more storybooks with Black representation.

"Given that muscle-wasting conditions are so rare, we want Roman to know there are other children, adults and families in the Black community who understand what he is going through. That is why it is so important for us to raise our voice to ensure that Roman feels part of a muscle-wasting community that better represents Black people and their families.

"I've been appointed as an ambassador for Muscular Dystrophy UK, and I'm excited to say I'll be specifically focused on connecting, representing and expanding the Black muscle-wasting community. I'm also really pleased that the charity has recently created an EDI working group and is working to improve its diversity.

I hope that in my role I can use my voice to make a difference, making life more inclusive for Roman and other Black families affected by neuromuscular conditions."



**I've been appointed as an ambassador for Muscular Dystrophy UK, and I'm excited to say I'll be specifically focused on connecting, representing and expanding the Black muscle-wasting community."**

# About us

**We're the leading charity for over 110,000 people in the UK living with one of over 60 muscle-wasting and weakening conditions.**

We connect our community of people living with muscle wasting and weakening conditions, and all the people around them, friends and family, healthcare professionals and scientists. So that everyone can get the healthcare, support and treatments needed to feel good, both mentally and physically.

We support people through every stage of their life, from the point of diagnosis to living the best life possible.

## **Our mission**

- We share expert advice and support people to live well now.
- We fund groundbreaking research to understand the different conditions better and lead us to new treatments.
- We work with the NHS towards universal access to specialist healthcare.
- Together, we campaign for people's rights, better understanding, accessibility, and access to treatments.

## **Our values**

- **Stronger together.** We believe in the power of community. That the whole is greater than the sum of its parts. Because the more of us who come together, the greater the impact we'll make.
- **Forward thinking.** We're here for every single one. Whoever you are. Wherever you're from. You are our sole focus. We set ourselves clear targets and measure our impact.

- **Here for you.** We are here for everyone, but we know support isn't one-size-fits-all. We take the time to listen to every individual, so we can tailor our support to you.
- **Never Stop.** We've already made advances that would have been unthinkable just 10 years ago, and we are determined to go even further and faster.

## **Objects of Muscular Dystrophy UK for the Public Benefit**

The Charity is established to promote awareness and care for those affected by the muscular dystrophy and allied neuromuscular conditions.

We do it:

- to promote research
- to promote the provision of care and treatment
- to assist those who care for persons affected by the conditions
- to provide education and training to persons affected
- 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 year in numbers

 £1.3m

awarded for research including 14 new grants, bringing the live portfolio to 43 active research grants being supported, with a total cost commitment of £6m

 £8.2m


income generated

 2,663


people living with, or affected by, a muscle-wasting condition supported through our phone and email support service

 10


treatment appraisals on which we were active, with two treatments recommended by NICE for NHS use

 99,103

visits to the care and support sections of our website

 15,696

unique page views to our online forum allowing people to share experiences and support each other

 3,973

online views of our muscles matter seminars

 1,857

views of the Standards of Care for Adults with Duchenne muscular dystrophy videos

 470

attendees at our Allied Health Professional upskilling webinars

 80

participants at our Physiotherapy Conference



# Looking back on what we achieved

**This year's achievements and performance measured against our 2021/22 objectives.**

Performance Indicator	Our achievements
<b>Fund high-quality research to find effective treatments, and ultimately identify cures for all muscle-wasting conditions</b>	<p>Funded 14 new research projects, including three three-year project grants; seven two-year project grants; two 12-month grants; and two four-year PhD studentships.</p> <p>This included providing <b>a further two year's funding</b> for both the paediatric and adult NorthStar networks.</p> <p>Supported LifeArc in its review of proposals to accelerate research projects to develop new treatments for congenital muscular dystrophy.</p> <p>Launched our annual grant round, for which the outcome will be announced in late autumn 2023.</p>
<b>Ensure everyone has access to specialist NHS care from a multidisciplinary team</b>	<p>Engaged in ten treatment appraisal processes for muscle-wasting and weakening conditions.</p> <p>Two treatments recommended by NICE for muscle-wasting and weakening conditions.</p> <p><b>80 attendees</b> at our Physiotherapy Conference.</p> <p><b>42 attendees</b> at our Care Advisor Conference.</p> <p><b>470 attendees</b> at Allied Health Professional upskilling webinars.</p> <p><b>20-50 monthly enrolments</b> on our e-learning modules.</p> <p>Five MDUK Regional Neuromuscular Networks managed.</p> <p>Two policy reports on commissioning reforms published.</p> <p>33 neuromuscular centres submitted an Expression of Interest to our audit of neuromuscular services and Centres of Excellence awards.</p> <p><b>Four cross-party parliament and assembly groups</b> on muscular dystrophy run across the UK.</p>

### This year's achievements and performance measured against our 2021/22 objectives – *Continued*

Performance Indicator	Our achievements
<p><b>Provide services and promote opportunities to enable each affected individual to live as independent a life as they wish</b></p>	<p>Handled 2,663 requests for support, a 22% increase on the previous year.</p> <p>99,103 visits to our website's care and support areas, a growth of 15 percent on 2021/22.</p> <p>15,696 people used our online forum to share experiences and support each other.</p> <p>169 people supported through our advocacy service.</p> <p>24 equipment grants provided through our JPT programme.</p> <p>389 bookings, 196 live attendees and 3,973 online views of our virtual Muscles Matter seminar series.</p> <p>78 people attended our two face-to-face information days.</p> <p>Two major resources launched to help people live well with muscle-wasting conditions, accessed 2,615 times.</p> <p>Major report launched into the Cost of Living with a Muscle Wasting Condition, which was mentioned in the House of Commons by two Members of Parliament.</p> <p>12 young disabled people supported by our Moving Up programme.</p> <p>177 Changing Places toilets registered.</p>
<p><b>Generate income to continue supporting the community</b></p>	<p>£8.2m total income generated this year, an 11% increase from 2021/22.</p> <p>Merged two teams with a view to cementing the fundraising strategies of both teams to maximise income from supporters, while establishing a firm foundation for future sustainability.</p> <p>£2.9m legacy income, up from £1.65k in 2021/22.</p>

# Our research advances

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

Our three-year research strategy, 'Transforming lives through research', remains the driving force for our research activity. We continue to support high-quality research that deepens our understanding of neuromuscular conditions and support studies into ultra-rare conditions.

## **Our grant awards**

This year, we were delighted to award grants to researchers with no prior history with the charity demonstrating our continued journey to encourage new researchers into the neuromuscular research field.

Our application process was opened further than the previous year, to include project grants and PhD studentships in any of the neuromuscular conditions supported by us. This resulted in a wide variety of very strong research proposals, which were subjected to a rigorous selection process. Of the grants we funded, two cover research relevant to a wide range of muscle-wasting conditions. While the others address the following

conditions: Charcot-Marie-Tooth disease (CMT), congenital muscular dystrophies (including LAMA2-RD, Collagen-VI and INPP5K-related), congenital myasthenic syndromes (CMS), Duchenne muscular dystrophy, mitochondrial myopathy, and spinal muscular atrophy (SMA).

It is the first time in several years that we have supported new research into CMT, CMS and mitochondrial myopathy. Some of the other projects build on work we've previously funded.

## **The European neuromuscular centre**

We continue to be an executive member of the European Neuromuscular Centre (ENMC). A network of neuromuscular research charities from across Europe who bring experts together to tackle challenges found in the field of neuromuscular research. The ENMC returned to hosting in-person workshops this year following a Covid-19 hiatus. As with previous years, many of these included UK clinicians, researchers and patient

representatives and could not have happened without our financial support.

## **Our Research Line**

We continue to ensure patients and families can find out about new studies, treatments, and clinical trials for muscle-wasting conditions via email through our Research Line.

## **Supporting the PREFER project**

This year saw the end of the six-year PREFER project for which we provided support. The project outlined the importance of using patient preferences in medical decision-making alongside clinical results from the drug development stage through to marketing. Following this six-year project PREFER published recommendations for pharmaceutical companies, developers, regulatory bodies, and other involved parties, towards a more personal approach to drug discovery and medical product marketing, factoring in patient considerations alongside evidence-based data.



**Improving  
lives today and  
transforming  
lives in the  
future."**

## Highlights of our research funding

**Research projects take time to deliver impact. Here are some highlights from grants that were active in 2022/23 that we awarded in previous years:**

### **Research into causes of muscle weakening in SMA**

We funded research carried out by Dr Melissa Bowerman's team, including PhD student Emma Sutton, at the University of Keele, investigating the mechanisms that drive skeletal muscle wasting. This has revealed a new cause of muscle weakening in spinal muscular atrophy (SMA) during early muscle development. These findings could eventually enhance existing treatments for SMA and similar conditions. SMA is a genetically inherited neuromuscular condition which causes progressive muscle weakness and loss of movement due to muscle wasting. It can affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing.

### **Research to help predict the severity and progression of Duchenne muscular dystrophy**

We provided partial funding to researchers led by Professor Francesco Muntoni at University College London whose research made progress in helping to understanding why the severity of Duchenne muscular dystrophy symptoms varies between boys. This could have major implications for clinical prognosis and future research in treatments. Duchenne muscular dystrophy is a muscle-wasting condition caused by a lack of protein called dystrophin.

### **Research to better understand the cause of myotonic dystrophy type 1**

We funded research by Dr Judith Sleeman at the University of St Andrews which culminated in findings that have linked myotonic dystrophy type 1 to an issue with the mechanism that controls stress response in cells in the body. This better understanding of the root cause behind the condition will in time lead to more targeted and effective therapies and treatments. Myotonic dystrophy is a genetic condition that causes progressive muscle weakness and wasting.

### **Research targeting the cell's energy system as a potential treatment for FSHD**

We funded research carried out by Professor Peter Zammit and his team at King's College London to investigate how the known genetic causes of FSHD translate into its symptoms, focusing on metabolism and mitochondria. The project successfully identified potentially novel therapies for treating FSHD, which could alleviate symptoms and be combined with other effective treatment options. Facioscapulohumeral muscular dystrophy (FSHD) is the third most common inherited muscular dystrophy, whilst it doesn't shorten lives, it drastically impacts on the quality of life.

# Driving change for access to specialist care and support

It has been an active and successful year for our work around securing access to treatments for muscle-wasting and weakening conditions. At the same time, we have continued to support health professionals involved in the care of our community and have sought to ensure that NHS neuromuscular services received appropriate attention from commissioners and decision makers – particularly as the Integrated Care System model and other health service commissioning changes began to be rolled-out.

**10**

NICE treatment appraisals in which we were active

**2**

treatments recommended for use by the NHS

**42**

attendees at our Care Advisor conference focusing on the mental health and wellbeing of our community

**20–50**

people per month enrolled on our e-learning modules

## Our role in treatment recommendations and appraisals



### We have been leading the fight for access to Translarna."

#### Duchenne muscular dystrophy

It was a major milestone in January 2023 when the National Institute for Health and Care Excellence (NICE) recommended **Translarna** (also called **ataluren**) as a treatment option for Duchenne muscular dystrophy which is a result of a 'nonsense mutation' in the dystrophin gene. We have been leading the fight for access to Translarna since 2016, working alongside families, clinicians, and other patient groups - co-ordinating a wide range of campaigning, policy, and parliamentary activity and representing the Duchenne community at NICE committee meetings.

This year NICE began the process of appraising **vamorolone**, a treatment for the inflammation associated with Duchenne muscular dystrophy. The treatment is a potential alternative to **corticosteroids** and evidence suggests it may have **fewer** acute side-effects. In October 2022, we took part in a NICE scoping workshop for Vamorolone, and subsequently made a joint submission to this stage of the appraisal.

In May 2022, NICE selected the investigational gene therapy

**fordadistrogene movaparvovec** for Duchenne muscular dystrophy for appraisal and we have begun preparations to engage in this process in 2023/24.

#### Pompe disease

We welcomed NICE's recommendation of **avalglucosidase alfa** as a treatment option for Pompe disease in August 2022. We engaged in the full appraisal process and our Honorary Life President Baroness Thomas of Winchester, who lives with Pompe disease, appeared before the NICE committee that appraised the treatment and made the final recommendation. In October 2022, we also submitted a joint response to the early stages of NICE's appraisal of a second potential treatment for Pompe disease, **cipaglucosidase alfa with miglustat**.

#### Spinal muscular atrophy

Considerable activity took place across three spinal muscular atrophy (SMA) treatments this year. Two of the treatments - **Evrysdi** (also called **risdiplam**) and **Spinraza** (also called **nusinersen**) - are currently available through Managed Access Agreements (MAAs) and we continued in our role as a member of the Managed Access Oversight Groups (MAOG) for them. We also worked in partnership with clinicians and other patient groups to successfully engage with NHS England to overcome a potential barrier to patients receiving these treatments while

participated in clinical trials for other SMA treatments. This was a serious potential challenge for the SMA community and the viability of future clinical trials in England.

Having submitted a joint response to the scoping stage of NICE's appraisal of **Zolgensma** (also called **onasemnogene abeparvovec**) in August 2022, we welcomed the news in March 2023 that NICE had recommended onasemnogene abeparvovec for pre-symptomatic babies.

#### Myasthenia gravis

In May 2022, we participated in the NICE scoping workshop for potential myasthenia gravis treatments **ravulizumab** and **efgartigimod**. We then submitted a joint response to the appraisal of ravulizumab in November, and successfully nominated an MDUK peer support volunteer to appear before the NICE committee who will be conducting the appraisal in 2023/24. In March 2023, we also made a joint submission and nominations to the appraisal of efgartigimod.

#### FSHD survey

In May 2022, we promoted an international survey co-ordinated by FSHD Europe about the FSHD community's preferences around involvement in clinical trials. Thanks to our support, approximately 350 people from across the UK completed the survey - the highest volume of responses from any one country.

## Connecting and upskilling health professionals

### Our conferences

This year saw the return of our face-to-face national conferences for two key groups of health professionals involved in the care of people living with muscle-wasting and weakening conditions, providing crucial opportunities to upskill, share best practice and network.

The **MDUK Neuromuscular Physiotherapy Conference** took place in April 2022 with over 80 physiotherapist participants from across the UK.

Our **Care Advisor Conference** returned in September 2023 with 42 attendees, with a focus on how to support the mental health and wellbeing of our community and looking after Care Advisors' own mental health.

### Virtual upskilling and networking opportunities

We continued to provide virtual upskilling and networking opportunities to health professionals; running a series of four webinars for Allied Health Professionals involved in the care of people living with muscle-wasting and weakening conditions with a combined attendance of around 470 health professionals. Across the year, 20–50 people per month enrolled on our e-learning modules.

### Our regional neuromuscular networks

We continued to manage five MDUK regional neuromuscular

networks and engaged with the four NHS funded networks across the UK, collaborating on regional upskilling and patient information events. These networks are an important way in which healthcare professionals and people who use neuromuscular services can be brought together to identify and address gaps and challenges in service provision.

This year major changes in the commissioning of neuromuscular services were introduced in England through the Integrated Care System model. We supported networks in a series of engagements with Integrated Care Boards and produced two policy reports that explored and explained the new commissioning landscape. These will also assist community services (such as community physiotherapy) to support people affected by muscle-wasting conditions.

### Our Centres of Excellence Awards

One of the ways we identify best practice and challenges across neuromuscular services is through a national audit, using these findings to create MDUK Neuromuscular Centres of Excellence Awards. This has traditionally been undertaken every three years but due to Covid-19 the last audit took place in 2018. This year, we began major work to update the process we use so that it is more flexible around different sizes of neuromuscular services and so that it can reflect the availability of new treatments and developments in standards of care. Thirty-three neuromuscular

centres across the UK submitted an Expression of Interest to participate in the 2023 audit.

## Parliamentary Work

### Support to muscular dystrophy parliamentary groups

We continue to support cross-party groups on muscular dystrophy in the Houses of Parliament, the Scottish Parliament, the Welsh Parliament, and the Northern Ireland Assembly, ensuring that issues affecting people with muscle-wasting conditions receive the political attention they deserve. We delivered a number of meetings across these groups this year, including launches of our report on the impact of the cost-of-living crisis on people affected by muscle-wasting and weakening conditions.

### Joint secretariat of UK SMA Newborn Screening Alliance

We continued in our role as joint secretariat of the UK SMA Newborn Screening Alliance, which is led by Professor Laurent Servais, Professor of Paediatric Neuromuscular Diseases at the MDUK Oxford Neuromuscular Centre. We launched an All-Party Parliamentary Group on Muscular Dystrophy inquiry into newborn screening for rare conditions.

# Living well

**Being diagnosed with a muscle-wasting condition means adjusting to a new, unexpected, and ever-changing reality.**

We believe it is vital that people have easy access to the information and support they require throughout their experience of living with a muscle-wasting or weakening condition. We provide personal, free, expert information resources and confidential support, covering every topic from the latest research to money worries, physical symptoms, and emotional well-being.

## **Our helpline service**

Our helpline team continue to provide practical advice and support and listen to people's concerns. The five topics people contacted us most about this year were welfare information requests, care plan/alert cards, the cost of living, housing and adaptations advice, and an introduction to MDUK. We responded to these requests by phone, email or through neuromuscular clinics. People also visited our website care and support areas and used our online forum to share experiences and to support one another.

## **Our advocacy service**

Our advocacy service supports people who may be struggling to get the care and services to which they are entitled - providing advice or acting on their behalf. This year, not only did we support people through this service, but we also provided people with the information and skills to advocate for their own needs.

## **Providing grants**

As well as supporting people to access financial support, we also provided grants through our grant-giving arm the Joseph Patrick Trust, to help meet the costs of powered mobility equipment. We also launched a one-off cost of living grant for individuals with muscle-wasting and weakening conditions this year.

## **Muscle group sessions and Muscles Matter seminars**

We continued to bring our community together through our Muscle Group sessions and our online Muscles Matter seminar series.



The programme of seminars covered a range of specific muscle-wasting conditions. For the first time since the Covid-19 pandemic, we also held two face-to-face information days in London and York, and our Muscle Groups held face-to-face events in the summer and online sessions during autumn and spring.

#### Living well resources

Working with clinicians and people living with muscle-wasting and weakening conditions, we produced two major resources this year. In July we launched a suite of videos to accompany the Consensus Guideline for the Standard of Care for Adults with Duchenne Muscular dystrophy, produced with MDUK funding and published in the Journal

of Neuromuscular disorders – having first been presented at the World Duchenne Organisation. The videos provide a summary of each section of the standards of care document with a focus on the key points a person with Duchenne should know, supporting their conversations with a range of health professionals involved in their care. During the year these were accessed 1,857 times.

We also launched a resource on managing fatigue for people with muscle-wasting conditions – a culmination of a long partnership with a range of neuromuscular health professionals. Ninety-five people attended the webinar to launch the guide and it was downloaded 758 times across the year.



**Fatigue has been a significant part of living with a muscle-wasting condition for me and it has taken over my life. MDUK's new fatigue management resource is vital to increasing awareness. It covers so many aspects of fatigue and signposts for further advice, which is of enormous help to those affected."**

Hilary, living with mitochondrial disease

## 28%

increase on the previous year in support requests

## 169

people supported by our advocacy service

## 24

people received a grant through our Joseph Patrick Trust

## 196

people attended our Muscles Matter online seminars: with 3,973 views on YouTube and Facebook

## 99,103

visits to the care and support sections of our website; a 15% increase on the previous year

## 15,696

unique page views to our online forum allowing people to share experiences and support each other

## 78

people attended our information days in London and York

### **The impact of rising costs on people living with a muscle-wasting condition report**

A major barrier facing people affected by muscle-wasting and weakening conditions is the rising cost-of-living, which has had a particularly acute impact on disabled people. We conducted a survey on the cost of living with 170 participants and held three focus group sessions. We used the insights gained - combined with our previous research and contemporary research and policy publications by other charities and policy groups - to produce our report 'The impact of rising costs on people living with a muscle-wasting condition'. The report sets out why the muscle-wasting community is particularly impacted by the rise in the cost of living and makes key recommendations to a number of decision makers as to the support our community need. We launched the report in October at the



**Having a muscle-wasting condition means there are lots of additional costs, which other households don't have. For example, my electric bill. I've got to charge my two power wheelchairs and an electric hoist. I can't use a manual wheelchair because the muscle weakness in my arms means I can't get out of it. We worry about whether we can look after ourselves."**

Trevor, living with Becker muscular dystrophy

All-Party Parliamentary Group on Muscular Dystrophy, with two Members of Parliament referencing the report in the House of Commons.

### **Our Moving Up programme**

This year, our Moving Up programme supported 12 young disabled people through work experience placements, paid internships, and employability support. Participants were supported in developing plans to help aid their long-term development and achieve their goals. They were also taught how to maximise their chances at landing a suitable role, whilst maintaining their mental health. The programme also provides individuals with information on their legal rights in relation to disability employment law, so they are aware of what they are entitled to and eligible for, either at interview stage, or when they have gained employment. Of the 12 participants on the programme, nine have successfully found work or gone onto the next stage of their education. It was great to see two Moving Up alumni return to the charity in short term contracts, alongside one alum who received a promotion to a new role following their return on a permanent contract last year.

### **Co-chairing the Changing Places Consortium**

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



**The money will help ensure that every family is able to have a day out with dignity and confidence."**

UK Prime Minister Rishi Sunak

largely driven by our connection to government programmes for which we support delivery. We continued to administer a £2m grant programme in partnership with the Department for Transport (DfT) to ensure increased provision of Changing Places toilets in motorway services across England and began delivery of a second DfT programme to increase provision across the rail network. We also agreed a third programme with DfT to increase provision of these facilities across the A road network.

Our partnership work with the Department of Levelling Up, Housing and Communities (DLUHC) continued to provide insights to help shape a scheme for the distribution of £30m government funding to install Changing Places toilets in existing buildings in England, and to provide advice and support to local authorities in receipt of this funding. We provided support in managing a second round of funding applications to the programme.

In total, we registered 177 new Changing Places toilets in 2022/23, 124 of which were installed outside of the government funded programmes.

**Moving Up is a project supporting young disabled people. It provides opportunities to participate in workplace internships to get the experience to move up and gain employment. Jack has end-to-end experience of the project and since November 2020 has been our Moving Up Project Manager.**

I joined the Moving Up project as a work experience participant after struggling to find work as a disabled person following graduating from university. My first placement was in the advocacy team at Muscular Dystrophy UK. Not only did it give me experience in an area I would not otherwise have known, but it also allowed me to experience balancing work with my disability. Most importantly, it boosted my confidence, which had taken a serious hit after years of unsuccessfully looking for work.

After leaving the project, I applied for and secured a job as a HR Assistant at the charity in October 2016. I got to work right across the organisation along with getting a bit of experience in nearly every part of HR. One area that I worked on a lot was recruitment for the charity. Now I'm the Moving Up Project Manager.

My personal experience of trying to find work as a disabled person, coupled with my years of experience in HR, have given me a passion for improving employment opportunities for young disabled people."

# Our work in Scotland

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

**£5,600**

raised by our Family Funds

**£4,504**

raised from our Spirit of Christmas event

**£4,820**

raised by two skydivers

**361**

support requests responded to

Over the past year, we continued to provide comprehensive and tailored information and advice and emotional and practical support to individuals and families living with muscle-wasting conditions in Scotland. Our focus has been on engagement, outreach, and connection, helping people to get the care, support, and equipment to which they are entitled.

This year we responded to 361 requests for support in Scotland, of which 53 were advocacy cases. Our close work with the Scottish Muscle Network

continued and we successfully carried out our role as the secretariat to the Cross-Party Group on Muscular Dystrophy in the Scottish Parliament. Our work in Scotland is guided by our Muscular Dystrophy UK Scottish Council, working closely with our Head of Information, Advocacy and Care and Regional Development Manager, both based in Scotland.

## **The Scotland Care and Support Alliance**

Scotland is currently in the process of setting up a National Care Service and care packages will be moved from local authorities to this new national system. In response to this, we established a Scotland Care and Support Alliance with other leading charities in Scotland, including MS Scotland and Epilepsy Scotland, to identify overarching barriers to access and to drive forward key recommendations on how the National Care Service can better meet the needs of the people we support.

## **Neuromuscular wellness sessions**

We worked closely with Neuromuscular Physiotherapy to develop a series of in-person holistic wellbeing sessions for adults living with muscle-wasting conditions. These sessions covered a range of topics including exercise, activity and fitness goals, fatigue management, sleep

and posture improvements, nutrition and benefits. We are hoping to run these sessions virtually over the next year so that we can reach more people across Scotland.

## **Free training and support sessions**

In collaboration with PAMIS, we supported people to access free training and support sessions (funded by the Scottish Government) throughout 2022/2023. Helping people with muscle-wasting conditions, their carers, family or friends, to understand some simple exercises and techniques. With our support, PAMIS have facilitated three four-week online training courses. This collaboration has also supported us in producing resources on postural care and will inform future postural care seminars/workshops. **We held a face-to-face Muscle Group meeting in August alongside the virtual ones in Spring and Autumn.**

## **Research**

We continued to support research in Scotland this year. Our grant to Professor Eric Schirmer at the University of Edinburgh ended, but we continue to support Dr Lyndsay Murray of the University of Edinburgh, and Professor Judith Sleeman at the University of St Andrews.



**"I have days that I call "Only my eyelashes do not hurt". On these days I cannot physically or mentally deal with all the calls, emails and messages. Jackie, Muscular Dystrophy UK Regional Information, Advocacy and Support Manager, is right there to help."**

Person living with muscular dystrophy

## **Regional development**

### **Family Funds**

We continued to grow the number of our Family Fund's this year, with Team Thomas joining in November 2022 and taking on a variety of successful fundraising activities. These included, a new year's dip and a team of runners entering into events as part of the Edinburgh Marathon Festival. Our family funds in Scotland raised a fantastic £5,600.

### **Supporting community fundraising activities**

Aligned with our new fundraising strategy, we took the decision to cancel all future Question of Support events and invest this time in supporting those planning their own fundraising activities for the wider community. One example was the return of our Spirit of Christmas (SOX) event for the first time since Covid-19, with two events successfully organised by Stagecoach Performing Arts who raised a brilliant £4,405. Plans are already underway for the 2023 events where the hope is that fundraising will be raised to £5,000.

### **Outdoor events**

With the growth of outdoor events, we have continued to see new and re-engaged supporters taking up challenges, these have included the Edinburgh Marathon, the Kiltwalk series, which has seen increased participation and income, in total raising £6,000 this year, with one supporter even taking on an Ultra challenge in the Isle of Wight.

### **Skydives**

Due to pandemic restrictions we had to postpone some skydives and are still in the process of trying to reschedule some, but we have also had some success with two skydivers raising a combined total of £4,820.

### **Our total fundraising in Scotland**

Despite the ongoing difficulties brought about by the pandemic, we have raised a fantastic £117,000 across Scotland in this financial year. Going forwards we will continue to raise the profile of muscle-weakening and wasting conditions and promote more fundraising activities that people enjoy doing, with the aim of increasing our targets year on year.

# Our President's Award winners

**These annual awards recognise outstanding people doing remarkable things to make muscles matter. This year's winners are...**

## **Alexander and Valerie Patrick Award for Carer of the Year**

### **Emma-Jayne Ashley**

Emma-Jayne is a dedicated caregiver to her son, Dregan, aged 23, who lives with congenital myotonic dystrophy. She also works as a consultant patient representative, supporting families and helping improve the quality of life for people with muscle-wasting conditions. Alongside her husband, Peter, she represents the myotonic dystrophy community in various European research and care organisations.

## **Volunteer of the Year**

### **Claire Boylan**

Claire lives with miyoshi myopathy which caused her to take early retirement aged 31. Since leaving full-time work, Claire has volunteered with us as an active campaigner, Peer Support Volunteer, and organiser of the Spirit of Christmas annual fundraising concert in Belfast.

## **Early Career Scientist of the Year**

### **Dr Vino Vivekanandam**

Dr Vivekanandam, a Neurologist & Clinical Research Fellow at University College London (UCL), is dedicated to finding new treatments, improving patient diagnoses, and increasing our understanding of rare muscle channelopathies with far-reaching benefits for patients across the UK and internationally.

## **Fundraiser of the Year**

### **The Chubb Family**

Charlotte and James Chubb, who set up The Chubb's Crusade - Understanding Ullrich family fund, won this award for raising £30,000 in their first year. They threw themselves into a range of fundraising activities including marathons and cycle rides, as well as inspiring friends and family to get involved. (Picture left)

## **Peter and Nancy Andrews Community Achievement**

### **Tiffany Hesson**

In her first year as our Equality, Diversity, and Inclusion (EDI) Ambassador, Tiffany has been an influential spokesperson, representing the charity, and championing EDI at a national level. Attending meetings with stakeholders to give her perspective as a parent of a son living with LMNA-CMD as well as championing diversity, and encouraging the development of our EDI document.

## **Richard Attenborough Award for Outstanding Achievement**

### **Chloe Ball-Hopkins**

Chloe lives with Nemaline Myopathy, a Team GB Para Athlete in Archery in 2014, model and fashion designer having designed an accessible jumpsuit in association with ASOS. She has been involved with us from a young age and has often spoken at our events.

# The difference your support made

Thanks to your amazing generosity, income from gifts, grants, and donations, campaigns and events totalled £4.4m this year.

## Highlights of this year's fundraising

### Games Nights

In July 2022, we hosted our first ever Games Night at Flight Club, Islington, an interactive darts venue where twenty teams of six joined us to take part in the tournament. We were delighted with the success of this inaugural event. Our event committee and guests had so much fun, we decided to organise a second games night at Electric Shuffle, London Bridge, an interactive shuffleboard venue. This sold out and together the games nights raised £36,700. Both events attracted a new audience of supporters, and we look forward to hosting our third Games Night very soon.

### Microscope Ball

Our annual Microscope Ball returned for a record-breaking year raising a phenomenal £424,000. The theme was 'Strike A Pose' and was hosted by the drag queen Miss Demeanour with entertainment from the fabulous Globe Girls, all of which helped to create a fun and uplifting evening. Chloe Ball-Hopkins was our guest speaker, who's rousing speech about living life to the fullest captivated the audience and generated the most successful live auction and pledge in the history of the event.

### Our fundraising year in numbers:

**£36,000**

raised at the BGC Charity Day thanks to the appearance of Gabby Logan MBE and Sam Allardyce alongside our families

**£12,000**

raised from the 10,000 participants from schools, workplaces and communities across the UK who took part in our Go Bright event

**£2.9m**

from 62 individual legacies

**£31,000**

won by Gabby Logan MBE by appearing on ITV's Celebrity Catchphrase and CH 4's I literally just told you hosted by Jimmy Carr

**£318,000**

raised by the 7,330 participants who took part in our Town & Gown running events

## Our challenge events

### Pedal Paddle Peak 2022

This was the seventh year of our Pedal Paddle Peak challenge event, which involves a 30-mile cycle ride, a two-mile canoe paddle across Ullswater lake, and a huge climb to the second highest peak in England, Helvellyn Mountain – all in one day. A total of 126 participants took part this year, raising a record £107,195.

### London Marathon 2022

We had 124 runners in the London Marathon this year, 108 with a charity place and 16 with their own. Nine people also took part in a virtual event across the UK. This team of runners raised a fantastic £323,194, our highest yet for the London Marathon.

## Our Family Funds

Our Family Funds continue to amaze us with their dedication to fundraising, having raised £70,000 this year. We held our first post covid Family Fund weekend at the Calvert Trust in Devon. The 11 families attending the weekend were given the

chance to do the unusual such as stack crates, abseil, ride horses and lots more outdoor activities. With the evening being a time to relax and build friendships, as well as take part in our Family Fund Big Quiz, with the opportunity to take the winner's trophy home!

## Supporter led events

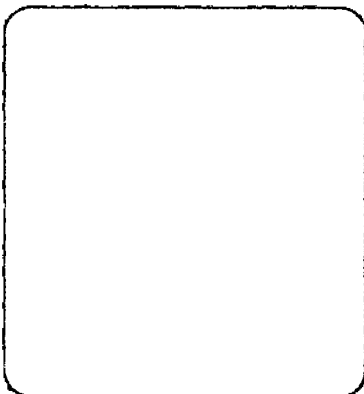
Rollits, with the support of Brian Deehan, Chair of the East Yorkshire Branch, held their 36th annual golf event for the charity this year – in total they've raised a fabulous £97k over the years. While the Source to Sea event, the brainchild of our supporter Andy Davies who has limb girdle muscular dystrophy, raised over £27,000. Around 90 walkers and 40 volunteers took part in this day event, following the Thames River from source to sea and finishing in central London. Eight members of the CMT Friends UK Support Group, set up by Peter Neville, dared to take on the world's longest zipline together to raise awareness of Charcot-Marie Tooth disease and raised an amazing £3k in the process.

## Our volunteers

Our volunteers and groups have really surpassed themselves with their community fundraising post pandemic, attending events, holding collections, nominating us to benefit from local organisation donations, running, jumping, dancing, walking and even wing walking all to raise funds.

## Medical Research Charity Support Fund

In the last year, we were delighted to receive £274,145 from the Medical Research Charity Support Fund, which has helped us regrow our grant portfolio since the pandemic. The Medical Research Charities Early Career Researchers Support Fund is administered by the Medical Research Council (MRC) and UK Research and Innovation (UKRI) on behalf of the Government. The donation has contributed towards six of our research grants, furthering our understanding of conditions and helping to develop interventions and therapies for muscle-wasting conditions.



Michael, who lives with Beckers muscular dystrophy, completed the marathon having trained using the couch to 5k programme, when only four years before he had been struggling to walk more than a few hundred metres, had a powered wheelchair and barely walked outside.



**It hurt so much, and I was so tired, but I later felt amazing. I was so proud that I was able to run, after being told for years, I couldn't do this...although it was very hard and took me just over eight hours the day was amazing, and the support was fantastic even for us back of the pack runners."**



Brian, aged 72, and his family team, which included his daughter, took on Pedal, Paddle, Peak in memory of his nephew Mark who died from Duchenne muscular dystrophy at the age of 17. Since Mark was diagnosed at the age of four, Brian has been dedicated to fundraising for us to help improve the lives of people with muscle-wasting and weakening conditions. Over the course of more than 35 years, Brian has raised £680,000 for the charity. He said of the event:

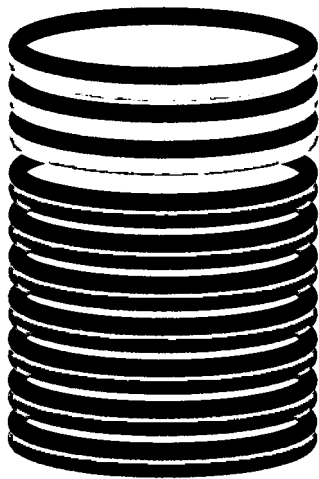


**This year will mark the 25th anniversary of Mark's death so we are taking on the Pedal Paddle Peak in his memory and honour...It will be fun - which will be a fitting tribute to Mark as he was full of fun and remained cheerful throughout his short life."**

# Our finances

## How we raised our funds

For every **£1** we spent we ensure:



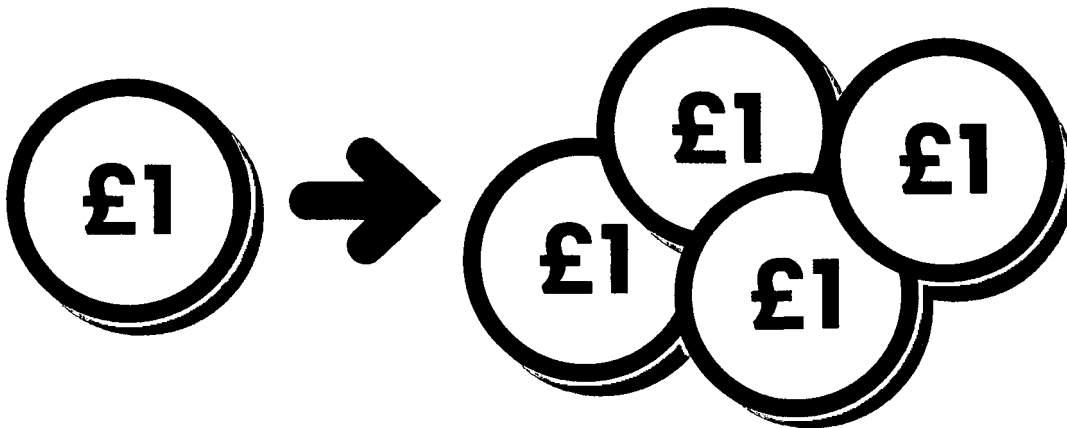
**30p**

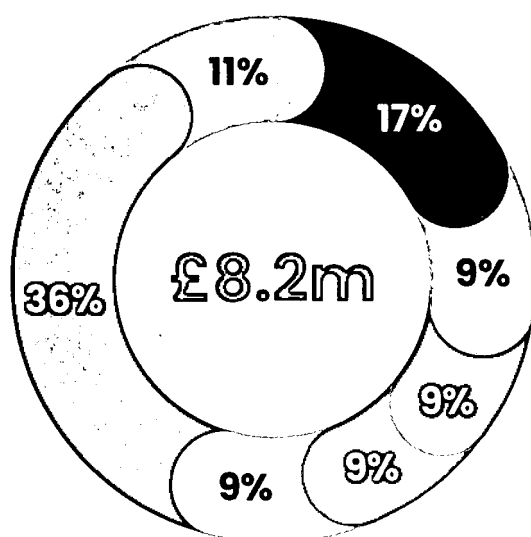
Invested in fundraising to ensure we maintain a diverse income portfolio to support our community

**70p**

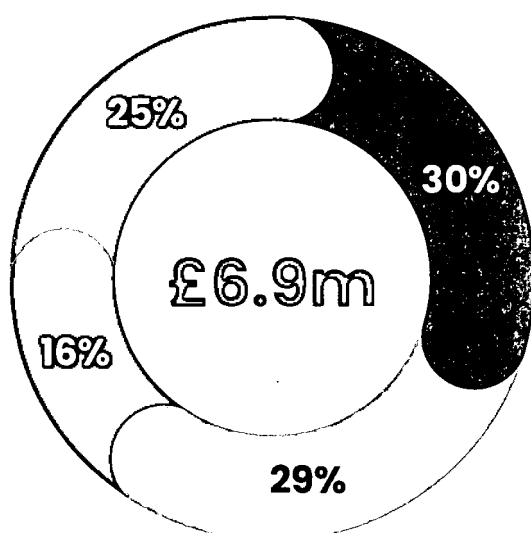
Charitable activities

For every **£1** invested in fundraising we raised **£4**



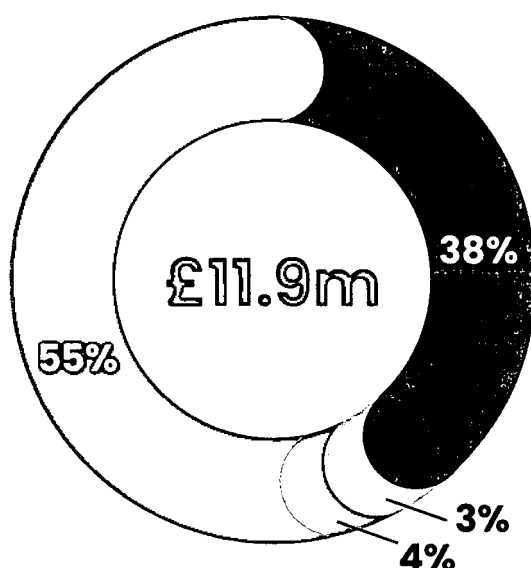


- ☒ **Events and promotions**  
(£1,394k)
- ☐ **Direct marketing**  
(£771k)
- ☐ **Major Donors and Corporate**  
(£773k)
- ☐ **Trusts**  
(£707k)
- ☐ **Regional development**  
(£769k)
- ☐ **Legacy**  
(£2,944k)
- ☐ **Other income**  
(£863k)



## Total expenditure

- ☒ **Fundraising**  
(£2,030k)
- ☐ **Medical research**  
(£1,997k)
- ☐ **Access to specialist care and support**  
(£1,110k)
- ☐ **Independent living**  
(£1,719k)



## Total funds

- ☒ **Restricted**  
(£4,578k)
- ☐ **Endowment**  
(£387k)
- ☐ **Designated**  
(£437k)
- ☐ **General**  
(£6,511k)

# Our future plans

## Going forwards, in 2023/24 we will:

- Award successful grants in our £1m joint fund with LifeArc to accelerate projects to develop new treatments for congenital muscular dystrophy.
- Launch a new £1.5m programme to pump-prime strategic research.
- Invest £500k into the 2022/23 new research grants programme.
- Launch a £90k three-year programme to drive innovative research into enhancing the quality of life for people living with muscle-wasting and weakening conditions.
- Engage in a range of partnerships to begin new projects, including Horizon Europe and UKRI funded grant "Next-generation models and genetic therapies for rare neuromuscular diseases", the nemaline myopathy natural history study at the University of Oxford and a jointly funded project with the Myotubular Trust.
- Engage with the largest number of neuromuscular centres and patient viewpoints, through our neuromuscular services audit and Centres of Excellence Awards.
- Continue to ensure that neuromuscular services and the needs of our community are represented in decisions about future provision as commissioning reforms continue; new treatments become available; and the needs of our community evolve.
- Launch two new initiatives through our Mental Health Matters work to provide psychological support to our community, with the aim of providing increased access to support from a specialist neuromuscular psychiatrist or receiving targeted counselling support.
- Contribute to virtual and physical support events for both people living with muscle-wasting and weakening conditions and professionals who support them.
- Provide support to neuromuscular services and fellow charities at their events.
- Deliver an Allied Health Professionals conference, a Care Adviser conference and two Information days in England and Northern Ireland, before the return of the Scottish Conference in March 2024.

- Continue to evolve our local muscle groups, with virtual events providing condition specific information and support.
- Continue to fight for access to treatments and for support services to be resourced for their roll-out. Engaging in the NICE and SMC appraisal processes for new treatments through to campaigning for SMA to be added to the NHS Newborn Screening Programme on the Newborn Screening list.
- Complete our role in supporting the roll-out of the Department for Levelling Up, Housing and Communities (DLUHC) £30m Changing Places fund and the Department for Transport (DfT) Motorway Service Area Changing Places programme.
- Deliver £6.6m gross budget through active fundraising (£4.2m), legacies (£1.6m) and other income (£772k), which will result in net figure of £4.4m available for our charitable activities.
- Invest in our legacy team to maximise the potential of this long-term income stream.
- Maximise the return on investment through effective deployment of resources and continued monitoring and improvement where possible of return on investment, maintaining at least 2.7 ratio or above.
- Work towards our Patient Information Forum (PIF) accreditation – a signal that we are a trusted information creator through our updated factsheets and alerts cards. A standard our community requires.
- Reduce our overhead costs to 15% of total costs as a result of moving to smaller office.
- Launch our refreshed brand, and our organisational strategy to reach more of the 110,000 people living with one of 60 muscle-wasting and weakening conditions.
- Continue working on reducing our surplus reserves through careful investment planning alongside the new strategy.
- Remain committed to responsible leadership in the sector, with a continued focus on our team's wellbeing, our impact on the environment, and equality, diversity, and inclusion for the whole community.

# Thank yous

## Our President

- Gabby Logan MBE

## Honorary Life Presidents

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## Our Patrons

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- Kate Bushby MD
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- Robbie Warner (from October 2022)

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- Brigid Sutcliffe (from October 2022)
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- Scott Keown
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## Senior Leadership Team

- Catherine Woodhead, Chief Executive
- Dr Kate Adcock, Director of Research and Innovation
- Rob Burley, Director of Care, Communications and Support
- Emma Jones-Parry, Director of Development (from April 2023)
- Wojtek B Trzcinski, Finance and Resources Director and Company Secretary
- Leanne Thorndyke, Director of Marketing (from May 2023)

## Key Donors

- Frances Carey
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- Tony and Monica Moorwood
- Bill and Jacky Ronald
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- Sally Whittet and Professor Michael Joy OBE
- The Q Trust
- MAP Nemaline

## Corporate Support

- Bidwells
- BGC Charity Day
- BMW North Oxford
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- Chimera
- Diligencia Group
- GE Foundation International Grants Fund

- Mail Metro Media
- Marchmont
- Mintel Group
- Tennants Consolidated

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- Clapp Family Charitable Trust
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- Hugh Fraser Foundation
- Sir Samuel Scott of Yews Trust
- The Albert Gubay Charitable Foundation
- The Annandale Charitable Trust
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- The Kirby Laing Foundation
- The True Colours Trust

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- Andrew Wedderspoon
- Charles Howard
- David Allen
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- Ian Mathieson
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- Michael Armstrong
- Scott Keown (Joined June 2023)

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- Modupe Joshua (from December 2022)
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- Hannah Langford
- William Love (from December 2022)
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- Andy Rose
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- Craig Hamilton
- Mairi Leitch
- Scott McIntyre
- Gill Mitan
- Allyson Townhill
- Stuart Townhill



# Our policies

## Fundraising statement

Our supporters are key to our advances in beating muscle-wasting conditions, and in observing and promoting a consistently high standard of fundraising. We regularly monitor our practices to identify training requirements and set policy priorities for our fundraising. We work to ensure a culture of honesty, integrity, and respect with the public, as well as transparency of process to our donors about our cause and the way that their donation will be used.

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

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

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

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

We offer many different opportunities for our fundraisers and donors to engage with us to allow us to fulfil

our charitable objectives. These include, special and challenge events; corporate partnerships; trusts and foundations; regional and community fundraising activities, including Family Funds; fundraising groups, branches and events; individual giving, which includes regular giving, major gifts, appeals, raffles and a weekly lottery, membership scheme; Christmas cards and online shop sales; legacy and in-memory programmes.

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

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

We received two complaints in total in 2022/23. These are included in the following: 0 from 19,094 mailings about our raffles to both warm and cold supporters; 0 complaints from 1,327 guests at our series of special events; 1 complaint from 501 participants at our national events; 0 complaints from 6,930 participants at our own running events (T&G), 1 from 452 volunteer fundraising events; 0 from 49,258 pieces of direct mailings sent out. We have worked together with the two individuals who made these complaints to ensure we will learn from our

mistakes for the future.

### Financial review and policies

Our total income for 2022/23 was £8,221k (2022: £6,669k). The increase in total income this year is a result of a substantial rise in the legacy income. Active fundraising income from donations, gifts, grants, and other fundraising activities remained stable and totalled £4,413k (2022: £4,586k). Legacies income for 2022/23 was £2,944k (2022: £1,648k), this includes £835k legacies accrual based on our best estimates. Investment income was £169k (2022: £151k). Other income amounted to £863k (2022: £557k). The total of £941k (2022: £604k) was received in government grants, including £274k (2022: £301k) of UK government Covid-19 Medical Research Charity Support Fund Grant, £217k (2022: £273k) from the Department of Levelling Up, Housing and Communities and £450k from the Department of Transport Government.

Expenditure on charitable activities was in respect of medical research, access to specialist NHS care and support, and the provision of information, support, and opportunities to enable independent living. The total charitable expenditure has increased by over £1m from that of the previous year to £4,825k (2022: £3,781k), because of the charity gradually returning to pre Covid-19 operational levels.

Medical research comprised 41% (2022: 51%) percent of the total charitable expenditure. Access to specialist NHS care and support comprised 23% (2022: 25%), and provision of information, support and opportunities to enable independent living comprised 23% (2022: 24%) of our charitable costs.

The charity ended 2022/23 with a net surplus of £1,084k (2022: £1,107), net of £281k (2022: ££47k gain) unrealised losses on investments. The surplus included £835k estimated accrual for legacy income, which we are expecting to receive in the future years when the legal matters relating to the estates are finalised.

### Reserves policy

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

The recommended free reserves level is revised annually as part of the budget process on the basis of the financial impact of the current risks facing the charity. The reserves policy is reviewed annually by the Trustees. The charity seeks to maintain free reserves to manage the risks to which the charity is exposed in the course of its business, including but not limited to safeguarding against volatile voluntary income. The Trustees consider that to meet these needs, and to operate effectively, the charity needs the free reserves between £1.65m to £2.2m, based on the current analysis of risk. This has been reviewed in line with 2022/23 budget and taking into consideration high inflation the figures were increased by 10% compared to the previous financial year.

The free reserves funds balance continues to be substantially higher than the target level agreed by the Trustees. We have managed to maintain our finances well though the pandemic and cost of living crisis and did not use our reserves to support day to day activities. It is intended that the surplus on reserves will support the development of the new strategic plan from March 2023, including major investments in research to be announced during the 2023/24 financial year, alongside investments in care, campaigns and support, and communications and fundraising, to increase our ability to deliver our charitable objectives and develop a sustainable fundraising strategy that will be future proof and resilient to changing external economic factors. Our main focus is:

- To continue developing sustainable and diverse income portfolio to increase our resistance to external economic factors.
- To commit to long-term high net research projects as we did with MDUK Oxford Neuromuscular Centre and NorthStar Programme.
- To be able to response to our community needs as they arise, investing in the areas such as policy, allowing us to support approval of future treatments.

The designated funds balance represents the remaining balance on the IT investment fund, part of which was reallocated to fixed assets as the customer relationship management (CRM) and IT projects were almost completed in 2022/23 financial year. This will allow us to be more flexible and agile organisation and will

reduce long term IT and office costs. We purposefully did not designate funds to our research or service support commitments to allow us to be more flexible and responsive in deploying our surplus where it will offer the best return for our community as we develop the new strategy for the organisation.

Having reviewed the strategic risks facing the charity and 2023/24 budget projections, the Board of Trustees considers that there are sufficient reserves held on 31 March 2023 to manage those risks effectively. Accordingly, they continue to adopt the 'going concern' basis in preparing the Annual Report and Accounts.

### Investment policy

The overall objectives are to create sufficient income and capital growth to enable the charity to carry out its purposes consistently year by year with due and proper consideration for future needs and the maintenance of, and if possible, the enhancement of, the value of the invested funds while they are retained. Both capital and income may be used at any time for the furtherance of the charity's aims. The objectives are to be achieved by investing prudently in a broad range of fixed interest securities and equities, which are quoted on a Recognised Investment Exchange and Unit Trusts and OEICs (open-ended investment companies), which are authorised under the Financial Services and Markets Act 2000.

There should be no direct investment in the following: derivative contracts, including futures and options; commodities and derivatives thereof, contracts for differences or structured products.

The investment policy is

reviewed by the Finance Committee on an annual basis.

### Ethical considerations

It has been decided not to invest directly in tobacco manufacture and distribution, this is defined as companies with more than 20 percent of their turnover in this activity. Since 2020/21, Trustees have reviewed the approach of the fund manager towards avoiding offenders in greenhouse gas emissions. It is felt that their approach continues to be sufficient. Trustees reserve the right to exclude companies or industry sectors that carry out activities contrary to the aims of the charity, or from holding particular investments that damage the charity's reputation. Trustees expect the fund manager to have considered the suitability of investments of the same kind as any particular investment proposed or retained. In 2022/23, Trustees and the Senior Leadership Team (SLT) confirmed that the fund manager was not investing in Russian businesses following the Russian invasion of Ukraine in February 2022.

### Remuneration policy

Salaries of the Chief Executive and the SLT are set by the Board's Appointments and Remuneration Committee, taking into account the performance of the charity overall, external comparisons, and the needs of the charity in the longer term. The Board's Appointments and Remunerations Committee reviews the performance of the CEO and the SLT annually.

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

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

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

### Risk management

The Trustees continue to support formal risk management procedures, to assess business risks and implement strategies to minimise risk. Risks have been identified and classified in terms of their potential impact and likelihood, as well as the processes in place to manage them. The comprehensive risk management strategy is based upon a detailed risk register, which is subject to regular scrutiny and review. Risks are reviewed against the strategic aims of the charity and are evaluated against controls in place. Action plans to minimise or remove risk where possible are in place and kept under review. A detailed risk approach review was conducted in 2022/23 with support of an external expert and training was provided to the Trustees and SLT.

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

- a. Maintaining income levels
  - the charity continues to monitor the risks associated with its diverse voluntary income streams using close budget controls, clear marketing plans and monthly reviews of management accounts against targets.
- b. Needing to hold a sufficient level of unrestricted funds to provide protection against loss of income, unplanned

expenditure and to support strategic growth, as well as enable the organisation to be flexible to respond to the community needs when / if required. We strategically focused on not using the reserves in the covid pandemic to ensure that we would come out of it stronger when our community needs us even more.

- c. The impact of a stock market crash on the value of the investment portfolio, mitigated by taking the advice of professional investment managers and long-term investment strategy and maintaining higher than expected reserves to protect the charity against external economic factors.
- d. Data protection breach, given GDPR, fines and attacks on data, this is a very real risk to the charity; leading professionals have been advising us and we continue to work proactively to address this issue. We have upgraded our database and data storage environment (cloud) to ensure we take advantage of the latest available technologies. We work closely with our external IT provided to ensure that we follow the best industry practices to protect the charity from cyber-security threats.
- e. Providing information that meets the needs of our users is essential for their continued support of the charity – the charity will continue to review all communications, publications, and the website to ensure they meet the needs of all our audiences. We have launched our EDI strategy in 2022/23 and have further investigated the need to diversify our

communication channels to ensure that we increase our outreach across the community of 110,000 people living with the muscle wasting conditions. As a result of that we have launched our new refreshed brand and language in June 2023.

- f. Staff recruitment and talent retention continues to pose a considerable risk among the third sector – the charity is engaging with team members on wellbeing, sustainability and equality, diversity and inclusion to build a workplace staff are proud to be part of. We have relocated to a smaller office and offered to our staff flexible and agile working conditions that caters for all.

Our risk management policy proved effective during the Covid-19 pandemic and in 2022/23 during the cost-of-living crisis.

#### **Grant-making policies**

MDUK provides grants for research. We carry out grant calls to attract grant applications.

These are peer-reviewed, and then recommended to the Trustees by the Medical Research Committee and members of the Lay Research Panel. Once a grant is approved, it is monitored annually to ensure that objectives are being met.

MDUK also makes grants for equipment through the Joseph Patrick Trust (JPT) subsidiary. The JPT committee considers applications against an approved criteria before approving grants. In 2022/23 the cost-of-living crisis was a key concern for the community; the JPT Committee agreed to offer a one-off cost of living grant to people living with muscular

dystrophy and the associated conditions we support. The process to deliver 470 grants launched in March 2023, with grants being paid out from April 2023. The volume of demand for the grants created technical and administrative challenges that resulted in two complaints being received and handled.

#### **Reference and administrative details**

The Muscular Dystrophy Group of Great Britain and Northern Ireland (Muscular Dystrophy UK) is a charitable company limited by guarantee registered with Companies House (Reg. 705357). It is also registered with the Charity Commission (Reg. 205395) and Office of the Scottish Charity Regulator (Reg. SC039445). The group also includes a trading subsidiary, Muscular Dystrophy Group (Trading) Limited, registered with the Companies House (Reg. 893086) and unincorporated charitable subsidiary, Joseph Patrick Trust, registered with the Charity Commission (Reg. 294475).

Principal office: 32 Ufford Street, London, SE1 8QD.

Bankers: HSBC, 28 Borough High Street, London SE1 1YB and Royal Bank of Scotland, 40 Islington Road, London N1 8XJ.

Investment Managers: Investec, 2 Gresham Street, London EC2V 7QN.

Auditors: Moore Kingston Smith LLP, 9 Appold Street, London EC2A 2AP.

The details of the President, Patrons, Honorary Life Presidents, Vice Presidents, Trustees, Committees, SLT and advisors are set out on pages 34 to 36.

# 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. Anybody over the age of 18 who supports and promotes the objectives of the charity can become a member, excluding current staff. Muscular Dystrophy UK has a wholly owned trading subsidiary, Muscular Dystrophy Group (Trading) Ltd. and not-for-profit grants giving subsidiary, Joseph Patrick Trusts.

## 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). Two Trustees who have served more than nine years (Professor Hanna, Chair, and Ian Gordon) were re-elected for a further term within the requirements of the Memorandum of Articles of Association. Their reappointment was subject to a particularly rigorous review

by the Appointments and Remuneration committee and Board of Trustees and takes into account the need for progressive refreshing of the board. Their reappointment was approved the members with a majority vote at the AGM.

## Trustee induction and training

New Trustees receive an induction pack of documents and attend briefings that cover 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. Development opportunities include ongoing training, briefings, and the annual Board Away Day.

## Organisation

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

## Members

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

## Volunteers

Volunteers are central to the work of MDUK. We rely on voluntary help in all aspects of the work of the charity. Volunteers work in the office, get involved in fundraising, provide their advice and guidance on many committees, provide support to individuals and families with muscle-wasting conditions, and get involved with campaigning and media work. All these efforts help the charity achieve its aims and objectives and we would like 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. The Board is reminded of the code, and we continually work together on how these principles and practices should be applied at MDUK during updates in the Board meetings, CEO reports and at the annual Board Away Day. In 2022/23 the Trustees engaged

in workshops about the organisational purpose, vision, and values, were regularly updated on the culture of the organisation, supported on the updated risk management plans and engaged in committees. These committees and the Board of Trustees are annually reviewed and updated to ensure that they are an effective team with a balance of skills, experience, and backgrounds to make informed decisions, and to ensure that no one individual has undue power or influence.

### Related parties

The Joseph Patrick Trust (JPT), an unincorporated charity, (Reg. 294475), is the welfare arm of MDUK, which is its sole corporate Trustee. Constituted on 30 April 1986, it provides direct financial assistance in the form of welfare grants to individuals and families living with muscle-wasting conditions, throughout the UK. The consolidated financial statements also include the trading subsidiary, Muscular Dystrophy Group (Trading) Limited (Reg. 893086).

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

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 Michael Hanna**  
Chair  
12 October 2023

# Independent Auditor's Report

## Opinion

We have audited the financial statements of Muscular Dystrophy Group of Great Britain and Northern Ireland (the 'parent charitable company') and its subsidiaries (the 'group') for the year ended 31 March 2023 which comprise the Consolidated Statement of Financial Activities (incorporating an Income and Expenditure Account), the Group and Parent Charitable Company Balance Sheets, the Statement of Group Cash Flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the group's and the parent charitable company's affairs as of 31 March 2023 and of the group's incoming resources and application of resources, including its income and expenditure, for the year then ended.
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 (as amended) and regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

## Basis for opinion

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

## Conclusions relating to going concern

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

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

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

## Other Information

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

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated.

If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

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

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

- the information given in the trustees' annual report (which includes the strategic report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- trustees' annual report (which includes the strategic report) has been prepared in accordance with applicable legal requirements.

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

In the light of the knowledge and understanding of the group and parent charitable company and their environment obtained in the course of the audit, we have not identified material misstatements in the trustees' annual report (which includes the strategic report).

We have nothing to report in respect of the following matters where the Companies Act

2006 or the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

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

#### **Responsibilities of the Trustees**

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

In preparing the financial statements, the trustees are responsible for assessing the group and parent charitable company's ability to continue as a going concern, disclosing, as applicable, matters related

to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group or parent charitable company or to cease operations, or have no realistic alternative but to do so.

#### **Auditor's Responsibilities for the audit of the financial statements**

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

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

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



We also:

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

in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the group or parent charitable company to cease to continue as a going concern.

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

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

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

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with

our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below.

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

Our approach was as follows:

- We obtained an understanding of the legal and regulatory requirements applicable to the charitable company and considered that the most significant are the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 (as amended), regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended), the Charity SORP, and UK financial reporting standards as issued by the Financial Reporting Council
- We obtained an understanding of how the charitable company complies

with these requirements by discussions with management and those charged with governance.

- We assessed the risk of material misstatement of the financial statements, including the risk of material misstatement due to fraud and how it might occur, by holding discussions with management and those charged with governance.
- We inquired of management and those charged with governance as to any known instances of non-compliance or suspected non-compliance with laws and regulations.
- Based on this understanding, we designed specific appropriate audit procedures to identify instances of non-compliance with laws and regulations. This included making enquiries of management and those charged with governance and obtaining additional corroborative evidence as required.

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

### Use of our report

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

*Moore Kingston Smith LLP*

Date: 18/10/2023

**Andrew Stickland**  
Senior Statutory Auditor

for and on behalf of  
Moore Kingston Smith LLP,  
Statutory Auditor

9 Appold Street,  
London EC2A 2AP

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

# **Financial statements and notes**

# Consolidated Statement of Financial Activities (Incorporating an Income and expenditure account)

For the year ended 31 March 2023

	Notes	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2023 £000	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2022 £000
<b>Income</b>							
<i>Income from charitable activities</i>							
Donations, gifts and grants	2	2,971	296	3,267	2,565	1,316	3,881
Government grants	2	-	941	941	-	604	604
Legacies	2	2,949	(5)	2,944	1,172	476	1,648
Income from other trading activities	11	206	-	206	101	-	101
Investment income	2, 10	169	-	169	151	-	151
Other income	2	19	675	694	243	41	284
<b>Total income</b>		<b>6,314</b>	<b>1,907</b>	<b>8,221</b>	<b>4,232</b>	<b>2,437</b>	<b>6,669</b>
<b>Expenditure</b>							
Expenditure on raising funds	3	1,921	13	1,934	1,748	-	1,748
Costs from other trading activities	3	96	-	96	80	-	80
		<b>2,017</b>	<b>13</b>	<b>2,030</b>	<b>1,828</b>	<b>-</b>	<b>1,828</b>
<i>Charitable activities</i>							
Medical research	3,5	999	998	1,997	932	998	1,930
Access to specialist care and support	3	901	209	1,110	815	117	932
Independent living	3	565	1,154	1,719	293	626	919
<b>Total – charitable activities</b>		<b>2,465</b>	<b>2,361</b>	<b>4,826</b>	<b>2,040</b>	<b>1,741</b>	<b>3,781</b>
<b>Total expenditure</b>		<b>4,482</b>	<b>2,374</b>	<b>6,856</b>	<b>3,868</b>	<b>1,741</b>	<b>5,609</b>
<i>Net gain/(loss) on investment assets</i>	9	(262)	(19)	(281)	46	1	47
<b>Net movement in funds</b>		<b>1,570</b>	<b>(486)</b>	<b>1,084</b>	<b>409</b>	<b>698</b>	<b>1,107</b>
<i>Reconciliation of funds</i>							
Total funds brought forward	15	5,378	5,451	10,829	4,969	4,753	9,722
Total funds carried forward	15	6,948	4,965	11,913	5,378	5,451	10,829

There are no recognised gains or losses other than those disclosed above. All results are derived from continuing activities. The accompanying notes on pages 52 to 63 form an integral part of the financial statements.

## Balance Sheets

As at 31 March 2023

Company Registration Number: 705357

	Notes	Group 2023 £000	Group 2022 £000	Charity 2023 £000	Charity 2022 £000
<b>Fixed Assets</b>					
Tangible Assets	8	401	323	401	322
Investments	9	5,399	5,781	5,168	5,387
<b>Total Fixed Assets</b>		<b>5,800</b>	<b>6,104</b>	<b>5,569</b>	<b>5,709</b>
<b>Current Assets</b>					
Stock	12	16	13	-	-
Debtors	13	1,498	881	1,620	923
Cash at Bank		8,641	7,507	8,296	7,442
<b>Total Current Assets</b>		<b>10,155</b>	<b>8,401</b>	<b>9,916</b>	<b>8,365</b>
<b>Creditors falling due within one year</b>	14	<b>(4,042)</b>	<b>(3,676)</b>	<b>(3,796)</b>	<b>(3,380)</b>
Net Current Assets		6,113	4,725	6,120	4,984
<b>Total Assets less current liabilities</b>		<b>11,913</b>	<b>10,829</b>	<b>11,689</b>	<b>10,693</b>
<b>Net Assets</b>		<b>11,913</b>	<b>10,829</b>	<b>11,689</b>	<b>10,693</b>
<b>The funds of the Charity</b>					
Unrestricted					
- Designated	15	437	419	437	322
- General	15	6,511	4,959	6,336	4,970
		6,948	5,378	6,773	5,292
Restricted	15	4,578	5,044	4,529	4,994
Endowment	15	387	407	387	407
<b>Total Charity Funds</b>		<b>11,913</b>	<b>10,829</b>	<b>11,689</b>	<b>10,693</b>

The Statement of Financial Activities for the year ended 31 March 2023 for the parent charitable company only was a surplus of £996k (2022: £1,041k).

Approved and authorised for issue by the Board of Trustees on 12 October 2023 and signed on its behalf by:



**Professor Michael Hanna**  
Chair



**Marcus Brown**  
Treasurer

The accompanying notes on pages 52 to 63 form an integral part of the financial statements.

# Statement of Group Cashflows

Year Ended 31 March 2023

	2023 £000	2022 £000
<b>Net cash inflow/(outflow) from operating activities (note a)</b>	<b>1,069</b>	<b>479</b>
Net Cash flow from investing activities		
Dividends from investments	159	151
Purchase of Tangible Fixed Assets	(196)	(211)
Proceeds of sale of Investments	3,006	2,821
Purchase of Investment	(2,904)	(2,927)
<b>Net Cash provided by investing activities</b>	<b>65</b>	<b>(166)</b>
<b>Increase/(decrease) in cash and cash equivalents in the year</b>	<b>1,134</b>	<b>313</b>
Reconciliation of net cash inflow to movement in net funds		
Increase/(decrease) in cash and cash equivalents in the year (note b)	1,134	313
Cash and cash equivalents at the beginning of the year	7,507	7,194
<b>Cash and cash equivalents at the end of the year</b>	<b>8,641</b>	<b>7,507</b>

## Notes to cash flow statement

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

Net movement in funds	1,084	1,107
Dividends from investments	(159)	(151)
Investment (gains) / losses	281	(47)
Depreciation	117	77
Decrease / (Increase) in debtors / stock	(620)	(511)
Increase / (Decrease) in all creditors	366	3
<b>Net cash provided by/(used in) operating activities</b>	<b>1,069</b>	<b>479</b>

	01-Apr-22 £000	Cashflows £000	31-Mar-23 £000
(b) Analysis of changes in net cash funds:			
Cash and cash equivalents	7,507	1,134	8,641
<b>Total cash and cash equivalents</b>	<b>7,507</b>	<b>1,134</b>	<b>8,641</b>

The accompanying notes on pages 52 to 63 form an integral part of the financial statements.

# Notes to the financial statements

For the year ended 31 March 2023

## Policies

### 1. Accounting policies

#### Accounting convention

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

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

#### Going concern accounting policies

The charitable company's level of free reserves available at the year end, were considered adequate resources to continue in operational existence for the foreseeable future, even with continuous impact of the cost-of-living crisis. The pandemic caused the Trustees to review the positions of the Charity and its subsidiaries in 2020/21 financial year, but there was no need for further reviews in 2021/22 and 2022/23. The budgets and cash flows for 2023/24 were reviewed in September 2023 and the Trustees have considered cash forecasts covering the twelve month period until October 2024. 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 these 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.

#### 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.

Services in kind are valued at the lower of their market value and equivalent market cost were these to be purchased directly by the charity. The Trustees consider that all services in kind received in 2022/23 do not meet recognition criteria outlined in module 6 of the charity SORP 2019.

Therefore, no estimates for these services were included in this set of accounts.

#### Expenditure

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

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

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

Muscular Dystrophy UK awards three types of grants:

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

#### Taxation

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

## 1. Accounting policies (Cont.)

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

### Listed investments

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

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

### Unlisted investments

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

### Financial instruments

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

### Intangible and tangible fixed assets and depreciation

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

### Operating leases

The charity provides for operating leases on property on an actual cost basis. Rent-free periods on property are apportioned over the life of the lease.

Any rent-free period is to offset the additional costs incurred by moving into new premises and reflects the inducement offered in that period by the landlord to let the property.

### Debtors

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

### Cash at bank and in hand

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

### Creditors and provisions

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

### Employee benefits

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

### Pensions

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

### Accounting estimates and areas of significant judgment

In preparing the financial statements, Trustees are required to make estimates, judgements and assumptions that affect the application of the charity's

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

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

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

### Stock

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

### Fund accounting policies

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

Designated funds are unrestricted funds earmarked by the Trustees for particular purposes.

Endowment funds are represented by capital assets held as investments which generate income which in turn is applied to specific objectives of the MDUK as laid down by the donor.

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



## Notes to the financial statements

For the year ended 31 March 2023

### 2. Income

	Unrestricted Funds £000	Restricted Funds £000	Total 2023 £000	Unrestricted Funds £000	Restricted Funds £000	Total 2022 £000
Events and promotions	1,304	90	1,394	1,034	131	1,165
Direct marketing	756	14	770	850	16	866
Major Donors and Corporate	412	362	774	247	236	483
Trusts	116	591	707	130	1,019	1,149
Regional development	589	180	769	556	245	801
Legacy	2,949	(5)	2,944	1,172	476	1,648
Other income	188	675	863	242	315	557
<b>Total income*</b>	<b>6,314</b>	<b>1,907</b>	<b>8,221</b>	<b>4,321</b>	<b>2,438</b>	<b>6,669</b>

\* Of this income £941k comes from Government Grants (2022: £604). The government grants included £274k from UK Government Covid Medical Research Charity Support Fund included in Trust income above, and £450k from the Department of Transport and £217k from the Department for Levelling Up, Housing and Communities included in Other income figure.

### 3. Expenditure

	Grants £000	Other £000	Support Costs £000	Total 2023 £000
<b>Raising Funds</b>				
Expenditure on raising funds	-	1,770	164	1,934
Costs from other Trading Activities	-	89	7	96
<b>Total</b>	<b>-</b>	<b>1,859</b>	<b>171</b>	<b>2,030</b>
<b>Charitable Expenditure</b>				
<i>Access to care and independent living</i>				
Access to care	-	930	180	1,110
Independent living	630	810	279	1,719
<b>Total</b>	<b>630</b>	<b>1,740</b>	<b>459</b>	<b>2,829</b>
<i>Pursuit of Knowledge</i>				
Medical research	1,294	378	325	1,997
<b>Total Charitable Expenditure</b>	<b>1,924</b>	<b>2,118</b>	<b>784</b>	<b>4,826</b>
<b>Total Expenditure</b>	<b>1,924</b>	<b>3,977</b>	<b>955</b>	<b>6,856</b>

### 3. Expenditure (Cont.)

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

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

'Support Costs' comprise of the following :

	2023 £000	2022 £000
Chief Executive and Human Resources	150	103
Finance and insurance	243	207
Office costs	377	454
Information Technology	156	129
Governance	29	27
<b>Total</b>	<b>955</b>	<b>920</b>

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

- 'Access to care' includes Policy, Communications and training activities. 'Independent living' includes advocacy, care, equipment grants and Changing Places.
- 'Research' includes the research grants and departmental running costs
- 'Governance' includes the annual audit fee and Trustees expenses.

### 4. Staff costs (Group and Parent Charity)

	2023 £000	2022 £000
<b>Remuneration of Staff</b>		
Wages and Salaries	2,205	1,928
Social Security Costs	206	187
Pensions	122	110
<b>Total</b>	<b>2,533</b>	<b>2,225</b>

"One redundancy was made in the year (2022: 11). The cost of the redundancy payments was £8k (2022: £24k). The monthly average number of employees during the period was 65 (2022: 57), of whom there were the following higher paid employees as detailed below."

Details of the Key Management Personnel, which consists of the Senior Management Team, can be found on page 34. Their total aggregate employment benefits were £465k (2022: £444k).

#### 4. Staff costs (Group and Parent Charity) (Cont.)

	2023	2022
<b>Earned between the ranges</b>		
£60,001 to £70,000	1	1
£70,001 to £80,000	1	2
£80,001 to £90,000	1	-
£100,001 to £110,000	-	1
£110,001 to £120,000	1	-
<b>Number of staff by activity</b>		
Direct Charitable Expenditure	24	18
Fundraising and Publicity	35	33
Management and Administration	6	6
<b>Total</b>	<b>65</b>	<b>57</b>

#### Pension Schemes

There were no outstanding contributions (2022: £0) at the Balance Sheet date.

#### 5. Grant expenditure

	Research Grants £000	Welfare Grants £000	Total 2023 £000	Total 2022 £000
Grants awarded in the year	1,315	642	1,957	1,393
Grants cancelled in the year	(21)	(12)	(33)	(120)
<b>Total</b>	<b>1,294</b>	<b>630</b>	<b>1,924</b>	<b>1,273</b>

2022 Comparatives	Research Grants £000	Welfare Grants £000	Total 2022 £000
Grants awarded in the year	1,326	67	1,393
Grants cancelled in the year	(90)	(30)	(120)
<b>Total</b>	<b>1,236</b>	<b>37</b>	<b>1,273</b>

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

Apart from the two strategic grants at University College London (North Star Project) and one grant at University of Oxford (MDUK Oxford Neuromuscular Centre), there were no institutions in receipt of material research grants (over £80k pa) in 2022/23.

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

	2023 £000	2022 £000
Payable between one and five years	3,016	2,371

## 5. Grant expenditure (Cont.)

Reconciliation of grant funding commitments :

	Research 2023 £000	Welfare 2023 £000	Total 2023 £000
Carrying amount at start of year	2,674	214	2,888
Additions	1,316	29	1,345
Amounts charged and cancelled in year	(1,200)	(30)	(1,230)
<b>Carrying amount at end of year</b>	<b>2,790</b>	<b>213</b>	<b>3,003</b>

## 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.

	2023 £000	2022 £000
Expiring up to one year	72	257
Expiring between one and five years	486	-
Expiring after more than five years	618	-

## 7. Net income

Net Income is stated after charging

	2023 £000	2022 £000
Auditor's remuneration	29	25
Auditor's remuneration - non audit services	5	3
Depreciation	117	77
Operating lease rentals	273	232

## 8. Tangible fixed assets

Group	Leasehold premises £000	Computer equipment £000	Motor Cars £000	Other assets £000	Other equipment £000	Total £000
Cost at 1 Apr 2022	213	582	24	15	48	882
Disposal	(12)	(205)	(8)	-	(47)	(271)
Additions	108	60	-	-	27	196
<b>At 31 Mar 2023</b>	<b>309</b>	<b>437</b>	<b>16</b>	<b>15</b>	<b>28</b>	<b>805</b>
Depreciation 1 Apr 2022	177	311	24	-	47	560
Disposal	(12)	(205)	(8)	-	(47)	(271)
Provided for year	35	82	-	-	-	117
<b>At 31 Mar 2023</b>	<b>200</b>	<b>188</b>	<b>16</b>	<b>-</b>	<b>-</b>	<b>404</b>
Net Book Value						
<b>At 31 Mar 2023</b>	<b>109</b>	<b>249</b>	<b>-</b>	<b>15</b>	<b>28</b>	<b>401</b>
At 31 Mar 2022	36	271	-	15	1	323

**8. Tangible fixed assets (Cont.)**

Parent Charity	Leasehold premises £000	Computer equipment £000	Motor Cars £000	Other assets £000	Other equipment £000	Total £000
Cost at 1 Apr 2022	213	579	24	15	48	879
Disposal	(12)	(205)	(8)	-	(47)	(272)
Additions	108	60	-	-	27	195
<b>At 31 Mar 2023</b>	<b>309</b>	<b>434</b>	<b>16</b>	<b>15</b>	<b>28</b>	<b>802</b>
Depreciation 1 Apr 2022	177	308	24	-	47	556
Disposal	(12)	(205)	(8)	-	(47)	(272)
Provided for year	35	82	-	-	-	117
<b>At 31 Mar 2023</b>	<b>200</b>	<b>185</b>	<b>16</b>	<b>-</b>	<b>-</b>	<b>401</b>
Net Book Value						
<b>At 31 Mar 2023</b>	<b>109</b>	<b>249</b>	<b>-</b>	<b>15</b>	<b>28</b>	<b>401</b>
At 31 Mar 2022	36	271	-	15	1	323

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 2023 £000	Group 2022 £000	Charity 2023 £000	Charity 2022 £000
Market Value at beginning of year	5,781	5,628	5,387	5,258
Acquisitions	2,904	2,927	2,871	2,732
Sales proceeds	(3,006)	(2,821)	(2,821)	(2,624)
	<b>5,679</b>	<b>5,734</b>	<b>5,437</b>	<b>5,366</b>
Realised (loss)/gain on disposals	334	28	325	(2)
Unrealised gain/(loss) on revaluation of Investments	(614)	19	(593)	23
<b>Market value at end of year</b>	<b>5,399</b>	<b>5,781</b>	<b>5,168</b>	<b>5,387</b>
<b>Historical Cost at end of year</b>	<b>5,186</b>	<b>4,983</b>	<b>4,992</b>	<b>4,042</b>

**Spread of Investments**

The investments of Muscular Dystrophy UK are held as follows:

	Group 2023 £000	Group 2022 £000	Charity 2023 £000	Charity 2022 £000
<b>Investments listed on a recognised Stock Exchange and Unit Trusts</b>				
UK and Overseas equities	3,978	4,234	3,809	4,063
UK and Overseas fixed interest	678	496	646	323
Property funds	233	375	223	341
Hedge funds	415	357	398	342
	<b>5,304</b>	<b>5,462</b>	<b>5,076</b>	<b>5,069</b>
Cash on Deposit awaiting investment	33	257	31	256
Unlisted equities	62	62	62	62
<b>Total</b>	<b>5,399</b>	<b>5,781</b>	<b>5,169</b>	<b>5,387</b>

Investment management costs for the year were £26k (2022: £30k).

There was no individual investment that constituted more than five percent of the total investment portfolio (at market value) as at the year end. (2022 : £nil)

## 10. Income from investments

	Group 2023 £000	Group 2022 £000	Charity 2023 £000	Charity 2022 £000
UK Equities, UK fixed interest and other	81	140	85	133
Short term Deposit and Bank interest	78	11	79	10
<b>Total</b>	<b>159</b>	<b>151</b>	<b>164</b>	<b>143</b>

## 11. Investments in subsidiary undertakings

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

- Joseph Patrick Trust, a separately registered charity, 294475, which makes grants towards welfare equipment. Muscular Dystrophy UK is the sole corporate Trustee.
- Muscular Dystrophy Group (Trading) Limited, 893086, which undertakes trading activities on behalf of the charity and covenants all profits to the charity. Muscular Dystrophy UK is the sole shareholder.
- They are both registered at 32 Ufford Street, London, SE1 8QD.

Their net assets and results for the year ended 31 March 2023 are summarised below:

	Muscular Dystrophy Group (Trading) Ltd £000	Joseph Patrick Trust £000
Fixed Assets	-	230
Current Assets	171	205
Current Liabilities	(168)	(214)
<b>Total Net Assets</b>	<b>3</b>	<b>221</b>
Represented by:		
<b>Total Funds</b>	<b>3</b>	<b>221</b>
 Total income	 207	 131
Total expenditure	(96)	(30)
Investment gains/losses and other B/S movements	-	(13)
<b>Surplus for the year</b>	<b>111</b>	<b>88</b>
 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 £16k (2022 : £13k).

## 13. Debtors

	Group 2023 £000	Group 2022 £000	Charity 2023 £000	Charity 2022 £000
Trade debtors	-	50	-	-
Amount due from subsidiary undertakings	-	-	21	92
Prepayments and accrued income	1,491	833	1,598	831
Other debtors	7	(2)	1	-
<b>Total</b>	<b>1,498</b>	<b>881</b>	<b>1,620</b>	<b>923</b>

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

**14. Creditors falling due within one year**

	Group 2023 £000	Group 2022 £000	Charity 2023 £000	Charity 2022 £000
Accruals for grant commitments	3,003	2,888	2,789	2,674
Accruals and Deferred Income	573	368	568	296
Taxation and Social Security	58	51	54	45
Other Creditors	408	369	385	365
<b>Total</b>	<b>4,042</b>	<b>3,676</b>	<b>3,796</b>	<b>3,380</b>

**15. Funds**

	April 2022 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2023 £000
<b>Endowment Fund</b>						
Orchid Ball	406	-	-	-	(19)	387
<b>Restricted Funds</b>						
<i>Provision of care</i>						
City Bridge Trust / Work experience	82	-	(78)	-	-	4
Scotland	19	17	(36)	-	-	-
Psychological support	28	30	(29)	-	-	29
Volunteering	60	3	(63)	-	-	-
Joseph Patrick Trust - AT and under 18's	50	-	(1)	-	-	49
Changing Places	2,456	695	(940)	-	-	2,211
The Garfield Weston CCS Fund	300	4	(187)	-	-	117
Other care	6	47	(51)	-	-	2
<b>Research</b>						
The Patrick Research Fund	298	-	(198)	-	-	100
Congenital LMNA MD	31	28	-	-	-	59
Oxford Neuromuscular Centre	219	3	(222)	-	-	-
Q Trust	4	17	-	-	-	21
FSHD Research	63	32	(18)	-	-	77
Duchenne Research	104	139	(76)	-	-	167
Ullrich Research	18	53	45	-	-	116
Nemaline Research	288	83	-	-	-	371
Congenital MD	465	-	-	-	-	465
Becker Research Fund	133	17	-	-	-	150
SMA Research	41	-	(27)	-	-	14
Limb Girdle research	45	3	(1)	-	-	47
Other research	335	736	(492)	-	-	579
<b>Total Restricted Funds</b>	<b>5,451</b>	<b>1,907</b>	<b>(2,374)</b>	<b>-</b>	<b>(19)</b>	<b>4,965</b>

**15. Funds (Cont.)**

	April 2022 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2023 £000
<b>Designated Funds</b>						
IT Investment Fund	96	-	-	(60)	-	36
Tangible Assets for Charity Use	323	135	(118)	60	-	401
<b>Total Designated Funds</b>	<b>419</b>	<b>135</b>	<b>(118)</b>	<b>-</b>	<b>-</b>	<b>437</b>
General Fund	4,959	6,179	(4,365)	-	(262)	6,511
<b>Total Unrestricted Funds</b>	<b>5,378</b>	<b>6,314</b>	<b>(4,482)</b>	<b>-</b>	<b>(262)</b>	<b>6,948</b>
<b>Total Funds</b>	<b>10,829</b>	<b>8,221</b>	<b>(6,856)</b>	<b>-</b>	<b>(281)</b>	<b>11,913</b>

<b>2022 Comparatives</b>	April 2021 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2022 £000
<b>Endowment Fund</b>						
Orchid Ball	405	-	-	-	1	406
<b>Restricted Funds</b>						
<i>Provision of care</i>						
City Bridge Trust / Work experience	75	60	(53)	-	-	82
Scotland	28	30	(39)	-	-	19
Psychological support	28	-	-	-	-	28
Volunteering	138	-	(78)	-	-	60
Joseph Patrick Trust - AT and under 18's	30	20	-	-	-	50
Changing Places	2,580	297	(421)	-	-	2,456
The Garfield Weston CCS Fund	-	300	-	-	-	300
Other care	59	99	(152)	-	-	6
<b>Research</b>						
The Patrick Research Fund	298	-	-	-	-	298
Congenital MD	-	465	-	-	-	465
Oxford Neuromuscular Centre	374	118	(273)	-	-	219
Q Trust	3	1	-	-	-	4
FSHD Research	114	31	(82)	-	-	63
Duchenne Research	38	199	(133)	-	-	104
Ullrich Research	129	28	(139)	-	-	18
Nemaline Research	154	134	-	-	-	288
Congenital LMNA MD	(5)	36	-	-	-	31
Becker Research Fund	84	49	-	-	-	133
SMA Research	68	14	(41)	-	-	41
Limb Girdle Research	44	1	-	-	-	45
Other research	110	556	(330)	-	-	336
<b>Total Restricted Funds</b>	<b>4,753</b>	<b>2,438</b>	<b>(1,741)</b>	<b>-</b>	<b>1</b>	<b>5,451</b>



**15. Funds (Cont.)**

<b>2022 Comparatives</b>	<b>April 2021 £000</b>	<b>Income £000</b>	<b>Expenditure £000</b>	<b>Movement between funds £000</b>	<b>Investment gains £000</b>	<b>March 2022 £000</b>
<b>Designated Funds</b>						
IT Investment Fund	251	-	(155)	-	-	96
Tangible Assets for Charity Use	189	211	(77)	-	-	323
<b>Total Designated Funds</b>	<b>440</b>	<b>211</b>	<b>(232)</b>	<b>-</b>	<b>-</b>	<b>419</b>
<b>General Fund</b>	<b>4,529</b>	<b>4,020</b>	<b>(3,636)</b>	<b>-</b>	<b>46</b>	<b>4,959</b>
<b>Total Unrestricted Funds</b>	<b>4,969</b>	<b>4,231</b>	<b>(3,868)</b>	<b>-</b>	<b>46</b>	<b>5,378</b>
<b>Total Funds</b>	<b>9,722</b>	<b>6,669</b>	<b>(5,609)</b>	<b>-</b>	<b>47</b>	<b>10,829</b>

**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 Fund**

*City Bridge Trust / Work experience* - this is funding received from the City Bridge Trust to support young disabled people in the London area to access work experience and develop their employability skills.

*Scotland* - this is used for activities in Scotland.

*Psychological Support* - This is used to support our Mental Health Matters work, identifying how MDUK can best improve the mental health and wellbeing support available for people affected by muscle-wasting conditions.

*Volunteering* - this is funding to support our work to identify a more strategic and sustainable approach to working with volunteers to help support our community.

The Joseph Patrick Trust is a restricted trust within Muscular Dystrophy UK as explained in Note 11. Some of its assets are restricted to Assistive Technology and children (under 18) grants.

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

- The provision of grants to motorway service areas in England to install Changing Places toilets.
- The provision of grants to operators of A road service areas in England to install Changing Places toilets.
- The provision of grants to train operating companies in England to install Changing Places toilets.
- The provision of information and advice to Local Authorities in England as they utilise c.£30m of government funding to install Changing Places toilets in existing buildings.
- Improvements to the Changing Places website and digital map.
- Support to cover the general costs associated with MDUK's role as co-chair of the Changing Places Consortium.

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

*Other Care* - this includes funding for our Muscle Group activity and work to connect families from South Asian backgrounds affected by muscle-wasting conditions with each other.

*The Patrick Research Fund* - this is a donation from the Patrick family. It is to be held for research activities relating to Duchenne muscular dystrophy.

*Congenital Muscular Dystrophy* - this is used to support research related to congenital muscular dystrophy condition.

*Oxford Neuromuscular Centre* - this is used to support the funding of the MDUK Oxford Neuromuscular Centre - much of the fund has come from the Q Trust.

*Q Trust* - this funding comes from the Q Trust. In the past these funds went to support the MDUK Oxford Neuromuscular Centre at request of the Trust. We are in a discussion with the Trust how the remaining funds will be used in the future.

*FSHD Research* - this is used to support research related to the condition FSHD (facioscapulohumeral muscular dystrophy).

*Duchenne Research* - this is used to support research related to the condition Duchenne muscular dystrophy.

*Ullrich Research* - this is used to support research related to the condition Ullrich congenital muscular dystrophy and other collagen-VI-related muscular dystrophies.

*Nemaline Research* - this is used to support research related to the condition nemaline myopathy. A significant proportion of these funds came via the MAP Nemaline family fund.

*Congenital LMNA MD* - this is used to support research related to the condition LMNA congenital muscular dystrophy.

*Becker Research Fund* - this is used to support research related to the condition Becker muscular dystrophy.

*SMA Research* - this is used to support research related to the condition spinal muscular atrophy.

*Limb Girdle research* – this is used to support research related into limb girdle muscular dystrophies.

*Other research* – this is used to support research grants for which there are no condition restrictions.

### Unrestricted Funds

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

The designation of balances is as follows:

- The Tangible Assets for Charity Use represent the amount of unrestricted funds represented by these assets.
- The General Fund is available for the ongoing operations of the charity.
- Designated Fund represents IT investment in CRM and Cloud migration projects.

Represented by: 2023	Fixed Assets £000	Investments £000	Net Current Assets £000	Total £000
Endowment Funds	-	387	-	387
Restricted Funds	-	-	4,578	4,578
Designated Funds	401	-	36	437
Unrestricted Funds	-	5,012	1,499	6,511
<b>Total Funds</b>	<b>401</b>	<b>5,399</b>	<b>6,113</b>	<b>11,913</b>

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

## 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:

	2023 £000	2022 £000
Residuary	694	1,138
Reversionary	252	247
<b>All sums are due to Muscular Dystrophy UK.</b>	<b>946</b>	<b>1,385</b>

## 17. Status of charity

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

## 18. Related party transactions

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

	2023 £000	2022 £000
Donations	5	21
Expenses	1	-

No Trustee received any remuneration during the year (2022: £nil).

There were no other related parties transactions.

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