MUSCULAR DYSTROPHY GROUP OF GREAT BRITAIN AND NORTHERN IRELAND

England & Wales · Charity number 205395

Details

Other names	MUSCULAR DYSTROPHY CAMPAIGN, MUSCULAR DYSTROPHY UK
Status	Registered
Legal form	Charitable company
Company number	00705357
Registered	1962-05-16
Register	View on the Charity Commission register

Contact

Address	32 Ufford Street London SE1 8QD
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Email	info@musculardystrophyuk.org
Website	www.musculardystrophyuk.org

Activities

Objects: TO PROMOTE RESEARCH INTO MUSCULAR DYSTROPHY AND ALLIED NEUROMUSCULAR CONDITIONS; TO PROMOTE THE PROVISION OF CARE AND TREATMENT AND OTHER RELIEF TO THOSE AFFECTED BY MUSCULAR DYSTROPHY AND ALLIED NEUROMUSCULAR CONDITIONS; TO ASSIST THOSE WHO CARE FOR PERSONS AFFECTED BY MUSCULAR DYSTROPHY AND ALLIED NEUROMUSCULAR CONDITIONS; TO PROVIDE EDUCATION AND TRAINING TO PERSONS AFFECTED BY MUSCULAR DYSTROPHY AND ALLIED NEURO MUSCULAR CONDITIONS; TO RAISE THE AWARENESS OF THE PUBLIC ON ANY MATTERS RELATING TO THE CHARITY'S OBJECTS.

Activities: We support research with the aim of finding treatments and effective cures and we drive improvements in health care. We provide information and advice, campaign to raise awareness, provide care and support. Further, we enable people to lead as full and rich a life as possible through the provision of advocacy support and equipment grants as well as campaigns to remove barriers to independence.

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Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£7,912,000	£10,091,000	£11,751,000	73
2024-03-31	£9,508,000	£8,042,000	£13,821,000	70
2023-03-31	£8,221,000	£6,856,000	£11,913,000	65
2022-03-31	£6,669,000	£5,609,000	£10,829,000	57
2021-03-31	£5,544,000	£3,574,000	£9,722,000	59

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Trustees

Name	Role	Appointed
Brigid Sutcliffe		2022-10-11
Carole Michelle Anthony		2021-07-20
Chloe Jasmine Hazel Docker		2024-10-17
Claire Louise O'Hanlon		2020-10-08
Dr Rosaline Christina Mary Quinlivan		2025-12-11
Gerard McMenemy		2023-10-12
JAMES HANYUNG LEE		2023-07-11
Jennifer Christine Howells		2025-10-16
Joseph Eoin Gordon		2019-10-12
Lord John Kevin Sharkey		2023-03-21
Marian Clare Ridley		2025-12-11
PROFESSOR MICHAEL HANNA		2013-12-02
Prof Deirdre Kelly CBE		2021-10-07
Prof Simon Guy Ray		2025-12-11
Thomas William Sara		2025-12-11

Linked charities

- ENGLERT TRUST FOR MUSCULAR DYSTROPHY AND SIMILAR RESEARCH (205395-1)
- NORTHUMBERLAND AND DURHAM BRANCH OF THE MUSCULAR DYSTROPHY GROUP OF GREAT BRITAIN (205395-2)

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MUSCULAR DYSTROPHY GROUP OF GREAT BRITAIN AND NORTHERN IRELAND

England & Wales - Charity number 205395

Accounts

MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Muscular Dystrophy Group of Great Britain and Northern Ireland

Annual Report 2024/25

Together we are stronger



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Front cover and opposite photographer: Chris O'Donovan

A message from our Chair and Chief Executive

Welcome to this year's Annual Report. A year in which we've continued to increase the impact of our research, services and influencing work. In November, we were delighted to welcome Andy Fletcher as our new Chief Executive. Since then, Andy has been getting to know the charity and meeting our extraordinary community.

In 2024/25, we continued to fund groundbreaking research into a range of muscle wasting conditions. We were delighted to commit significant funding to the LifeArc Centre for Rare Mitochondrial Diseases, as well as to three projects focused on developing treatments for congenital muscular dystrophy, as part of our strategic partnership. And, following a new strategic grant round, a £1m award to Professor Mary Reilly at University College London to develop a new scanning method to spot small changes in Charcot-Marie-Tooth disease (CMT).

As part of our regular grant round, we funded a further 12 projects with a lifetime funding commitment of £1.7m. This brought the number of our live research programmes to 45, focusing on 25 different conditions. These grants, alongside our strategic research investment, show our commitment to funding innovative programmes designed to better understand and treat muscle wasting conditions for the benefit of our community.

After research and clinical trials comes access to treatments, and this too has accelerated at pace since the first treatment for a muscle wasting condition became available in the UK in 2016. This year, we were delighted to have helped secure the approval of Vamorolone, a new treatment for Duchenne muscular dystrophy. We were also involved in a further eight NHS treatment appraisals that could potentially benefit our community.

As well as funding research to give hope for the future, we also continue to provide direct support to people with muscle wasting conditions so they can live their life fully today. This year we supported more than 3,300 people through our helpline, and provided equipment grants to 131 people living with a muscle wasting condition. Our peer-to-peer support network also continues to grow and thrive.

This year, we continued to support and influence the NHS and the development of neuromuscular services, and speak up for our community. Our conferences for Allied Health Professionals and Care Advisers had more than 170 in-person attendees and our upskilling webinars continued to grow and attract professionals from across health and care services.

We were delighted that our wonderful garden at the RHS Chelsea Flower Show exceeded all our expectations. The unique opportunity presented by Project Giving Back for a fully funded garden at the RHS Chelsea Flower Show 2024 culminated in winning Best in Show. The garden allowed us to reach people who had never heard of muscle wasting conditions, to give our community a voice, and to raise awareness of our work.

While we live in uncertain times, we are committed to continuing to grow our impact to ensure that people living with muscle wasting conditions have the support they need. During the past year we have been developing a new, bold and ambitious strategy to lead our work over the next decade. This was launched in September 2025.

We finish this year once again proud of our wonderful community. Our research partners, support services and funders, volunteers, fundraisers, staff and trustees. Thank you for your support, your involvement, your stories, your requests and your continued passion to make our charity matter, because we all know how much our muscles matter.

Thank you for your support.



Andy Fletcher
Chief Executive



Professor Michael Hanna
Chair

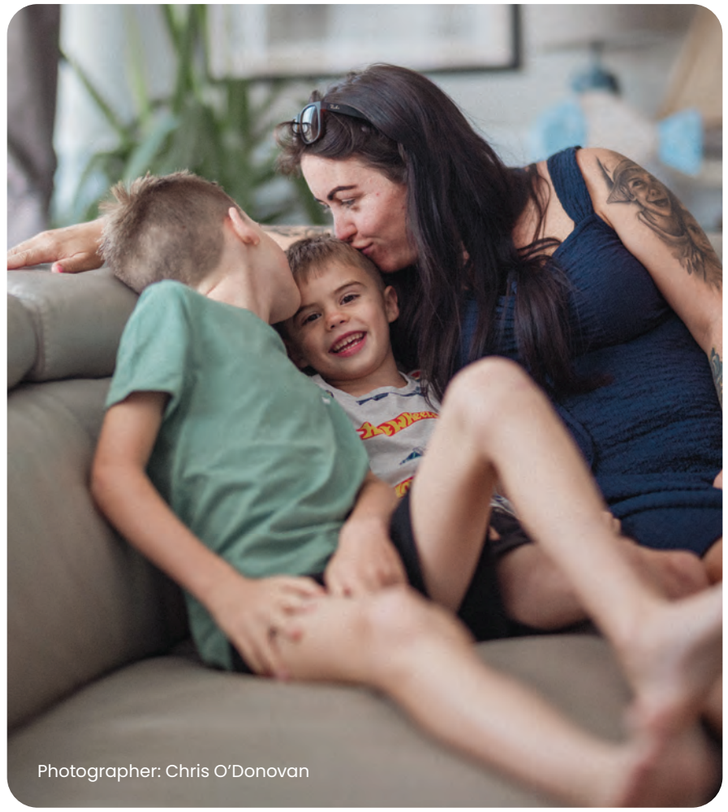
Zoe and Archie's story

Zoe's son, Archie, was diagnosed with Duchenne muscular dystrophy in June 2024 at six years old. Our helpline team supported Zoe and her partner through the initial diagnosis with information about the condition, understanding what the genetics meant for their other son, Alfie, and providing counselling for Zoe.

"For years, I had a gut feeling something wasn't right, but doctor after doctor dismissed my concerns. We were told Archie was just anaemic and would grow out of it. But he was always tiny, constantly ill, and exhausted — eventually needing a buggy for long walks. Even when we saw a paediatrician, we were brushed off. It was heartbreaking.

"Everything changed when we were referred to Evelina London Children's Hospital. For the first time, we felt listened to. A few weeks later, we received the devastating diagnosis: Archie had Duchenne muscular dystrophy.

"Evelina told us about Muscular Dystrophy UK, and reaching out to them was one of the best things I've done. Their helpline team was kind, compassionate, and gave me clear, reliable information. It's so much to take in about what the future holds for our little boy. I didn't know how to cope at all.



Photographer: Chris O'Donovan

Muscular Dystrophy UK offered me one-to-one counselling sessions, which were a lifeline. Being able to speak openly and grieve in a safe space helped me begin to process what was happening."

"The charity has supported our whole family. Archie's grandma raised money at Christmas, and when she called to donate, they reminded her that they're here for everyone. It meant so much for her to feel seen and supported too.

"We were also confused about the genetic side of Duchenne and whether our older son, Alfie, needed testing. We got back in touch with the helpline team, and I had a long phone call where they explained the science behind Duchenne. I had tried to Google the information, but speaking to someone allowed me to understand the facts so I could stop panicking unnecessarily. They gave me easy to understand leaflets too so that I could properly digest the information.

"It's still incredibly hard, but knowing we're not alone, and that support is always there, has made all the difference."

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 people living with muscle wasting and weakening conditions, and all those 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 everyone. 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're 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 muscular dystrophy and allied neuromuscular conditions.

We work to:

- Promote research
- Promote the provision of care and treatment
- Assist those who care for persons affected by the conditions
- Provide education and training to persons affected
- Raise public awareness 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

£1.7m
committed to 12 new research projects

£7.9m
raised this year

£2.15m
committed in strategic research grants

More than 260
healthcare professionals attended our upskilling webinars

Over £500,000
raised at the 40th Anniversary Microscope Ball

Nearly 3,500
people supported through our helpline

More than 460
people joined our WhatsApp communities

Nearly 80
Trusts and Foundations supported our work this year

Nearly 630,000
visits to our website, up 20% on the previous year

Over 1,750
pieces of media coverage. A 18% increase in volume of coverage year-on-year

Looking back on what we achieved

This year's achievements and performance measured against our 2024/25 objectives.

Performance indicator	Our achievements
Award a grant as part of our partnership with the LifeArc Translational Rare Disease Centre	• Awarded a grant of £1.15m to Professor Patrick Chinnery at the University of Cambridge
Launch a new call for £1m strategic programmes grant	• Awarded a grant of £1m to Professor Mary Reilly at University College London
Invest over £500,000 into the 2024 new research grants programme	• Invested £640,000 into new research grants, with a total lifetime commitment of £1.7m
Continue to engage in research partnerships, including the MAGIC consortium and the LifeArc programmes	• Announced new grants through the LifeArc partnership programme and contributed to communication activities of the MAGIC consortium
Award grants as part of three-year programme to drive innovative research into enhancing the quality of life for people living with muscle wasting conditions	• Awarded two new grants as part of this scheme
Relaunch our partnership with the Medical Research Council to support clinical fellowships	• This scheme is now live
Deliver at least £6m gross fundraising budget	• Delivered a gross budget of £7.9m through active fundraising (£4.5m), legacies (£2.6m) and other income (£820k), which has resulted in a net figure of £4.9m

This year's achievements and performance measured against our 2024/25 objectives - continued

Performance indicator	Our achievements
Invest in a new legacy proposition to maximise the potential of this long-term income stream	• Successfully launched our *Change the Story* legacy campaign in March 2025
Invest in a portfolio review of our events and campaigns to inform our strategic direction from 2025/26 onwards	• Using sector expertise and external market knowledge carried out a portfolio review resulting in invaluable evidence-based insights
Deliver a successful garden at the RHS Chelsea Flower Show 2024	• Delivered beyond expectations, culminating in winning Best in Show. This allowed us to reach new audiences and raise awareness of our work
Provide accurate and accessible information, support and signposting, through our helpline service and advocacy support	• Supported over 3,300 people through our helpline, a 23% increase on previous years • Supported 130 advocacy cases • Achieved the Patient Information Forum (PIF) accreditation
Connect people living with muscle wasting conditions through our national events and webinars, local groups, and our network of trained peer support volunteers	• Held in-person Information Days/conferences in England, North Wales and Scotland. Along with a disability sports event, holistic physiotherapy events, and seven condition specific webinars.
Provide grants to members of our community for essential powered mobility equipment	• Provided 131 grants for essential mobility equipment • Collaborated with SMA UK (SMArtMoves) and Whizz Kidz to jointly fund grants for power wheelchairs
Deliver targeted campaigns on key areas of concern to our community and drive-up UK wide political awareness and support for muscle wasting conditions	• Launched *Missing People. Missing Support* report on unmet health and care needs in Scotland at the Scottish Parliament • Advocated for improved financial security throughout the year, highlighting the widespread financial insecurity impacting on our community
Continue as co-chair of the Changing Places Consortium and complete UK Government funded Changing Places programmes	• Continued role as co-chair of the Changing Places Consortium until 31 March 2025, then formally handed over to PAMIS as sole chair from April 2025 • Successfully concluded all government-funded programmes under our management and ensured full distribution of allocated funds

This year's achievements and performance measured against our 2024/25 objectives - continued

Performance indicator	Our achievements
Provide unique national conferences and virtual training opportunities for specialist and non-specialist health professionals involved in the care of people living with muscle wasting conditions	• Held upskilling webinars for 266 healthcare professionals across different specialties • Held neuromuscular conferences attended by 177 care advisors, clinical nurse specialists, and allied health professionals • Ran e-learning modules attended by 711 healthcare professionals
Provide regional networking, information and intelligence sharing, and upskilling opportunities to health professionals involved in the care of people living with muscle wasting and weakening conditions	• Hosted eight regional neuromuscular networks to support intelligence sharing and strategic discussions on challenges faced by different regions
Map the provision of specialist neuromuscular services across the UK, seek to protect the provision of specialist NHS neuromuscular services, and secure additional NHS resource. Recognise and disseminate best practice and support neuromuscular services to navigate ongoing healthcare commissioning and delivery reforms	• Published report highlighting best practice and key challenges in neuromuscular services evidenced by the findings of our Centre of Excellence audit
Help to facilitate access to treatments for muscle wasting and weakening conditions	• Participated in eight treatment appraisals this year
Deliver £10m charitable expenditure budget investing our reserves to cover the deficit	• Spent total of £10.1m on work supporting our community
Launch our new website providing a better user experience and improved navigation	• Launched our new website in May 2024
Launch a brand campaign to reach people affected by the conditions who aren't currently engaging with the charity	• Following insight and research we decided to test and learn from a number of different activities to further increase our reach including Meta ads, engagement with healthcare professionals and developing an online referral form

Our research advances

High-quality research continues to play a key role in our work to improve the lives of people living with a muscle wasting condition. It helps us to better understand conditions and maximise treatment improvements.

Our research strategy *Transforming lives through research* remains the driving force for our research activity.

Our grant awards this year

This year, we committed £1.7m into 12 new research projects as part of our 2024 grant round. We're proud to report that these new research projects cover a range of different conditions, including:

- Desminopathy
- Periodic paralysis
- Charcot-Marie-Tooth disease (CMT)/SORD neuropathy
- Duchenne muscular dystrophy
- Mitochondrial myopathy
- Limb girdle muscular dystrophies
- Myotonic dystrophy type 1
- Facioscapulohumeral muscular dystrophy (FSHD)

By funding innovative research, we're accelerating progress in diagnosis, the monitoring of progression, and treatment development for muscle wasting conditions.

Our lay research panel helps us with the selection and approval process for this funding, and we would like to thank the members and our medical research committee for their time and expertise.

This year over 100 people contacted us through our research line.

Celebrating 20 years of the NorthStar programme

This year we celebrated 20 years of the NorthStar programme in which we've invested over £1.5m since 2004.

Over the past 20 years, the programme, led by Professor Francesco Muntoni and Dr Adnan Manzur, has transformed care and research for people living with Duchenne muscular dystrophy (DMD).

Today, it's the world's largest study tracking the progression of DMD over time. It currently involves over 2,000 boys and men across 23 centres in the UK. The findings of the programme have been instrumental in shaping clinical trial design, improving standards of care, and enhancing the quality of life for people living with DMD.

"The NorthStar Network was established 20 years ago to help improve standards of care for boys with Duchenne muscular dystrophy across the entire country. Today, the improved standards have helped many boys living with the condition extend their lives into adulthood.**"**
Professor Francesco Muntoni

Spotting small changes in CMT to support greater accuracy in clinical trials

This year we committed £1m to University College London (UCL) for a project led by Mary Reilly, Professor of Clinical Neurology, to develop a new scanning method to spot small changes in Charcot-Marie-Tooth disease (CMT) and collect information from people living with CMT about how their condition affects their daily life.

This work will help make trials more accurate, showing more clearly if treatments are working, and will



Emily is a Muscular Dystrophy UK funded PhD student working on a project to explore whether controlling stress signals and taking nutritional supplements can help to treat non-reversible mitochondrial myopathies.

"My interest in research began with my own health struggles. Knowing something's going wrong inside your body, but being unable to control it is hard. I wanted to contribute to research that creates tangible outcomes that help individuals."

Photographer: Chris O'Donovan

put the UK in a strong position to lead the way in finding effective treatments.

This funding also covers an initiative to get the UK ready for more CMT clinical trials. At present only one centre is set up to run clinical trials for CMT. With potential new treatments on the way, more centres are needed so a greater number of people can take part in trials closer to their homes.

New centre to accelerate mitochondrial disease treatments

We awarded just over £1m to the LifeArc Centre to Treat Mitochondrial Disorders, led by Professor Patrick Chinnery, this year. The Centre brings together top clinicians, researchers, and the voices of people affected by mitochondrial diseases and works towards accelerating mitochondrial disease diagnosis and the development of much-needed treatments.

A collaboration between the University of Cambridge, UCL, Newcastle University, The Lily Foundation, and sites in Birmingham, Manchester and Oxford, the centre is backed by a £7.5m grant from LifeArc.

Our investment will fund and train a new generation of scientists to lead future research into muscle wasting conditions.

Partnerships to drive forward new treatments for congenital muscular dystrophy

Working with partners helps our funding go further, allowing us to support more research and have a greater impact. Together with LifeArc we co-funded three research grants this year with the aim of developing new treatments for congenital muscular dystrophy, a group of early-onset muscle weakening conditions with no effective treatments. This vital partnership was made possible thanks to an incredibly generous legacy gift and could bring us closer to potentially life-changing breakthroughs.

"This funding is pivotal. Success would break the longstanding therapeutic bottleneck in COL6-CMD and establish a modular delivery platform adaptable to other neuromuscular disorders where muscle fibroblast targeting is critical.**"**

Professor Haiyan Zhou, funding recipient

Research to support people living well with muscle wasting conditions

When we asked people living with muscle wasting conditions what research we should be focusing on, it was clear that quality of life was a priority.

In response, we launched a new funding programme to support this area. So far, we've backed two research projects aiming to ensure people with these conditions can live the best life possible.

Dr Christopher Morse is working with people affected by facioscapulohumeral muscular dystrophy (FSHD) and limb girdle muscular dystrophy (LGMD) to understand what helps, or gets in the way of, living well and how things can be improved. Dr Philip Hennis and his team are exploring methods that might help people with glycogen storage disease, like Pompe disease, exercise more safely.

"When you live with a serious degenerative muscle wasting condition, having a good knowledge of the aspects that can improve your quality of life is important."

John, living with Pompe disease

Highlights of our research funding

Research projects take time to deliver impact. Here are some key outcomes from grants we funded that came to an end in 2024/25.



Speeding up diagnosis

Diagnosing muscle wasting conditions can take a long time. Professor Jordi Diaz-Manera from the University of Newcastle has developed a tool which, using body scans, can predict a diagnosis for 20 different conditions.

We're now supporting the continuation of this research to increase the number of conditions the tool can predict. There is also a focus on improvements to make it more accurate, and easy for clinicians to use in appointments with patients.

"A new web application called Myo-Guide has been developed to help clinicians around the world make sense of complex scans using artificial intelligence."

Samantha Fitzsimmon, Project Manager, John Walton Muscular Dystrophy Centre

Finding potential new treatments for CMT

We funded research to look for new treatments for CMT, a condition where nerve signals struggle to reach the muscles, leading to weakness.

Dr Ivana Barbaric's team at the University of Sheffield focused on mitochondria, the parts of cells that produce energy and are known to move poorly in CMT. By growing nerve cells in the lab, they developed a way to track how mitochondria move.

Using this method, they found several existing drugs that help improve movement in CMT nerve cells. These early results are promising, and the next step is to better understand how these drugs work and prepare them for further testing.

Working towards a less invasive test for muscle wasting conditions

Diagnosing muscle wasting conditions often involves inserting a needle into the muscle to measure how signals from the brain are received and processed. This test can be painful and uncomfortable, especially for children.

We funded Dr Eduardo Martinez-Valdes at the University of Birmingham in developing a less invasive method that children preferred. Encouragingly, it collected almost the same information as a traditional needle test. With further development, it could support more accurate diagnosis and help track how these conditions change over time.

Over £1.5m

invested into the NorthStar programme over the past 20 years

£1.15m

invested in a new strategic award for mitochondrial disease research

£1m

invested in a new strategic award for Charcot-Marie-Tooth disease

12

new grants worth over £1.7m committed this year

43

active research projects

£19,000

invested in a new grant scheme for improving quality of life

Over 100

people contacted our research line

Driving change for access to specialist care and support

We successfully worked to secure access to treatments for muscle wasting conditions this year. At the same time, we continued to support healthcare professionals by upskilling them in the needs and care of our community while also providing them with networking opportunities. We also ensured NHS neuromuscular services received appropriate attention from commissioners and decision makers.

1
new treatment approved for NHS use

8
treatment assessments participated in

711
enrolments to our e-learning module

177
attendees at our two conferences

266
attendees at our three healthcare professional upskilling webinars

Our role in treatment recommend-ations and appraisals

This year, we continued to work tirelessly to ensure that once new and effective treatments are found people with muscle wasting conditions can access them. We championed the voices of our community in eight assessments that determine whether new treatments should be made available on the NHS. By working closely with people affected by muscle wasting conditions, healthcare professionals, researchers, other charities, and patient groups, we made sure lived experiences were at the heart of every discussion. We also supported and empowered patients, families and carers to contribute as expert voices in these vital decisions.

We're especially proud to have played a key role in securing NHS access to a new treatment, vamorolone (Agamree), for people living with Duchenne muscular dystrophy right across the UK.

Connecting and upskilling healthcare professionals

Our healthcare professional conferences

We continued to support our healthcare professional community this year, organising conferences for professionals involved in the care and support of people living with muscle wasting conditions, providing them with the opportunity to upskill, share best practice, and network.

Our Neuromuscular Care Advisor Conference

It was another successful year for our Neuromuscular Care Advisor Conference, with 51 care advisors and clinical nurse specialists attending from across the UK. The conference focused on quality of life for people living with a muscle wasting condition through the topics of travel, sexuality and relationships, along with increasing attendees' understanding of the welfare benefits and employment systems, housing provision, and education. This holistic knowledge is extremely important for care advisors in supporting the physical and emotional needs of people living with a condition and in acting as coordinators across all aspects of their health and social care.



Photographer: Teri Pengilley

Our Allied Health Professional Conference

Our Allied Health Professional Conference brought together 126 allied health professionals both in-person and online, in a hybrid conference model, this year. The conference covered a wide range of topics such as physiotherapy management, respiratory care, wheelchair seating recommendations, condition-specific upskilling of myasthenia gravis, and ways of multidisciplinary team working in supporting patient care and partnering with health and social care professionals in the community. Accessing specialist therapists is important to our community. This programme of upskilling and supporting allied health professionals working with people living with muscle wasting conditions to maintain and improve the quality of care provided is an important aspect of our work.

Upskilling webinars

This year we provided CPD-accredited upskilling webinars to 266 healthcare professionals, including specialist neuromuscular professionals and non-neuromuscular specialists such as GPs and A&E staff. For specialist neuromuscular professionals, webinars were provided to upskill their understanding of mental health and wellbeing of people living with a muscle wasting condition. For non-neuromuscular professionals, webinars provided a more general understanding and awareness about muscle wasting conditions. A further 642 professionals received resources from these webinars.

Centre of Excellence awards

Following on from the decisions of our 2023/24 Centre of Excellence audit, we spent this year conducting engagement visits to 19 adult and paediatric neuromuscular centres. These visits provided an opportunity to present awards and strengthen our relationships with neuromuscular services and their NHS Trust. They also provided room to discuss the challenges faced by neuromuscular services and what we as a charity can do to support.

Combined with this, we also produced a report analysing the outcome from our 2023/24 audit, with the data providing a unique insight into the current state of neuromuscular services. Our audit found many examples of excellent achievements by neuromuscular teams across the UK, with their high level of dedication and commitment. However, it also showed the challenges facing services due to current pressures in the NHS.

"Sharing of sensible, expert approach to supporting children with neuromuscular disease, which will make my job as a general paediatrician easier and safer in emergencies."

Webinar participant

Our policy and parliamentary work

Community survey - setting out priorities

A central part of our mission is to campaign for people's rights, better understanding, and accessibility. Last year, we launched a community survey to discover more about what our community would like us to prioritise in our policy and campaigning work. We received almost 700 responses from people living with a muscle wasting condition, their families and carers. In May 2024, we published the results of this survey. This vital community feedback has informed our new and updated position statements on the biggest priorities for our community, around awareness of muscle wasting conditions, access to healthcare, and financial security. We will continue in-depth engagement going forwards to ensure our efforts to drive change are focused on the issues that matter most to our community.

Reporting on the financial insecurity of our community

Financial security emerged as one of the leading concerns (49% of respondents) in our community survey. This led us to explore this further; writing and publishing a report on the financial insecurity of our community, which was published in November 2024. The *Financial Insecurity Report* was based on 400 survey responses, as well as interviews and case studies with people living with a condition. It highlighted a decline in financial wellbeing since last year and revealed that 53% of people living with a muscle wasting condition feel financially insecure, 17% of whom feel very insecure. The report also showed the widespread negative impact this can have on people's physical and mental health, ability to work, and quality of life. This all provided crucial evidence and stories to help us influence government policy, particularly at a time when support for disabled people is under threat.



"One of the biggest expenses for us is our energy bills which we spend roughly half our income on. We both have air mattresses to ensure we don't get pressure sores, we have four ventilators between us, which are running or charging 24 hours a day, two wheelchairs which need to be charged regularly, to name just a few things."

Charlotte and Tom, case study from our *Financial Insecurity Report*

Photographer: Jo Ritchie

Living well

We understand that living with a muscle wasting condition can be overwhelming and isolating for people affected and their families. This is especially true if they don't have access to the right information and support to help them live well. We're here to listen and provide information and advice about all aspects of living with a muscle wasting condition.

Our helpline service

This year 3,392 people contacted our helpline. Our team provided tailored information and emotional support to people living with a condition, their family, carers and friends. Delivering advice and support by phone, email, face-to-face, or through a referral from NHS neuromuscular clinics. The five topics people most contacted us about were alert cards, peer support, welfare information requests, medical questions, and equipment advice.

Our advocacy service

We supported 133 people through our advocacy service this year. Supporting them to express their views and wishes and to challenge decisions made about them in relation to things like access to care, equipment, benefits and education. Helping people to develop self-advocacy skills in the face of these challenges and clearly communicate their needs and rights. The most support we provided was on Personal Independence Payment (PIP), housing and adaptations, and care packages.

"The challenges felt like being in a maze, but I called the helpline, and they answered so many of my questions and supported me through the process."

Lauren, living with SMA type 1



Photographer: Jo Ritchie

Mobility equipment grants

This year, we provided 131 grants for the cost of mobility equipment through our grant giving arm the Joseph Patrick Trust to people living with a muscle wasting condition. We also collaborated with two other grant providers, Whizz Kidz and SMArt Moves, to jointly fund power wheelchairs.

Our tailored therapeutic support groups

Following the successful launch of our therapeutic support groups in 2023, we partnered with Louise Halling, a professional counsellor and psychotherapist living with limb girdle muscular dystrophy, and Julie Oates, a counsellor and psychotherapist, to continue to deliver virtual therapeutic support groups. These sessions provided a confidential, supportive space to foster open discussions and build connections. Ten therapeutic groups took place over the year covering newly diagnosed, mums, dads, partners, grandparents, siblings, and parents of children living with a condition.

Our tailored peer support

Our peer support groups continue to flourish. In the past year we've facilitated support groups based on condition, age or circumstances, such as recently receiving a diagnosis. We've also worked in partnership with the Teapot Trust, a mental health charity providing art therapy for children and families living with long term health conditions, to pilot a support programme for primary school aged children living with muscle wasting conditions.

Our peer support WhatsApp groups have grown significantly and are now a core part of our support services. Moderated by staff and volunteers, these groups enable peer connection, shared experiences, and timely guidance, supporting members in managing their condition.

Alongside these new groups, we continue to offer one-to-one peer support from our trained peer support volunteers with lived experience.

3,392
people supported through our helpline

Over 130
people supported through our advocacy service

More than 200
people attended our information days across the UK

462
people joined our WhatsApp communities

447
people attended our Muscle Groups

109
referrals supported by our peer volunteers

62
peer volunteers in our volunteer network

131
people provided with a wheelchair and other equipment grants

Muscle Groups – keeping people updated and connected

We ran 37 Muscle Group meetings this year across 14 regions of England, and in Scotland, Wales and Northern Ireland. A total of 447 people attended a local meeting. Our regional Muscle Group meetings provide a safe, welcoming space where people affected by muscle wasting conditions can share experiences, meet other people in their local community, and learn more about the services we offer.

Our webinars

We held seven webinars this year, providing research updates, condition-specific information and practical and lifestyle talks to help people live well with their condition. Condition management topics included cardiac management, physiotherapy, emotional support, speech and language therapy, and diet and nutrition. Our webinar sessions focused on Duchenne muscular dystrophy, FSHD, nemaline rod myopathy, Becker muscular dystrophy, LMNA, myotonic dystrophy, and limb girdle muscular dystrophy.

Our Information Days

We held four in-person Information Days/conferences in England, North Wales and Scotland as well as a disability sports event and some holistic physiotherapy events. Bringing together a total of 209 people living with muscle wasting conditions. These events provide an opportunity for people to connect with others in the muscle wasting community, share stories, hear from experts to help them live well, meet our team, and find out more about the advice and support we offer.

PIF accredited for trusted health information

Following our second-year assessment with the Patient Information Forum (PIF), we're proud to be successfully recertified under the PIF TICK Quality Mark for Health Information as a producer of trusted information. The PIF TICK logo now features on our health information providing assurance that our content is evidence-based, accessible, and produced to the best possible standard.

Our Employability Programme

Our Employability Programme provided 162 interactions of support over the past year. The three main areas supported by the service are career advice, application support, and workplace advice for those already in work. We also launched a workplace adjustment passport, which gives people with any disability a way of communicating their workplace needs with their employer and to put a plan in place. This can be taken with someone as they change roles, or their manager changes.

My overarching takeaway is that I am not alone and there is great support available."

Information Day participant



Photographer: Chris Fairweather/Huw Evans Agency

Our work in Scotland

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

We significantly expanded our reach and impact across Scotland this year, ensuring more equitable and accessible support for people living with a muscle wasting condition, their families and carers. We welcomed two new members of staff to our Scotland team, one covering Central Scotland and the other supporting the North – they joined our Head of Regional Support, Outreach, and Information. This expansion has allowed us to offer tailored support across a broader geographic area, including remote and rural communities.

Our support services

Our support services in Scotland are wide-ranging and holistic, providing emotional support from the point of diagnosis continuing through every stage of living with a muscle wasting condition. We also offer practical assistance to help people make informed decisions and access the services and entitlements they need to live well. This year, we responded to 426 support requests across Scotland, including 50 advocacy cases.

Scottish disability sports

In August 2024, we once more partnered with Scottish Disability Sport to host a free family sports day at Grangemouth Sports Complex. Children under 18 had the chance to try adaptive sports like curling, boccia, and swimming in a supportive and inclusive environment. This event not only encouraged physical activity but also created valuable opportunities for families to connect with one another and learn more about our support in Scotland.

Neuromuscular physiotherapist sessions

Between September 2024 and January 2025, we delivered a hybrid series of four in-person and virtual sessions for adults living with muscle wasting conditions, in collaboration with a specialist neuromuscular physiotherapist in central Scotland. Each session explored a key area of wellbeing, including fatigue and sleep management, physical activity and posture, nutrition, mental health, and navigating benefits, housing, and care systems.

Missing People. Missing Support report

In November 2024, we launched our new *Missing People. Missing Support* report shining a light on the gaps in neuromuscular care in Scotland and advocating for stronger, more consistent support across the country.

Scotland Information Day

We were delighted to host our Scotland Information Day in Inverness in March 2025. Families from the North of Scotland came together for a day of education, support, and community. Sessions covered physiotherapy, fatigue management, emotional wellbeing, and adaptive sports.

Our work in Scotland continues to be shaped by the invaluable insight and experience of our Scottish Council.



Photographer: Phil Wilkinson

462
support requests responded to this year, 50 of which were for advocacy support

£143,813
total funds raised

£12,000
raised through Kiltwalk by 32 participants

Fundraising update

Family Funds

Two new family funds joined us this year, taking our total in Scotland to eight. Vanessa from Shetland hosted a Bake a Difference fundraiser raising a phenomenal £13,000 for research into Facioscapulo-humeral muscular dystrophy (FSHD), the condition her five-year-old daughter Phoebe lives with. Their efforts didn't stop there. Vanessa has since launched their Family Fund, Phenomenal Phoebe, ensuring that both fundraising and awareness will continue to grow in support of Phoebe and others like her.

Community fundraising activities

An array of supporter led activity has contributed to our fundraising total this year; however, the Spirit of Christmas continues to be our stand-out event, raising £4,800 this year, and a total of nearly £40,000 since its inception.

We have seen a huge uptake for our Scotland events including Kiltwalk where we had 32 participants across the four different cities raising around £12,000. Supporters used these events to fundraise and raise awareness about muscle wasting conditions. Back in August we held a really successful Zipslide across the Clyde as one of our supporters Sophie, 21, who lives with limb girdle muscular dystrophy, took on the event with eight friends and family members and raised a fantastic £8,000.

Our total fundraising in Scotland

Our total fundraising in Regional Development for Scotland was £143,813 this year – an increase of £7,221 from 2023/24.

Research

We continued to support research in Scotland this year. We are now funding Dr Jarod Wong at the University of Glasgow as part of our 2024 grant round. While our funding continues to support a PhD student in the laboratory of Dr Lyndsay Murray and a research project with Professor Tom Gillingwater at the University of Edinburgh.

'We significantly expanded our reach and impact across Scotland this year'

The difference your support made

Thanks to your amazing generosity, income from donations, gifts, grants, sponsorship, events and campaigns totalled £4.5m this year.

Highlights of this year's fundraising

Climbing Mount Kilimanjaro to raise funds

In October 2024, 15 incredible supporters travelled to Tanzania to take on the life-changing challenge of climbing Mount Kilimanjaro – the highest peak in Africa – in support of the charity. Over the course of six tough and demanding days, the team faced altitude, exhaustion, and extreme conditions. Pushing themselves to the limit to increase awareness and raise a remarkable £85,500 (£101,000 including gift aid).

A record-breaking year for our Bidwells Town and Gown series

A landmark year for our Bidwells Town and Gown 10K running series, this year we had both record-breaking participation and fundraising across our Oxford and Cambridge events.

In May, our Oxford Bidwells Town and Gown 10K sold out for the first time in its history, with over 5,600 runners raising more than £245,000 for the charity. Just a few months later in October, the Cambridge event welcomed 2,978 participants, just 22 places away from capacity, and raised an impressive £113,000 – its highest total to date.

Celebrating our Microscope Ball's 40th anniversary

We were extremely grateful this year to the 720 members of the commercial property sector who brought the 80s back to life at London Hilton on Park Lane by attending our 40th Microscope Ball anniversary event. We raised an event record of over half a million pounds on the night, thanks to our incredible pledge speaker Lou Hill, Trustee James Lee, our fantastic host Miss Demeanour, the amazing Globe Star Entertainments for their unforgettable performances, auctioneer Jonny Gould, and of course, our amazing Microscope Ball committee and chair Michelle Anthony.

Our running events are booming

In 2024, 8,994 participants took part in 41 different running events – from 5ks, 10ks to some of the most sought-after marathons – across the UK and internationally raising a phenomenal £1.2m for the charity.

76

Trusts and Foundations supported our work this year

£1.2m

raised across 41 different running events

£176,000

raised from our 43 Family Funds

Over £500,000

raised at the 40th Anniversary Microscope Ball

£245,500

raised at a sellout Bidwells Oxford Town and Gown 10k

£101,000

raised by 15 supporters climbing Mount Kilimanjaro

£80,000

raised in just three days through Double your Donation

£74,157

raised from activities related to our RHS Chelsea Flower Show Garden



"It was the most amazing six days of our lives. It tested every single ounce of mental and physical strength. To do it with other people who are raising money for MDUK has been really rewarding."

Simon, who climbed Mount Kilimanjaro

Photographer: Cathey Cullum/Muscular Dystrophy UK

Strength to strength – our Pedal Paddle Peak triple challenge events

Our Pedal Paddle Peak flagship triple adventure challenge continued to go from strength to strength this year. We not only celebrated the ninth successful year of our Lake District event, but also launched a brand-new edition in Snowdonia, expanding the series and growing our participation.

In the Lake District, 150 participants raised over £115,000 (including gift aid). This marked the second consecutive year the event raised over £100,000, a sign of the event's growing popularity.

Our inaugural Snowdonia challenge welcomed 64 adventurers who raised an impressive £62,500 (including gift aid) in the event's first year. This new location proved a huge success and lays the foundation for continued growth of the series.

With the growing success of these events, we're laying the way to increase participation at both events and explore a third location over the next few years to form a Pedal Paddle Peak trilogy.

London Marathon 2024 – A record-breaking year

A record 172 runners took on the TCS London Marathon in support of the charity this year – our largest team to date. Together, they raised an incredible £580,000, the highest total ever raised for the charity through a single event.

We also secured 160 places for the 2025 event, including two assisted wheelchair entries for members of our community – a step towards a more inclusive event and shaping the 2025 event to be another special one.



"This team was by far the best team I have ever had the pleasure to run for. The communication and support were excellent!"



Photographer: Tom McNally

Supporters fundraising their way

Supporters from across the UK continued to show their incredible commitment this year by fundraising in their own unique ways. From bake sales, zip slides and personal challenges, we're always blown away by our community finding new and unique ways to raise awareness and funds. Highlights of their inspirational fundraising include:

Eight marathons in eight weeks

Tom Penzer Adams ran eight marathons in eight weeks in support of his close friends, Gary and Paul, who live with limb girdle muscular dystrophy. In total, he ran over 209 miles and raised over £17,000 from this mammoth challenge, which saw good luck messages from the likes of Mo Farah.

Three peaks in memory

In April 2024, nine friends tackled the Yorkshire Three Peaks Challenge in memory of their school friend Simon Mirfin, who lived with Facioscapulo-humeral muscular dystrophy (FSHD) and sadly passed away in 2023. Their heartfelt tribute raised over £7,900 to honour Simon and support other people living with muscle wasting conditions.

Cycling across Europe

Tim Norton, 68, flew to Gibraltar to undertake a 1,700 mile cycling adventure across Europe travelling through the likes of Spain, over the Pyrenees, through France and back to his hometown in Lancashire. Tim raised in excess of £2,300 in support of his friend Andy who lives with Facioscapulohumeral muscular dystrophy (FSHD)

Coast to coast for Josie

The Chubbs Crusade Family Fund took on and completed their very own challenging 84 mile coast to coast trek from Bowness-on-Solway on Cumbria's West Coast to the East Coast of Northumberland in Newcastle upon Tyne, completing the challenge in just two days. James Chubb and five friends raised over £13,000 in support of James' daughter Josie, seven, who lives with Ullrich congenital muscular dystrophy.

Golf days – driving strong support

Golf days continue to be a popular way for our supporters to raise funds and awareness. In 2024, events were held across the UK. From our very own Property Golf Day at the Centurion Club in Hertfordshire to supporter-led days organised by the Evans Family in the West Midlands, Family Fund Fighting Back for Jack 10th annual golf day also in the West Midlands, and David Salt's golf day in Staffordshire. Together, these fantastic events raised an incredible £100,500 to support our work.

Star-studded comedy night

Our Hywood's Heroes Family Fund once more organised a night of comedy with seven comedians led by Jon Richardson. Coming together to entertain an audience of over 1,000 people at Aylesbury Waterside Theatre and raise over £43,000. The money raised from the night, and other fundraising activities, brings the phenomenal total raised by Hywood's Heroes over the last six years to over £300,000.

Our Family Funds

Our Family Funds are an incredibly important part of our community. We have 43 active Family Funds who this year raised an impressive £176,000 between them by organising their own events, encouraging their networks to take part in challenge events, as well as national campaigns and appeals. Their ongoing efforts are truly invaluable.

Welcome Tahira's Team

In 2024, we were delighted to welcome Tahira's Team to our family funds. Tahira nominated the charity as Charity of the Year at her workplace, Optimum Strategic Solutions, and didn't stop there – recruiting a London Marathon runner, volunteering at the MDUK Celebrity Sports Quiz, and hosting GNE Myopathy coffee mornings. In her first year alone, Tahira has raised over £10,000.

Our Family Fund Weekend

In September 2024, we bought together families from our Family Fund network at the Barnstondale Centre in Wirral for our annual Family Fund Weekend. The event offers a warm, welcoming space for families to unwind, connect with others who truly understand, and make lasting memories.


"Just such a brilliant weekend full of precious memories which we really appreciate from the bottom of our hearts." – Family Fund Weekend 2024 attendee

Photographer: Jo Ritchie

RHS Chelsea Flower Show success

We were hugely fortunate to have a garden at the 2024 RHS Chelsea Flower Show this year. Our Japanese-inspired Forest Bathing Garden was designed by Ula Maria, 2017 RHS Young Designer of the Year, and fully funded by Project Giving Back, a charity who fund gardens for good causes at the show. Not only was the garden a gold medal winner but was also awarded the coveted Best in Show Garden. Winning both these titles led to us receiving unprecedented media coverage and visits to our website more than doubled.



The Muscular Dystrophy UK Forest Bathing Garden is a peaceful, accessible garden, created with people living with a muscle wasting condition, their families and carers, and clinicians in mind. Following the RHS Chelsea Flower Show the garden has been relocated to the Prince and Princess of Wales Hospice in Glasgow where it will provide a unique outdoor space for patients, their families, and the local community to benefit from.

Maximising the opportunity

We were determined to maximise the opportunities our garden offered us in engaging existing and new audiences to increase our reach and awareness of muscle wasting conditions. We did this through activities which included running ticket competitions, hosting business breakfasts for key supporters and their networks, and organising after hours receptions for sponsors and non-neuromuscular specialist healthcare professionals.

Raising awareness with non-neuromuscular healthcare professionals

We were able to use our platform at the Show to act on a priority from our community survey findings, which is to increase awareness of muscle wasting conditions among non-neuromuscular specialist healthcare professionals. We invited over 100 GPs and other healthcare professionals to an engagement and networking event at the show. This included talks from experts in neuromuscular care, networking opportunities with people from our community, an opportunity to talk to staff about the training we offer to upskill healthcare professionals, along with details about our Regional Neuromuscular Networks.

The Medical Director for Professional Development at the Royal College of General Practitioners (RCGP) attended and spoke about the importance of taking part in e-modules for neuromuscular conditions.

Photographer for both: Rebekah Kennington

Connecting with the muscle wasting community

Many visitors were moved by our garden. Our volunteers took time to speak to them and when a connection to our cause was discovered, they were invited onto the garden. We heard stories of family, friends and neighbours of people living with a condition who were appreciative and delighted that muscle wasting conditions were being represented on a national stage. On the final day of the show, we let all wheelchair users, and those with mobility issues, onto the garden. The impact of the garden being fully accessible was fully realised and our disabled visitors felt the joy of experiencing something designed just for them.

Immeasurable impact, exceeding expectations

There is no doubt that the garden funding from Project Giving Back achieved our aims of raising awareness of muscle wasting conditions. The opportunity gave us a huge uplift in social media and media coverage, enabling more people to find out about our work. What was also surprising was the impact it had on our existing supporters. Many supporters who donate regularly doubled their donation immediately after the show, and members of our events committees – who already give up lots of their time to organise fundraising events - did even more, with some signing up for challenges such as the London Marathon and trekking Kilimanjaro. All 2024/2025 challenge events in our portfolio sold out early, which we also put down to the 'Chelsea effect'.





Photographer for both: Rebekah Kennington

"There are still so many people who have never heard of muscular dystrophy, so it's amazing the charity has been given the opportunity to raise awareness in such a high profile event"

Community attendee

Our President's Award winners

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

Peter and Nancy Andrews Community Achievement Award

Liz Keenan

A devoted mother, fundraiser and advocate, Liz has tirelessly campaigned for the charity while raising her three boys, all of whom live with Duchenne muscular dystrophy. Always up for a challenge, she has tackled some of our demanding fundraisers, including our Pedal Paddle Peak triple challenge event. Over the past decade, Liz and her family have raised over £100,000 to support our work.

Early Career Scientist of the Year Award

Dr Ami Ketley

Based at the University of Nottingham, Ami recently secured one of our research grants to study genetic variations in different tissues of people living with myotonic dystrophy. Using new technology called single-cell transcriptional profiling, results should highlight which potential genes could be targeted for treatments. Ami is also a Trustee of the Myotonic Dystrophy Support Group and actively engages with the patient community.

Fundraiser of the Year Award

Tom Penzer Adams

Inspired by two friends who live with a muscle wasting condition, Tom set out to run eight marathons in eight weeks to raise £8,000 for us. His challenge saw him travel around the UK as well as taking part in overseas marathons in Tokyo and Boston and organising a community marathon event in his hometown. In total, he ran 209 miles and raised over £20,000.

Volunteer of the Year Award

Phil Grant

Well known for appearances in his local area dressed as Wonder Woman, Phil has been fundraising and volunteering for us since 1992. He does this in memory of his son who lived with Duchenne muscular dystrophy, to raise awareness to help others. He already has a long list of Wonder Woman appearances booked for 2025.

Alexander and Valerie Patrick Award for Carer of the Year

Isabel Spragg

A remarkable young carer, 13-year-old Isabel goes above and beyond to support her brother Harry who lives with Duchenne muscular dystrophy. Helping Harry with day-to-day activities like dressing, washing and feeding, as well as just making him laugh, Isabel's support is invaluable to her family.

Richard Attenborough Award for Outstanding Achievement

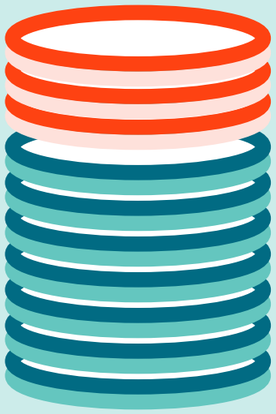
Sheila Hawkins

A former charity Trustee, Sheila sits on our Services Development and Improving Quality of Life Research Committees and is also President of FSHD Europe. Living with Facioscapulohumeral muscular dystrophy (FSHD), Sheila brings invaluable lived experience and is a dedicated supporter and volunteer.

Our finances

How we raised our funds

For every £1 we spent:

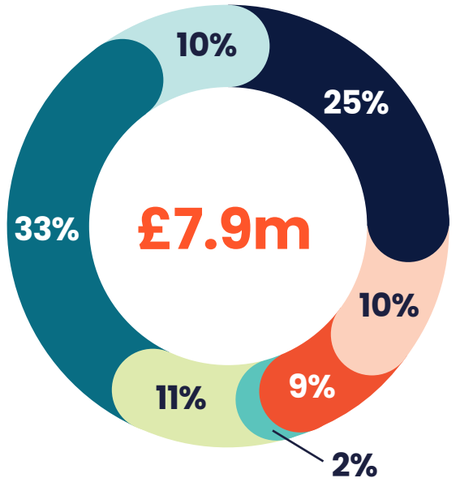


32p is invested in fundraising to ensure we maintain a diverse portfolio to support our community

68p is spent on our charitable activities

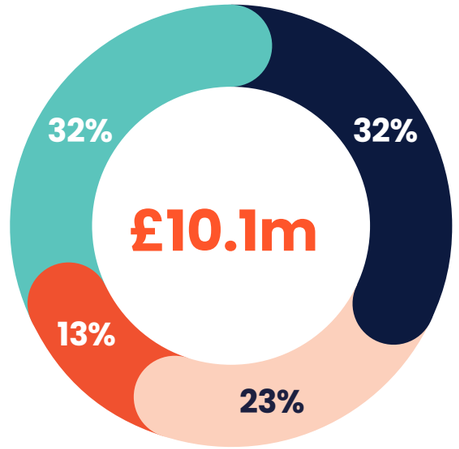
For every £1 we invested in fundraising we raised £2.50
(total income / fundraising costs)





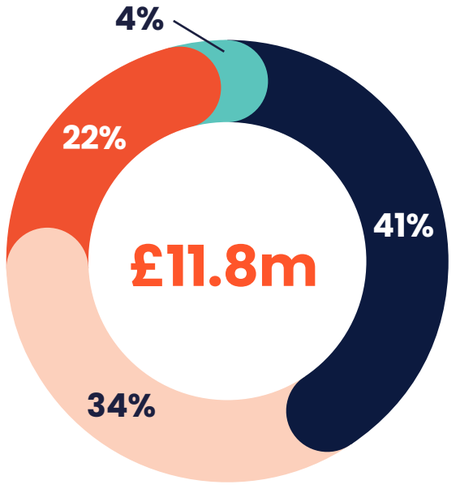
Total income

- **Events and promotions** (£2m)
- **Individual giving** (£802,000)
- **Major Donors and Corporate** (£678,000)
- **Trusts** (£193,000)
- **Regional development** (£873,000)
- **Legacy** (£2.6m)
- **Other income** (£821,000)



Total expenditure

- **Fundraising** (£3.2m)
- **Medical research** (£2.3m)
- **Access to specialist care and support** (£1.3m)
- **Independent living** (£3.2m)



Total funds

- **Designated** (£4.8m)
- **General** (£4m)
- **Restricted** (£2.5m)
- **Endowment** (£415,000)

Our future plans

In 2025, we'll be publishing an ambitious new strategy to improve the lives of people living with muscle wasting conditions over the next ten years.

We will be focusing on four strategic goals:



Strategic goal one
Transforming diagnosis

Misdiagnosis and delays to diagnosis mean people living with muscle wasting conditions can miss out on vital treatment and support and feel more alone with their condition. For some conditions, newborn screening can have life-changing benefits allowing for early diagnosis and faster access to treatment that can radically transform lives.

We'll help speed up and improve the accuracy of diagnosis so that by 2035, no one will wait longer than six months to be diagnosed.

How we will do it – our focus for the first three years:

- We will **campaign** for better newborn screening for relevant muscle wasting conditions.
- We will **invest in research** to explore how we can improve diagnosis and better understand the prevalence of people with muscle wasting conditions.
- We will **educate** thousands of healthcare professionals responsible for identifying potential muscle wasting conditions for timely referral.



Strategic goal two
No one faces their journey alone

Getting the right support at the point of diagnosis can be crucial to living well with a condition. Yet too many people face this journey alone.

We'll reach every person with a muscle wasting condition by 2035, so no one faces this journey alone.

How we will do it – our focus for the first three years:

- We will develop a **new diagnosis referral service**, with tailored support materials for people newly diagnosed with a muscle wasting condition.
- We will develop a programme of **in reach into neuromuscular centres** and clinics, developing staff and volunteers to offer direct and peer support.
- We will **significantly increase awareness** of muscle wasting conditions and the charity so more people can access support when they need it.



Strategic goal three
New treatments, universal support

For the first time new treatments are being developed which can slow the progression or reduce the impact of some conditions. However, too often people are unable to access them due to a lack of capacity in the NHS. While some areas of the UK have specialist clinical support local to them, there is a stark postcode lottery in the availability of services for people living with muscle wasting conditions. This means that some people miss out on the care and support needed to help them live well with their condition.

We'll help accelerate the development of new treatments so that by 2035 they'll be available everywhere, and everyone living with a muscle wasting condition will be able to access specialist support when and where needed.

How we will do it – our focus for the first three years:

- We will **fund groundbreaking research** into new treatments and better understanding of muscle wasting conditions.
- We will **campaign and influence the NHS** across the UK to end the postcode lottery and ensure there is capacity in the system to treat and support those who need it.
- We will **support the growth of neuromuscular services and workforce** through education and quality improvement.



Strategic goal four
Living life to the full

Living with a muscle wasting condition can lead to poor physical and mental health. People living with muscle wasting conditions also face huge societal barriers to living a full and independent life, including inaccessible transport, housing, education and employment.

We'll campaign for a more equal and accessible world and directly support every person who needs it by 2035 to live independently with better physical and mental health.

How we will do it – our focus for the first three years:

- We will **significantly grow our direct services** and review our existing model of support to reach more people with practical and emotional support.
- We will **campaign for a more just and inclusive society** with accessible services and state support to live a full life.
- We will **grow our community** of people affected by muscle wasting conditions to improve self-advocacy and peer support.



Our vision is clear, a world without limits for people with muscle wasting conditions, and we won't stop until we achieve it."

Andy Fletcher, Chief Executive

Thank you

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- Lord Sharkey
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- Catherine Woodhead, Chief Executive (until June 2024)
- Wojtek B Trzcinski, Chief Operating Officer / Interim Chief Executive (June 2024-November 2024)
- Dr Kate Adcock, Director of Research and Innovation
- Rob Burley, Director of Care, Campaigns and Support (until December 2024)
- Neeru Naik, Director of Services and Support (from January 2025)
- Emma Jones-Parry, Director of Development
- Leanne Thorndyke, Director of Marketing

With special thanks
- Jeremy and Mary Champion
- Frances Carey
- Team Jed
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- Mayo Marriott
- The McAlister Family
- Ann McNeil and Bamburgh Castle Golf Club
- Peter and Frances Meyer
- Tony and Monica Moorwood
- MAP Nemaline
- The Q Trust
- Jon Richardson
- Bill and Jacky Ronald
- Charles and Donna Scott
- John Watson and Janis Higgie
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Corporate Support
- AirNow Technology
- Baker PR
- Bidwells
- BGC Charity Day
- Barratt East London
- Penningtons Manches Cooper
- CeX
- Chimera
- Crocus
- DC Merrett
- Diligencia Group
- Forex Clear
- Mail Metro Media
- Malcolm Group
- Marchmont Investment Management
- Nurture Landscapes
- Orbis
- Premier Paper Group Ltd
- Project Giving Back
- Property Week
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- Scottish Power
- Siren
- Tennants Consolidated
- Ula Maria Studio

Trusts and Foundations
- Anonymous Donors
- The Albert Gubay Charitable Foundation
- The Annandale Charitable Trust
- The Austin and Hope Pilkington Trust
- The Barbour Foundation
- The Cranbury Foundation
- The Edinburgh Trust
- The Elizabeth Hardie Ferguson Charitable Trust Fund
- The Grace Trust
- The Inman Charity
- The John Raymond Tijou Charitable Trust
- The P F Charitable Trust
- The RS Macdonald Charitable Trust
- Vale of Glamorgan Welsh Church Acts Fund / Bro Morgannwg Cronfa Deddf Eglwysi Cymru

Golf Day Committee
- Stephen Rigby

Charity Shoot Day Committee
- John Eaglesham
- Nick Moldon
- Simon Tann

Strike Night Committee
- Gillian Campbell
- Bill Ritchie
- Lynn Smith

Sports Quiz Committee
- Martin Cardoe
- Rich Cumbers
- Rob Driver
- Lou Hill
- Hussein Ismail
- James Pearson
- Ravi Seesurrun
- Vanessa van Blerk

Microscope Ball Committee
- Michelle Anthony, Chair
- David Allen
- Matt Allen
- Jack Beeby
- Ed Betts
- Anna Biggin
- Guy Bowring
- Lucy Burns
- Adam Cradick
- Rhys Davies
- Fraser Draycott
- Jon Eaglesham
- Abigail Francis
- Harry Foster
- Charles Howard
- Jonny Lee
- Tim Lumsdon
- Ben Miller
- Nick Moldon
- Matt Nimmo
- Rich Oliver
- Stephen Rigby
- Simon Tann
- Trish Watson
- Andrew Wedderspoon

Joseph Patrick Trust Management Panel
- Julian Pritchard, Chair
- Ian Gordon
- Robert Warner

Joseph Patrick Trust Grants Panel
- Karen Duckmanton
- Jane Field
- Jane Freebody
- James Lee
- Patricia Lock
- Julian Pritchard, Vice Chair
- Kirsty Read
- Robert Warner, Chair

Finance Committee
- Joseph Gordon, Chair
- Brigid Sutcliffe, Vice Chair
- Helene Crutzen
- James Lee
- Gerry McMenemy
- Charles Scott

Appointments and Remuneration Committee

- Professor Mike Hanna, Chair
- Ian Gordon
- Charles Scott
- Lord Sharkey
- Brigid Sutcliffe

Medical Research Committee

- Dr Gillian Butler-Browne PhD, Chair
- Professor Tracey Willis MBChb MD MRCPI PhD, Vice Chair
- Dr Arianna Fornili PhD
- Dr Heidi Fuller PhD
- Professor Grainne Gorman MD PhD
- Professor Rita Horvath, MD PhD
- Dr Meredith James PhD
- Dr James Lilleker MBChB PhD
- Professor Ketan Patel PhD
- Professor Linda Popplewell PhD
- Professor Frédéric Relaix PhD
- Professor Laurent Servais MD PhD
- Professor Peter Zammit PhD

Improving Quality of Life Committee

- Dr Anna Mayhew PhD, Chair
- Dr Stephan Cano PhD
- Professor Jill Carlton PhD
- Graham Gornall
- Shiela Hawkins
- Dr Alison Kay PhD
- Dr Gita Ramdharry PhD

Lay Research Panel

- Alison Kay, Chair (from November 2024)
- Andy Rose, Vice Chair (from November 2024)
- Peter Ashley, Chair (until November 2024)
- Graham Cloke (until February 2025)
- Richard Davenport
- Tammerin du Preez
- Graham Gornall
- Alexa Gummow
- Victoria Houghton
- Corinthia Joseph (until November 2024)
- Modupe Joshua
- Hannah Langford
- William Love
- Amber Tirimanna
- David Towler
- Roli Roberts, Scientific Advisor

Services Development Committee

- Professor Deirdre Kelly CBE, Chair
- Claire Boylan
- Carolyn Brennan
- Chloe Docker
- Sheila Hawkins
- Tiffany Hesson
- Dr Maymunah Khries
- Dr Chiara Marini-Bettolo
- Professor Francesco Muntoni
- Dr Niranjanan Nirmalananthan
- Dr Jatin Pattni (until July 2024)
- Professor Rosaline Quinlivan
- Lloyd Tingley
- Tanvi Vyas

Northern Ireland Council

- Janet Bailie
- Claire Boylan
- Suzanne Glover
- Bethany Jackson
- Laura Jackson
- Jim McKeogh
- Maggi McKeogh
- Stephen Myall
- Claire O'Hanlon
- Catherine Taggart
- Aaron Thompson
- Julie Thompson

Scottish Council

- Dr Sheonad Macfarlane BSc Med Sci, MB ChB, Chair
- David Gale
- Catherine Gillies
- Elizabeth McHugh
- Gerry McMenemy
- Joe Moan
- Allyson Townhill
- Jon Watkins



Photographer: Chris O'Donovan

Our policies

Fundraising statement

Our supporters are key to changing the future of 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 our 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 three complaints in total in 2024/25. These are included in the following: 0 complaints from 16,021 mailings about our lottery and raffle to warm supporters; 0 complaints from 1,047 guests at our series of special events; 0 complaints from 407 participants at our National Third Party Challenge Events; three complaints from 8,824 participants at our own running events (Bidwells Town and Gown and Pedal, Paddle, Peak), 0 from 400 volunteer fundraising events; 0 from 43,773 pieces of direct mail sent out; 0 complaints from 6,015 pieces of mail sent out about gifts in Wills. We have worked together with the individuals who made the three complaints mentioned to ensure we will learn from our mistakes for the future.

Financial review and policies

Our total income for 2024/25 was £7.9m, compared to £9.5m in 2023/24. The £1.6m decrease is primarily due to the conclusion of the Government-funded Changing Places programme and one-off grants such as the Chelsea Flower Show, both recognised in the previous year. Additionally, there was a natural variation in legacy income.

Fundraising income from donations, gifts, grants, and other activities remained stable at £4.5m.

Legacy income decreased by 11% to £2.6m (2023/24: £2.9m), reflecting normal fluctuations in this income stream. This figure includes a £1.4m accrual based on best estimates of future receipts.

Other income, including investment and trading, totalled £820,000 (2023/24: £1.3m). Government grants amounted to £15,000 (2023/24: £847,000), as expected, due to the end of support from the UK Government's Covid Medical Research Charity Support Fund, the Department for Transport, and the Department for Levelling Up, Housing and Communities.

Total expenditure on charitable activities rose by £2m (25%) to £10m (2023/24, £8m). This increase was spread across all areas but primarily driven by the final distribution of Changing Places grants.

Breakdown of charitable expenditure:

- Medical Research 34% (2023/24, 40%)
- Access to Specialist NHS Care and Support 19% (2023/24, 23%)
- Independent Living 47% (2023/24, 37%)

The shift in proportions reflects the final allocation of Changing Places funding, which was fully attributed to Independent Living.

The charity ended the year with a planned deficit of £2.1m (2023/24: surplus of £1.9m), including a £109,000 gain on investment assets (2023/24: £442,000 gain). The reported surplus figure includes the £1.4m legacy accrual, expected to be received in future years once legal matters are resolved.

Reserves policy

Free reserves available to the charity exclude restricted, endowment, and designated funds, as well as tangible fixed assets held as unrestricted funds. The charity considers it essential to hold free reserves to provide sufficient protection to cover core costs, including salaries and central overheads, and to meet forward unrestricted commitments in the event of an immediate or unforeseen drop in income.

The recommended level of free reserves is reviewed annually by Trustees and the Senior Leadership Team (SLT) as part of the budget-setting process, considering the financial impact of current risks facing the charity. The charity aims to maintain a certain level of free reserves to manage the risks it is exposed to in the course of its operations, including but not limited to fluctuations in voluntary income.

Following a strategic review aligned with our future growth ambitions, the free reserves requirement has been increased to reflect six months of operating costs, now set at £4m.

The rationale for this decision is based on three key factors:

- Increased expenditure and strategic growth plans
- Uncertainty in legacy income, which now accounts for over 30% of total income and includes substantial accruals (income recognised in the accounts but not yet received in cash due to pending estate matters)
- Alignment with prudent budgeting practices to mitigate risks associated with income shortfalls and year-on-year variations

The total unrestricted funds balance of £8.8m on 31 March 2025 includes:

Designated and fixed assets (£4.8m) set aside for specific strategic purposes:

- Strategic Investment Fund – £2.8m – established to support the initial years of the charity's ambitious 10-year strategy, aiming to grow income and service delivery to £15m by 2035. This fund will cover anticipated deficits over the next two to three years, including the budgeted deficit of £1.5m for 2025/26, thereby protecting the free reserves of £4m.
- Strategic Research Grants – £1.6m – designated for two five-year research initiatives: LifeArc Centre to Treat Mitochondrial Disorders (Cambridge University) and Trial Readiness for Charcot-Marie-Tooth Disease (University College London). The balance on 31 March 2025 represents the fund value after £540,000 of this fund was distributed during the 2024/25 financial year.
- Data and IT Improvements – £133,000 – set aside to enhance data collection, CRM systems, and impact analysis – £53,000 of this fund was used in 2024/25.
- Net tangible fixed assets – £274,000 – represents the value of physical assets held by the charity.

Free reserves (£4m)

- Revised free reserves – £4m. This represents approximately six months of operating costs for the 2025/26 budget. It is the portion of unrestricted funds not committed to specific projects or assets and is available to support ongoing operations and respond to unforeseen needs.

Having reviewed the strategic risks and the 2025/26 budget projections, the Board of Trustees considers the reserves held as of 31 March 2025 to be sufficient to manage these risks effectively. Accordingly, the Trustees 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. The portfolio aims to achieve a return several percentage points over the annual increase in the Consumer Price Index, over the medium to long term. 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 2023. 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 charity maintains a balanced risk profile, seeking moderate growth with a diversified portfolio. The portfolio is managed to avoid excessive volatility and to ensure liquidity for operational needs.

The investment portfolio is managed by Rathbones' Charity Multi Asset Team, supported by experienced professionals. The charity's Finance Committee reviews performance quarterly and ensures alignment with strategic objectives. The investment managers' performance is reviewed by the Finance Committee on an annual basis. This policy is reviewed annually and updated as necessary.

Ethical considerations

Environmental, Social, and Governance (ESG) factors are integrated into the investment process. The charity supports investments in sectors such as diagnostics, medical devices, software, and financial services that demonstrate strong ESG credentials. The Charity does not invest directly in tobacco, armaments, high-interest rate lending, gambling, adult entertainment, thermal coal and tar sands (defined by companies which derive >10% of their revenue from these).

In 2023/24, Trustees have reviewed the approach of the fund manager towards avoiding offenders in greenhouse gas emissions. It is felt 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 2024/25, Trustees and the SLT confirmed that the fund manager was not investing in Russian businesses following the Russian invasion of Ukraine in February 2022.

Renumeration policy

Salaries for the Chief Executive and the SLT are set by the Board's Appointments and Remuneration Committee. This process takes into account the overall performance of the charity, external benchmarking, and the long-term needs of the organisation.

The charity is committed to fair pay and pays above the London Living Wage for all roles. Vacancies are advertised on our website and external recruitment platforms, with applications welcomed from both internal and external candidates. Some roles can be advertised only internally before opening external candidates when no suitable internal candidates come forward. Recruitment agencies are used when direct recruitment proves difficult.

No member of the SLT receives a car allowance or vehicle from the charity. All staff and Trustees travel on standard fares when undertaking charity business. Trustees do not receive any remuneration or other benefits for their work. Details of reimbursed expenses to Trustees are disclosed in Note 18.

In 2024/25, the charity undertook a comprehensive benchmarking exercise across all staff salaries. To ensure competitiveness and fairness, the recommendations from this review were implemented in June 2025.

Risk management

The Trustees continue to support formal risk management procedures to assess business risks and implement strategies to mitigate them. Risks are identified and classified based on their potential impact and likelihood, with appropriate controls and processes in place to manage them.

The charity operates a comprehensive risk management strategy underpinned by a detailed risk register, which is regularly reviewed and updated. The risk register is reviewed monthly by the SLT, quarterly by the Finance Committee and the Board, and undergoes an extensive review each March during the budget approval process. Risks are assessed in relation to the charity's strategic objectives and evaluated against existing controls. Action plans are developed to minimise or eliminate risks where possible and are kept under ongoing review. A detailed review of the charity's risk approach was last conducted in 2022/23 with the support of an external expert, including training for Trustees and the SLT.

The following risks were identified in 2024/25 as the most significant to the charity's financial and operational sustainability:

a. Maintaining sufficient income levels: The charity closely monitors its diverse voluntary income streams through robust budget controls, targeted marketing plans, and monthly reviews of management accounts against targets.

b. Sufficient unrestricted reserves: To safeguard against income loss, unplanned expenditure, and to support strategic growth, the charity must maintain adequate unrestricted reserves. This risk was addressed through a review of the reserves policy in March 2025, resulting in an increased reserves target in line with strategic growth plans.

c. Investment market volatility: A downturn in the stock market could impact the value of the charity's investment portfolio. This risk is mitigated through a long-term investment strategy, professional investment advice, and maintaining sufficient reserves. At 31 March 2025 over 50% of the charity's balance sheet value is held in investments.

d. Data protection and cybersecurity: In light of GDPR and increasing cyber threats, the charity maintains strong controls over its database, cloud storage, and cybersecurity tools. Staff receive regular training, and the Finance Committee reviews cybersecurity quarterly. The charity works closely with its external IT provider to ensure best practice, and 24-hour network monitoring was introduced in 2024/25.

e. Effective communication and outreach: Providing accurate and accessible information is essential to maintaining user trust and engagement. The charity continues to review all communications, publications, and its website to ensure they meet audience needs. A refreshed brand was launched in June 2023, followed by a new website in May 2024. A comprehensive review of health information materials concluded in June 2025.

f. Staff recruitment and retention: Talent acquisition and retention remain sector-wide challenges. The charity promotes wellbeing, sustainability, and equity through flexible, agile working arrangements and a commitment to diversity and inclusion. Since relocating to a smaller office in March 2023, the charity has expanded its recruitment reach nationally.

The Trustees continue to regularly review the charity's risk management framework to ensure it remains balanced and responsive to emerging risks.

Grant-making policies

The charity provides grants to support research through formal grant calls designed to attract high-quality applications. All applications undergo a peer-review process and are assessed by the Medical Research Committee and members of the Lay Research Panel. Recommendations are then made to the Board of Trustees for approval. Once awarded, grants are monitored annually to ensure progress against agreed objectives.

Grants for equipment are administered through the charity's subsidiary, the Joseph Patrick Trust (JPT). Applications are reviewed by the JPT Committee against established criteria before approval.

As part of our new strategy, the charity is undertaking a comprehensive review of its welfare grants programme to ensure it continues to meet the evolving needs of our community.

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 subsidiarity, 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: Rathbones London, 30 Gresham St, 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 38 to 40.

Governance, structure 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 Trust.

Appointment of Trustees

Muscular Dystrophy UK currently has 13 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). During the financial year 2024/25, one Trustee stepped down having completed their term, two Trustees were re-elected for a second term, and one new Trustee was elected. Their appointment was subject to a rigorous review by the Appointment and Remuneration Committee and Board of Trustees, bearing in mind the need for progressive refreshing of the Board's skills and experience. All appointments and resignations were approved by the Company Members with a majority vote at the AGM in October 2024.

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 Muscular Dystrophy UK. The Board meets quarterly, and there are standing committees covering key areas of activity: for research, the Medical Research Committee (MRC) and the Lay Research Panel (LRP); for care, the Services Development Committee (SDC); for finance and fundraising, the Finance Committee; for marketing, the Content Advisory Group (CAG); for appointments, the 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 the charity and the delivery of operational plans.

Members

Following a review in January 2024, we now have a body of 87 charity members, who carefully monitor the charity's progress. The charity members are volunteers drawn from the various stakeholder groups 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 our work. 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 and weakening 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 we should apply these principles and practices during updates in the Board meetings, CEO reports and at the annual Board Away Day. In 2024/25 the Trustees engaged in strategic 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 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 our welfare arm, of which Muscular Dystrophy UK is its sole corporate Trustee. Constituted on 30 April 1986, with the support of the Patrick family, it provides direct financial assistance in the form of welfare grants to individuals and families living with muscle wasting and weakening conditions, throughout the UK. The consolidated financial statements also include the trading subsidiary, Muscular Dystrophy Group (Trading) Limited (Reg. 893086). We maintain extremely close working relationships with partner charities that also assist those living with muscle wasting conditions.

Statement of Trustees' responsibilities

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

In preparing these financial statements, the directors are required to:

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

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

Provision of information to auditors

So far as each of the directors is aware at the time the report is approved, there is no relevant audit information of which the company's auditors are unaware; and the directors have taken all steps they ought to have 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, 17 October 2025

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 2025 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 2025 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

Andrew Stickland
Senior Statutory Auditor

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

9 Appold Street,
London EC2A 2AP

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

Date: 27 October 2025

Financial statements and notes

Consolidated statement of financial activities (Incorporating an income and expenditure account)

For the year ended 31 March 2025

	Notes	Unrestricted funds £000	Restricted and endowment funds £000	Total 2025 £000	Unrestricted funds £000	Restricted and endowment funds £000	Total 2024 £000
Income							
Income from charitable activities							
Donations, gifts and grants	2	3,933	548	4,482	3,340	1,131	4,471
Government grants	2	-	15	15	-	847	847
Legacies	2	2,466	128	2,595	2,219	701	2,920
Income from other trading activities	11	194	-	194	67	-	67
Investment income	2, 10	554	-	554	340	-	340
Other income	2	56	16	72	5	858	863
Total income		**7,205**	**707**	**7,912**	**5,971**	**3,537**	**9,508**
Expenditure							
Expenditure on raising funds	3	2,754	336	3,090	2,135	347	2,482
Costs from other trading activities	3	132	–	132	114	-	114
		2,887	**336**	**3,222**	**2,249**	**347**	**2,596**
Charitable activities							
Medical research	3, 5	1,785	562	2,346	523	1,653	2,176
Access to specialist care and support	3	1,339	(57)	1,282	1,180	53	1,233
Independent living	3	1,070	2,171	3,241	813	1,224	2,037
Total – charitable activities		**4,194**	**2,675**	**6,869**	**2,516**	**2,930**	**5,446**
Total expenditure		**7,080**	**3,011**	**10,091**	**4,765**	**3,277**	**8,042**
Net gain/(loss) on investment assets	9	112	(4)	109	410	32	442
Transfer between funds		-	-	-	-	-	-
Net movement in funds		**237**	**(2,308)**	**(2,071)**	**1,616**	**292**	**1,908**
Reconciliation of funds							
Total funds brought forward	15	8,564	5,257	13,821	6,948	4,965	11,913
Total funds carried forward	15	8,801	2,949	11,751	8,564	5,257	13,821

There are no recognised gains or losses other than those disclosed above. All results are derived from continuing activities.
The accompanying notes on pages 56 to 67 form an integral part of the financial statements.

Balance sheets

As at 31 March 2025
company registration number: 205395

	Notes	Group 2025 £000	Group 2024 £000	Charity 2025 £000	Charity 2024 £000
Fixed assets					
Tangible assets	8	274	370	274	370
Investments	9	5,924	6,013	5,796	5,767
Total fixed assets		**6,197**	**6,383**	**6,070**	**6,137**
Current assets					
Stock	12	17	14	-	-
Debtors	13	1,787	2,458	1,803	2,517
Short term investments		1,000	1,000	1,000	1,000
Cash at Bank		7,194	7,608	7,077	7,494
Total current assets		**9,998**	**11,080**	**9,880**	**11,011**
Creditors falling due within one year	14	(4,444)	(3,642)	(4,294)	(3,417)
Net current assets		5,553	7,438	5,585	7,594
Total assets less current liabilities		**11,751**	**13,821**	**11,655**	**13,731**
Net assets		**11,751**	**13,821**	**11,655**	**13,731**
The funds of the Charity					
Unrestricted					
- Designated	15	4,801	2,876	4,801	2,876
- General	15	4,000	5,688	3,926	5,598
		8,801	8,564	8,727	8,474
Restricted	15	2,534	4,838	2,512	4,838
Endowment	15	415	419	415	419
Total charity funds		**11,751**	**13,821**	**11,655**	**13,731**

The Statement of Financial Activities for the year ended 31 March 2025 for the parent charitable company only was a deficit of £2,076K (2024: surplus of £2,040K).

The accompanying notes on pages 56 to 67 form an integral part of the financial statements.

Approved and authorised for issue by the Board of Trustees on 17 October 2025 and signed on its behalf by:



Professor Michael Hanna
Chairman
17 October 2025



Joseph Gordon
Treasurer
17 October 2025

The accompanying notes on pages 56 to 67 form an integral part of the financial statements.

Statement of group cashflows

Year ended 31 March 2025

	2025 £000	2024 £000
Net cash inflow/(outflow) from operating activities (note a)	**(1,129)**	**(182)**
Net cash flow from investing activities		
Dividends from investments	554	407
Purchase of tangible fixed assets	(37)	(86)
Proceeds of sale of Investments	2,214	976
Purchase of Investment	(2,016)	(2,148)
Net cash provided by investing activities	**715**	**(851)**
Increase/(decrease) in cash and cash equivalents in the year	**(414)**	**(1,033)**
Increase/(decrease) in cash and cash equivalents in the year (note b)	(414)	(1,033)
Cash and cash equivalents at the beginning of the year	7,608	8,641
Cash and cash equivalents at the end of the year	**7,194**	**7,608**

Notes to cash flow statement

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

Net movement in funds	(2,071)	1,908
Dividends from investments	(554)	(407)
Investment (gains) / losses	(109)	(442)
Depreciation	109	117
Loss on assets disposal	25	-
Decrease / (Increase) in debtors / stock	668	(958)
Increase / (Decrease) in all creditors	802	(400)
Net cash provided by/(used in) operating activities	**(1,129)**	**(182)**

	01-Apr-24 £000	Cashflows £000	31-Mar-25 £000
(b) Analysis of changes in net cash funds:			
Cash and cash equivalents	7,608	(414)	7,194
Total cash and cash equivalents	**7,608**	**(414)**	**7,194**

The accompanying notes on pages 56 to 67 form an integral part of the financial statements.

Notes to the financial statements

For the year ended 31 March 2025

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. The budgets and cash flows for 2025/26 were reviewed in October 2025 and the Trustees have considered cash forecasts covering the twelve month period until October 2026. 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:

i. Entitlement – when Muscular Dystrophy UK has control over the rights to the resource, enabling it to receive the economic benefit.

ii. Probability – when it is probable, more likely than not that the economic benefit will be received.

iii. Measurement – when the monetary value can be measured with sufficient reliability.

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

Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably through estate accounts (or cash receipt) and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is not recognised in the accounts.

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 2024/25 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 and weakening 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 11 of the Corporation Tax Act 2010 or section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains

1. Accounting policies (Cont.)

are applied exclusively to charitable purposes. No tax charge arose in the period.

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

Listed investments

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

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

Unlisted investments

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

Financial instruments

Basic financial instruments are initially recognised at transaction value and subsequently measured at amortised cost with the exception of investments which are held at fair value. Financial assets held at amortised cost comprise cash at bank and in hand, together with trade and other debtors. A specific provision is made for debts for which recoverability is in doubt. 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
- 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 2025

2. Income

	Unrestricted funds £000	Restricted funds £000	Total 2025 £000	Unrestricted funds £000	Restricted funds £000	Total 2024 £000
Events and promotions	1,926	24	1,951	1,582	144	1,726
Direct marketing	790	12	802	810	14	824
Major donors and corporate	564	114	678	414	692	1,106
Trusts	28	164	193	50	844	894
Regional development	625	248	873	484	284	768
Legacies	2,466	128	2,595	2,219	701	2,920
Other income	805	16	821	412	858	1,270
Total income*	**7,205**	**707**	**7,912**	**5,971**	**3,537**	**9,508**

** Of this income £15k net comes from Government Grants (2024: £847k). The government grants included a refund of £10k (2024 payment of £740k) to the Department of Transport and £25k (2024: £106k) from Ministry of Housing, Communities and Local Government included in Other income figure.*

3. Expenditure

	Grants £000	Other £000	Support Costs £000	Total 2025 £000
Raising funds				
Expenditure on raising funds	-	2,855	235	3,090
Costs from other Trading Activities	-	123	10	132
Total	**-**	**2,977**	**245**	**3,222**
Charitable expenditure				
Access to care and independent living				
Access to care	-	1,101	181	1,282
Independent living	1,887	896	458	3,241
Total	**1,887**	**1,997**	**639**	**4,523**
Pursuit of Knowledge				
Medical research	1,613	402	331	2,346
Total charitable expenditure	**3,500**	**2,399**	**970**	**6,869**
Total expenditure	**3,500**	**5,377**	**1,215**	**10,091**

3. Expenditure (Cont.)

2024 Comparatives	Grants £000	Other £000	Support Costs £000	Total 2024 £000
Raising funds				
Expenditure on raising funds	-	2,329	153	2,482
Costs from other trading activities	-	109	5	114
Total	**-**	**2,438**	**158**	**2,596**
Charitable expenditure				
Access to care and independent living				
Access to care	-	1,085	148	1,233
Independent living	1,018	774	245	2,037
Total	**1,018**	**1,859**	**393**	**3,270**
Pursuit of knowledge				
Medical research	1,578	337	261	2,176
Total charitable expenditure	**2,596**	**2,196**	**654**	**5,446**
Total expenditure	**2,596**	**4,634**	**812**	**8,042**

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

'Support costs' comprise of the following:

	2025 £000	2024 £000
Chief Executive and Human Resources	194	134
Finance and insurance	430	263
Office costs	337	220
Information Technology	213	160
Governance	41	36
Total	**1,215**	**813**

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 departamental running costs.
- 'Governance' includes the annual audit fee and Trustees expenses.

4. Staff costs (Group and Parent Charity)

	2025 £000	2024 £000
Remuneration of staff		
Wages and salaries	2,659	2,386
Social security costs	278	239
Pensions	154	127
Total	**3,090**	**2,752**

There were three redundancies made in the year (2024: No redundancies were made in the year). The cost of the redundancy payments was £2.5k (2024: £nil). The monthly average number of employees during the period was 73 (2024: 70), 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 38. Their total aggregate employment benefits were £552k (2024: £469k).

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

	2025 No.	2024 No.
Earned between the ranges		
£60,000 to £70,000	4	1
£70,001 to £80,000	3	1
£80,001 to £90,000	1	1
£100,001 to £110,000		
£110,001 to £120,000	1	1
Number of staff by activity		
Direct charitable expenditure	25	25
Fundraising and publicity	40	38
Management and administration	8	7
Total	**73**	**70**

Pension schemes
There was £21k outstanding pension contribution (2024: £nil) at the Balance Sheet date.

5. Grant expenditure

	Research grants £000	Welfare grants £000	Total 2025 £000	Total 2024 £000
Grants awarded in the year	1,708	1,904	3,612	2,874
Grants cancelled in the year	(95)	(17)	(112)	(279)
Total	**1,613**	**1,887**	**3,500**	**2,595**

2024 comparatives	Research grants £000	Welfare grants £000	Total 2024 £000
Grants awarded in the year	1,785	1,089	2,874
Grants cancelled in the year	(208)	(71)	(279)
Total	**1,577**	**1,018**	**2,595**

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.

Two institutions were in receipt of a total of three material research grant awards exceeding £80k in 2024/25. Two of these went to the Unversity of Cambridge (one strategic grant of £188k and one project grant £87k) and one to University College London (strategic grant £352k). Grant expenditure includes a repayment of £273k (2024: £nil) to the Department for Transport in respect of unutilised funds following the closure of a project. In addition, £99k was transferred during the year from the A Road Project to the Rail Network Project.

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 of £2,565k (2024: £1954k).

5. Grant expenditure (Cont.)

Reconciliation of grant funding commitments:

	2025 £000	2024 £000
Carrying amount at start of year	3,113	3,003
Additions	3,612	2,874
Amounts charged and cancelled in year	(3,513)	(2,764)
Carrying amount at end of year	**3,212**	**3,113**

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.

	2025 £000	2024 £000
Expiring up to one year	148	90
Expiring between one and five years	440	522
Expiring after more than five years	-	540

7. Net income

Net Income is stated after charging

	2025 £000	2024 £000
Auditor's remuneration	37	32
Auditor's remuneration - non audit services	3	4
Depreciation	109	117
Operating lease rentals	128	129

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 2024	126	500	16	15	31	688
Additions		35	-	-	1	37
At 31 Mar 2025	**117**	**359**	**9**	**15**	**37**	**537**
Depreciation 1 Apr 2024	11	282	16	-	9	318
Disposal	-	(157)	(8)	-	-	(164)
Provided for year	12	89	-	-	9	109
At 31 Mar 2025	**23**	**213**	**9**	**-**	**19**	**264**
Net Book Value						
At 31 Mar 2025	**94**	**146**	**-**	**15**	**19**	**274**
At 31 Mar 2024	115	218	0	15	21	370

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 2024	126	497	16	15	31	685
Additions		35	-	-	1	37
Disposal	(9)	(175)	(8)	-	5	(187)
At 31 Mar 2025	**117**	**357**	**9**	**15**	**37**	**535**
Depreciation 1 Apr 2024	11	279	16	-	9	315
Disposal	-	(156)	(8)	-	-	(164)
Provided for year	12	89	-	-	9	109
At 31 Mar 2025	**23**	**211**	**9**	**-**	**19**	**261**
Net Book Value						
At 31 Mar 2025	**94**	**146**	**-**	**15**	**19**	**274**
At 31 Mar 2024	115	218	0	15	22	370

All tangible fixed assets are used in the promotion of Muscular Dystrophy UK's work; none are 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 2025 £000	Group 2024 £000	Charity 2025 £000	Charity 2024 £000
Market value at beginning of year	6,012	5,399	5,765	5,169
Acquisitions	2,016	1,148	1,757	1,070
Sales proceeds	(2,214)	(976)	(1,826)	(896)
Total	**5,815**	**5,571**	**5,696**	**5,343**
Gain/(loss) on investment	109	442	100	424
Market value at end of year	**5,924**	**6,013**	**5,796**	**5,767**
Historical cost at end of year	**5,020**	**5,409**	**4,894**	**5,165**

Spread of investments

The investments of Muscular Dystrophy UK are held as follows:

	Group 2025 £000	Group 2024 £000	Charity 2025 £000	Charity 2024 £000
Investments listed on a recognised Stock Exchange and Unit Trusts				
UK and overseas equities	4,549	4,665	4,549	4,477
UK and overseas fixed interest	775	757	653	725
Property and Infrastructure funds	569	219	564	210
Hedge funds	-	310	-	293
Total	**5,893**	**5,951**	**5,767**	**5,705**
Cash on deposit awaiting investment	30	-	29	-
Unlisted equities	-	62	-	62
Total	**5,924**	**6,013**	**5,796**	**5,767**

Investment management costs for the year were £49k (2024: £27k).

During the year, the sale of an unlisted investment resulted in a realised gain of £145k included in the gain in the Statement of Financial Activities.

10. Income from investments

	Group 2025 £000	Group 2024 £000	Charity 2025 £000	Charity 2024 £000
UK Equities, UK fixed interest and other	118	46	113	45
Short term deposit and bank interest	436	294	435	286
Total	**554**	**340**	**548**	**331**

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 2025 are summarised below:

	Muscular Dystrophy Group (Trading) Ltd £000	Joseph Patrick Trust £000
Fixed assets	-	128
Current assets	118	43
Current liabilities	(100)	(93)
Total net assets	**18**	**77**
Represented by:		
Total funds	**18**	**77**
Total income	194	160
Total expenditure	(132)	(225)
Investment gains/losses and other B/S movements	-	8
Surplus for the year	**62**	**(57)**
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 £17k (2024 : £14k).

13. Debtors

	Group 2025 £000	Group 2024 £000	Charity 2025 £000	Charity 2024 £000
Trade debtors	23	32	-	-
Amount due from subsidiary undertakings	-	-	42	97
Prepayments and accrued income	1,764	2,424	1,760	2,418
Other debtors	-	2	-	2
Total	**1,787**	**2,458**	**1,803**	**2,517**

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 2025 £000	Group 2024 £000	Charity 2025 £000	Charity 2024 £000
Accruals for grant commitments	3,212	3,113	3,027	2,939
Accruals and deferred Income	478	350	421	344
Taxation and social security	64	6	64	-
Amount due from/to subsidiary undertakings	-	-	94	-
Trade creditors	670	120	667	115
Other creditors	21	53	21	19
Total	**4,444**	**3,642**	**4,294**	**3,417**

15. Funds

	April 2024 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2025 £000
Endowment fund						
Orchid Ball	419	-	-	-	(4)	415
Restricted funds						
Provision of care						
City Bridge Trust / Work experience	-	5	(5)	-	-	-
Scotland	603	94	(93)	-	-	604
Psychological support	8	2	(10)	-	-	-
Volunteering	-	11	(11)	-	-	-
Joseph Patrick Trust - Assistive technology	43	1	(21)	-	-	22
Changing Places	1,885	17	(1,902)	-	-	-
The Garfield Weston CCS Fund	-	2	(2)	-	-	-
SMA screening	26	-	(23)	-	-	3
Chelsea Flower Show	284	44	(328)	-	-	(-)
Other care	2	69	(54)	-	-	17
Research						
The Patrick Research Fund	100	-	(100)	-	-	(-)
Congenital LMNA MD	92	12	(26)	-	-	78
Q Trust	97	5	-	-	-	102
FSHD Research	96	52	(75)	-	-	73
Duchenne Research	120	86	-	-	-	206
Ullrich Research	142	48	(75)	-	-	116
Nemaline Research	282	26	-	-	-	308
Congenital MD	284	-	(63)	-	-	221
Becker Research Fund	75	18	-	-	-	93
SMA Research	7	30	(12)	-	-	25
Limb Girdle Research	165	77	(75)	-	-	168
Other research	526	108	(135)	-	-	498
Total restricted funds	**4,838**	**707**	**(3,011)**	**-**	**-**	**2,534**

15. Funds (Cont.)

	April 2024 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2025 £000
Designated funds						
IT Investment fund	36	-		-	-	36
Research	2,150	-	(540)	-	-	1,610
Fundraising	170	-	(170)	-	-	-
Data team	150	-	(53)	-	-	97
Tangible assets for charity use	370	201	(297)	-	-	274
Strategic investment fund	-	-	-	2,784	-	2,784
Total designated funds	**2,876**	**201**	**(1,060)**	**2,784**	**-**	**4,801**
General fund	5,688	7,004	(6,020)	(2,784)	112	4,000
Strategic investment fund	-	-	-	-	-	(2,784)
Total general fund	**5,688**	**7,004**	**(6,020)**	**(2,784)**	**112**	**4,000**
Total unrestricted funds	**8,564**	**7,205**	**(7,080)**	**-**	**112**	**8,801**
Total funds	**13,821**	**7,912**	**(10,091)**	**-**	**109**	**11,751**

2024 comparatives	April 2023 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2024 £000
Endowment fund						
Orchid Ball	387	-	-	-	32	419
Restricted funds						
Provision of care						
City Bridge Trust / Work experience	4	-	(4)	-	-	-
Scotland	-	634	(31)	-	-	603
Psychological support	29	-	(20)	-	-	9
Volunteering	-	21	(21)	-	-	-
Joseph Patrick Trust - Assistive technology	49	-	(6)	-	-	43
Changing Places	2,211	868	(1,194)	-	-	1,885
The Garfield Weston CCS Fund	117	-	(117)	-	-	-
SMA screening	-	95	(69)	-	-	26
Chelsea Flower Show	-	605	(321)	-	-	284
Other care	2	17	(16)	-	-	3
Research						
The Patrick Research Fund	100	-	-	-	-	100
Congenital LMNA MD	59	33	2	-	-	94
Q Trust	21	85	(9)	-	-	97
FSHD Research	77	35	(16)	-	-	96
Duchenne Research	167	240	(287)	-	-	120
Ullrich Research	116	63	(38)	-	-	141
Nemaline Research	371	8	(97)	-	-	282
Congenital MD	465	1	(182)	-	-	284
Becker Research Fund	150	6	(82)	-	-	74
SMA Research	14	23	(30)	-	-	7
Limb Girdle Research	47	118	-	-	-	165
Other research	579	685	(739)			525
Total restricted funds	**4,578**	**3,537**	**(3,277)**	**-**	**-**	**4,838**

15. Funds (Cont.)

2024 comparatives	April 2023 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2024 £000
Designated funds						
IT Investment fund	36	-	-	-	-	36
Research	-	-	-	2,150	-	2,150
Fundraising	-	-	-	170	-	170
Data team	-	-	-	150	-	150
Tangible assets for charity use	401	86	(117)	-	-	370
Total designated funds	**437**	**86**	**(117)**	**2,470**	**-**	**2,876**
General fund	6,511	5,885	(4,648)	(2,470)	410	5,688
Total unrestricted funds	**6,948**	**5,971**	**(4,765)**	**-**	**410**	**8,564**
Total funds	**11,913**	**9,508**	**(8,042)**	**-**	**442**	**13,821**

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. Its assets are restricted to 'provide welfare, relief and support to those living with muscle wasting conditions.'

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

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

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

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

The Patrick Research Fund - this is a donation from the Patrick family. It is used to support research activities relating to Duchenne muscular dystrophy.

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

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

Q Trust Fellowship - this funding comes from the Q Trust - the restriction is reviewed annually by the Q Trusts representatives in line with their wishes and projects of interest.

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

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

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

Nemaline Myopathy 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 MD 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.

Designated Fund represents IT investment in CRM and Cloud migration projects and two strategic programmes.

Unrestricted funds

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

The designation of balances is as follows:

- 'Tangible assets for charity use' represent the amount of unrestricted funds represented by these assets.
- The General Fund is available for the ongoing operations of the charity.

Represented by: 2025	Fixed assets £000	Investments £000	Net current assets £000	Total £000
Endowment funds	-	415	-	415
Restricted funds	-	-	2,534	2,534
Designated funds	274	1,508	3,019	4,801
Unrestricted funds		4,000	-	4,000
Total funds	**274**	**5,924**	**5,553**	**11,751**

Represented by: 2024	Fixed assets £000	Investments £000	Net current assets £000	Total £000
Endowment funds	-	419	-	419
Restricted funds	-	-	4,838	4,838
Designated funds	370	-	2,506	2,876
Unrestricted funds	-	5,594	94	5,688
Total funds	**370**	**6,013**	**7,438**	**13,821**

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:

	2025 £000	2024 £000
Residuary	22	341
Reversionary	167	252
All sums are due to Muscular Dystrophy UK.	**189**	**593**

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 to the charity and received reimbursement of their expenses incurred in travelling to attend Muscular Dystrophy UK's business, as per below. The charity also contracted with Chimera, to provide services to the value of £29k (2024: £25k) for the Microscope Ball. Chimera is owned by the husband of the charity's Director of Development. Emma Parry-Jones had no involvement in the Trustees decision to use this supplier:

	2025 £000	2024 £000
Donations	17	5
Expenses	2	5

No Trustee received any remuneration during the year (2024: £nil).
There were no other related parties transactions.

MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Registered with FUNDRAISING REGULATOR

Muscular Dystrophy Group of Great Britain and Northern Ireland. Registered charity in England and Wales (205395) and Scotland (SC039445) and a company limited by guarantee without share capital registered with Companies House (705357). Registered office address: 32 Ufford Street, London, England, SE1 8QD

MUSCULAR DYSTROPHY GROUP OF GREAT BRITAIN AND NORTHERN IRELAND

England & Wales - Charity number 205395

Accounts

MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Annual Report 2023/24

Together we are stronger



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1 in 600

people in the UK live with a muscle wasting and weakening condition. We're here for everyone, from the point of diagnosis to living the best life possible.

Photographer: Rebekah Kennington

Front cover photographer: Rose Dedman

A message from our Chair and Chief Executive

Welcome to our annual Impact Report. A year in which research for our community advanced at pace, the demand on our services increased and we planned for our appearance at the RHS Chelsea Flower Show in May 2024.

In 2023/24, the community and our charity became even more creative in delivering our work. Helping us move towards a future where everyone living with a muscle wasting and weakening condition can get the healthcare, support and treatments needed to feel stronger, both physically and mentally.

The new grants we awarded for research this year brought our total portfolio of live grants to 43.

This year we celebrated our successful five-year partnership with Oxford University in the MDUK Oxford Neuromuscular Centre, set up in 2019. During the past five years our partnership has transformed the clinical trial landscape in Oxford from almost no trials in 2019 to over 20 either in progress or being set up by end of 2023. This is all thanks to our community of fundraisers and donors and the £1.2m investment we've been able to make in the centre during this time.

These incredible donations and fundraising efforts have also enabled us to plan for a strategic grant call, which went live in Spring 2024 for projects worth up to £1m, allowing us to drive research further and faster. This was in addition to our over £1m commitment to the LifeArc Centre for Rare Mitochondrial Diseases.

After research and clinical trials comes access to treatments, and this too has accelerated at pace since the first treatment for a muscle wasting and weakening condition became available in the UK in 2016. This year alone we were involved in 10 NHS treatment appraisals that could potentially benefit our community.

It's vital that NHS services for our community support access to new treatments and provide necessary wider care and support. This year we concluded our first Neuromuscular Centres of Excellence audit since the pandemic, awarding 24 neuromuscular services with a Centre of Excellence or Centre Pursuing Excellence Award. This helps us to identify best practice in provision and the challenges services face that we can help overcome.

We were delighted to see an estimated 80% of the neuromuscular care advisor and clinical nurse specialist UK workforce attend our annual Neuromuscular Care Advisor Conference this year. This is just one area where our partnership with the NHS continues to drive improvements in support, advice, and care.

This year, our direct activities expanded to include targeted mental health support, with both psychological and counselling programmes for people living with a condition. Our GriefChat support function reminds us that December, particularly Christmas, can be a time to gather with loved ones and remember those we've lost. This is why we appreciate the work of the Northern Ireland Council, who continue to lead our Belfast annual Spirit of Christmas event.

Throughout the year, our work was positively impacted by our brand refresh which we successfully rolled out – making us more accessible, bolder, brighter than before, but still orange. During this period our website visits went up by a third on the previous year and our reach on Facebook by 140%.

We finish this year once again proud of our wonderful community. Our research partners, support services and funders, volunteers, fundraisers, staff and trustees. Thank you for your support, your involvement, your stories, your requests and your continued passion to make our charity matter, because we all know how much our muscles matter.



Wojtek Trzcinski
Chief Operating Officer
and Interim Chief Executive



Professor Michael Hanna
Chair

Thank you for your support, your involvement, your stories, your requests and your continued passion to make our charity matter, because we all know how much our muscles matter.

Naomi's story

Naomi was pregnant when she found out she had muscular dystrophy at age 23. Her two sons also have the condition. Our helpline team has supported Naomi in getting Disability Living Allowance for her children, and appropriate housing for all their needs.



Photographer: Rose Dedman

"I was told for most of my life that I just had severe scoliosis (curvature of the spine). But when I fell pregnant, I was referred to a specialist maternity unit. They told me they thought I had more than just scoliosis and, shortly after, I was diagnosed with Bethlem myopathy.

"It's shocking to be diagnosed with a condition. But to be pregnant at the same time – I was terrified. When Frankie was born and they confirmed he had the condition, I found out about Muscular Dystrophy UK shortly after and contacted the helpline team to get information. I read stories of people who had similar conditions on the charity website, and they gave me so much hope.

"A couple of years after my second son, Freddie, was born and diagnosed with the same condition, I got back in touch when my partner and I were struggling. The support team has been phenomenal in helping us fight for a better house and Disability Living Allowance (DLA) for the boys.

"We received the news we'd all been waiting for recently: a property that will suit both my children's needs has finally been found for us. For years, we'd been refused mobility equipment for the boys because the house was too small. Moving in and seeing the boys have plenty of space for their mobility needs and their own bedrooms has been amazing.

"I don't think we'd be where we are now without Muscular Dystrophy UK. Thank you from the bottom of our hearts for improving my family's life."

"Frankie's DLA got taken away a few months ago due to a processing issue. I had to reapply for his DLA from scratch, which was really stressful and time consuming. Thankfully, the team at Muscular Dystrophy UK was great in helping me with the paperwork and providing advice. We've now be granted Frankie's full entitlement again, which is a huge relief."

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 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 everyone. 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're 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 muscular dystrophy and allied neuromuscular conditions.

We work:

- 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 public awareness 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

We funded 11 new research projects totalling £1.3m.

Nearly 3,000 people were supported through our helpline.

Over 150 people were supported through our advocacy service.

We raised £9.5m. A 16% increase on the previous year.

More than 160 people attended our Information Days across the UK.

There were nearly 530,000 visits to our website, up one third on the previous year.

Our reach on Facebook was 3.2m, up 140% on the previous year.

Nearly 500 people were provided with a cost-of-living grant by us.

Nearly 500 healthcare professionals attended our six upskilling webinars.

We had nearly 1,500 pieces of media coverage with a potential reach of 356m. A 23% increase in volume of coverage year-on-year.

Looking back on what we achieved

This year's achievements and performance measured against our 2023/24 objectives.

Performance indicator	Our achievements
Award successful grants in our £1m joint fund with LifeArc to accelerate projects to develop new treatments for congenital muscular dystrophy.	• We awarded joint funded grants with LifeArc and will be making a formal announcement when contracts have been signed.
Launch a new £1.15m programme to pump-prime strategic research.	• We agreed to contribute £1.15m over five years in a partnership with the LifeArc Centre for Rare Mitochondrial Diseases. This followed LifeArc's £40m grant call for Translational Rare Disease Centres in which we announced we would contribute this sum to any successful centres addressing muscle wasting and weakening conditions.
Invest £500k into the 2023/24 new research grants programme.	• We invested over £500k into new research grants.
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.	• We finalised the work for this in 2023/24 and the programme was officially launched April 2024.
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.	• We're actively involved in the Next-generation models and genetic therapies for rare neuromuscular diseases (the MAGIC consortium). • The nemaline myopathy natural history study is in its final stages of approval with the regulatory authorities and should begin recruiting patients in 2024. • We've committed to providing up to £60k towards a three-year partnership with the Myotubular Trust to fund a project to understand liver disease in people with X-linked myotubular myopathy.

This year's achievements and performance measured against our 2023/24 objectives - continued

Performance indicator	Our achievements
Engage with the largest number of neuromuscular centres and patient viewpoints through our neuromuscular services audit and Centres of Excellence Awards.	• We engaged with 27 centres through our audit of neuromuscular services and Centres of Excellence Awards process and awarded 24 Centres of Excellence and Pursing 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.	• We provided health professionals with e-learning modules and upskilling webinars. • We carried out our role as a member of the NHSE Specialised Services Stakeholder Forum and a core member of the England Rare Disease Action Plan Patient Advisory Group.
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.	• Our Mental Health Matters steering group, chaired by a neuromuscular clinical psychologist, met twice this year to shape support for our community. • We launched four therapeutic support groups, facilitated by a counsellor with lived experience of a muscle wasting and weakening condition.
Contribute to virtual and physical support events for both people living with muscle wasting and weakening conditions and professionals who support them.	• We held Information Days in Northern Ireland and England, a Scottish Conference, and accessible golf day, along with seven virtual information webinars.
Provide support to neuromuscular services and fellow charities at their events.	• We managed and facilitated five Muscular Dystrophy UK Regional Neuromuscular Networks. • We attended seven external events supporting other charities and neuromuscular services.
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.	• We held two health professional conferences, two Information Days and a Scottish Conference.
Continue to evolve our local Muscle Groups, with virtual events providing condition specific information and support.	• We held 33 Muscle Group meetings and delivered seven virtual information webinars.
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.	• We took part in 10 treatment appraisal processes. Two culminated in recommendations the treatment should be made available as an NHS treatment option; one was withdrawn part way through the appraisal process by the manufacturer; and seven continue into 2024/25. • We continued our role as co-secretariat of the UK SMA Newborn Screening Alliance, the work of which contributed to the securing of 'in-service evaluation' (pilot) of newborn screening by the NHS Newborn Screening Committee.

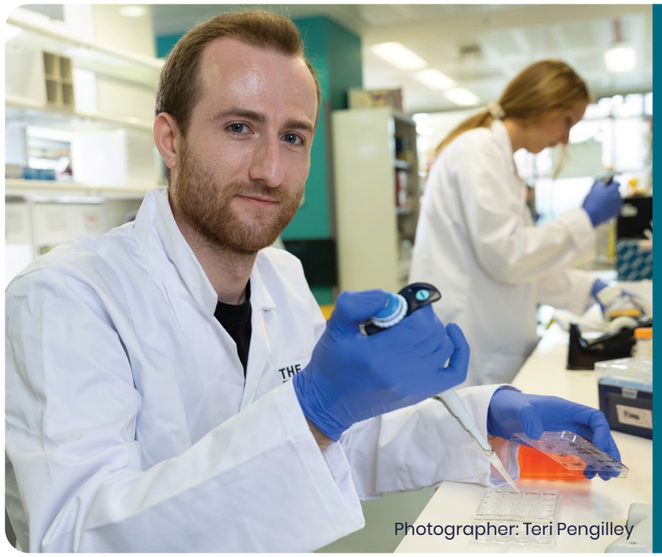
This year's achievements and performance measured against our 2023/24 objectives - continued

Performance indicator	Our achievements
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.	• We successfully helped register a total of 324 Changing places toilets under the Changing Places scheme this year. 252 of these were part of the DLUHC and DfT programmes.
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.	• Delivered a gross budget of £9.5m through active fundraising (£5.3m), legacies, (£2.9m) and other income (£1.3m), which has resulted in a net figure of £6.9m available for our charitable activities. Work is being done on a new legacy proposition to ensure we maximise on the potential of this long-term income stream.
Maximise return on our 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.	• We have continued to maintain a fundraising cost to income ratio above 2.7. In 2023/24 for every £1 we spent on fundraising we raised £3.70.
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.	• We were successfully awarded PIF Tick accreditation.
Reduce our overhead costs to 15% of total costs as a result of moving to smaller office.	• Our support costs in 2023/24 financial year were £812k, which represents 10% of our total expenditure of £8,042k.
Launch our refreshed brand to reach more of the 110,000 people living with one of 60 muscle wasting and weakening conditions.	• We launched our new brand in July 2023 and continued to roll it out throughout 2023/24.
Continue working on reducing our surplus reserves though careful investment planning alongside the existing strategy.	• We have designated £2.1m of our free funds for the two strategic research calls. Both of which were announced in early 2024/25.
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.	• We continued to focus on our team's wellbeing, our impact on the environment, and equality, diversity, and inclusion for the whole community by carrying out various initiatives. These included: wellbeing champion mental health first aiders group, financial wellbeing webinars and wellbeing resources, our EDI working group, and offsetting the carbon emissions from the 2023 Oxford 10k, making it our first carbon neutral Town and Gown event.

Our research advances

High-quality research continues to play a key role in our ambition to improve the lives of people living with a muscle wasting and weakening condition, helping us to better understand these conditions and maximise treatment improvements.

Our research strategy, *Transforming lives through research*, remains the driving force for our research activity.



Photographer: Teri Pengilley

Teams based in London, led by Professors Saverio Tedesco and Peter Zammit, have developed a way to transform cells donated from people with laminopathies into 'mini muscles' complete with fibres, blood vessels and nerve cell. This could hugely impact our understanding of what drives muscle wasting and weakening conditions and aid the development of more effective treatments."

Our 2023 grant awards

We awarded 11 new grants worth over £1.3m to research projects this year. These projects aim to improve diagnosis, monitor progression, and test potential new treatments for muscle wasting and weakening conditions. This brings the total number of research projects we fund to 43. Our new grants cover conditions such as ADSSL1 myopathy, Becker muscular dystrophy, Charcot-Marie-Tooth disease, Duchenne muscular dystrophy, mitochondrial myopathy, myasthenia gravis, myotonic dystrophy type 1, and spinal muscular atrophy.

The European Neuromuscular Centre

We're proud to have been an executive member of The European Neuromuscular Centre (ENMC) since it first began, and this year it celebrated its 30th anniversary. Through its network of European neuromuscular research charities, it has the important role of bringing together experts in the field of muscle wasting and weakening conditions to tackle challenges in this area.

Our Research Line

Through our research line, we continued to ensure patients and families could access information about new research studies, treatments, and clinical trials for muscle wasting and weakening conditions.

Five years working in partnership to change the landscape for clinical trials

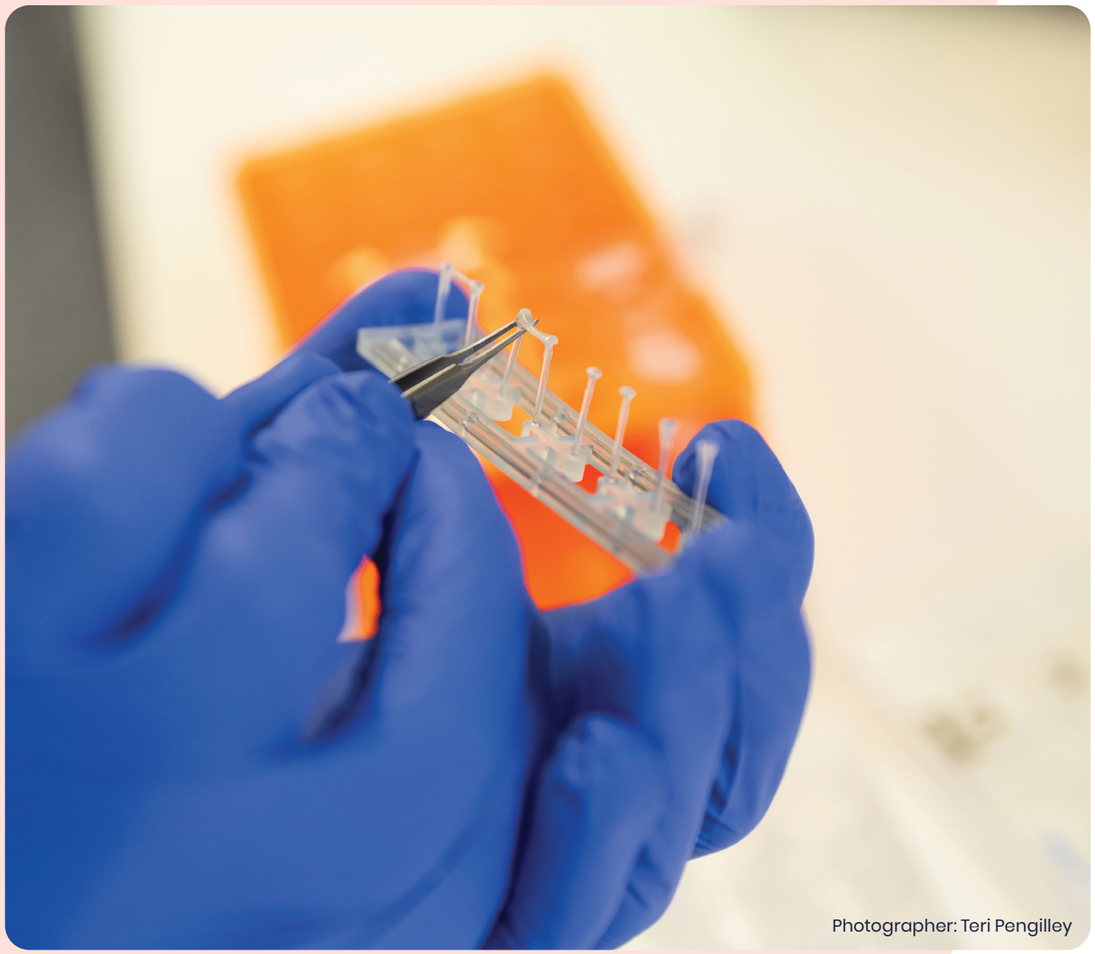
In January 2019, we partnered with the University of Oxford to form the MDUK Oxford Neuromuscular Centre to drive forward the development of new therapies and increase clinical trial capacity for muscle wasting and weakening conditions. This year we celebrated the fifth anniversary of the Centre with its Director

Photographer: Teri Pengilley

Professor Matthew Wood and co-Directors Professors Kevin Talbot and Dame Kay Davies. The Centre is now the third hub for muscular dystrophy research in the UK - along with London and Newcastle. In 2019, almost no clinical trials for muscle wasting and weakening conditions took place in Oxford, and we're proud to say that in 2024 over 20 clinical trials are either in progress or being set up. We've invested £1.2m into the MDUK Oxford Neuromuscular Centre over the past five years.

Medical Research Charities Early-Career Researcher Fund

The Medical Research Charities Early-Career Researcher Fund was set up in 2021 by Government departments to provide financial help and security to medical research charities amid the Covid pandemic. We received a further £382,000 from the fund this year, bringing the total we've received over the past three years to almost £1m, for which we are very grateful. This has helped us regrow our grant portfolio and help fund young scientists to become future leaders in the field of muscle wasting and weakening conditions.



Photographer: Teri Pengilley

Highlights of our research funding

Research projects take time to deliver impact. Here are some of the highlights we published in 2023/24 from our grants awarded in previous years.

The role of periostin in Duchenne muscular dystrophy

Duchenne muscular dystrophy (DMD) is a condition caused by genetic changes in the dystrophin gene that result in blocked production of dystrophin protein. Without dystrophin the muscle breaks down and is replaced by fatty and scar tissue - a process called fibrosis. Professor Linda Popplewell, Dr Alberto Malerba, and their team revealed high levels of periostin in mice with DMD. These results suggest periostin could be linked with muscle fibrosis in DMD. Knowing how periostin contributes to muscle damage could lead to new ways to stop or ease the progression of DMD.

Making 'muscles in a dish' to study laminopathies and other muscle wasting conditions

We use skeletal muscles to move our bodies. They are made up of long fibres supported by an intricate range of other cells. Recreating this intricate system in the laboratory is invaluable to scientists researching skeletal muscles and muscle wasting and weakening conditions. Teams based in London, led by Professors Saverio Tedesco and Peter Zammit, have developed a way to transform cells donated from people with laminopathies into 'mini muscles' complete with fibres, blood vessels and nerve cells. Harnessing laboratory-engineered muscles could hugely impact our understanding of what drives muscle wasting and weakening conditions and aid the development of more effective treatments.

Successful use of a self-management support programme in neuromuscular specialist centres

We funded research looking at whether a self-management support programme called Neuromuscular Bridges could successfully be used in neuromuscular specialist centres. The programme focuses on building patients' confidence and includes special training for healthcare professionals. As part of his PhD studies, Dr Laurence Lee, supervised by Dr Gita Ramdharry, found the programme was helpful to clinicians and people living with muscle wasting and weakening conditions.

£1.2m

invested into the MDUK Oxford Neuromuscular Centre over the past five years

£382,000

received this year from the Medical Research Charities Early-Career Researcher Fund

11

new grants worth over £1.3m awarded this year

43

active research projects

"As an academic group leader, I continue to benefit from funding from Muscular Dystrophy UK. For me, this funding enables the bench science required as a first step for the development of potential gene therapies for Duchenne and Becker muscular dystrophy."

Professor Linda Popplewell, Professor of Genetic Medicine at Teesside University

Driving change for access to specialist care and support

We've worked successfully to secure access to treatments for muscle wasting and weakening conditions this year. At the same time, we've continued to support health professionals in the care of our community, providing upskilling and networking opportunities, while ensuring NHS neuromuscular services receive appropriate attention from commissioners and decision makers.

Our role in treatment recommendations and appraisals

This year we continued to be active in 10 muscle wasting or weakening treatment appraisal processes with the National Institute for Health and Care Excellence (NICE) and Scottish Medicines Consortium (SMC). These appraisals result in recommendations as to whether a treatment should be made available on the NHS. As a formal stakeholder, we ensure the experience of our community is fully represented, submitting evidence on their behalf and supporting people to deliver in-person evidence in appraisal committee meetings. This year we were selected as the formal Patient Expert for the NICE appraisal of Duchenne muscular dystrophy treatment vamorolone, which meant we also took part in an appraisal committee meeting.



Photographer: Jo Ritchie



10
treatment appraisal processes participated in

80%
of the neuromuscular care advisor workforce attended our Care Advisor Conference

155
attendees at our Allied Health Professional virtual conference

507
enrolments on our e-learning modules

465
attendees for our six health professional upskilling webinars



Photographer: Jo Ritchie

Connecting and upskilling health professionals

24 Centres of Excellence or Pursuing Excellence awarded

In January 2024 we awarded 24 neuromuscular services with a Centre of Excellence or Centre Pursuing Excellence Award. This followed the culmination of our national audit of neuromuscular services through our Centres of Excellence Awards programme. This programme is one of the main ways we identify and promote best practice in service delivery, and also the national challenges facing neuromuscular services.

Our health professional conferences

We continued to support our health professional community, organising conferences for two key groups involved in the care and support of people living with muscle wasting and weakening conditions, providing them with the opportunity to upskill, share best practice, and network.

Our Allied Health Professionals Conference

We expanded our traditional Physiotherapy Conference into an Allied Health Professionals Conference, responding to requests from health professionals in other disciplines wishing to deepen their understanding of the multidisciplinary care of people living with muscle wasting and weakening conditions. The event was very well attended, with 155 participants hearing about a wide range of topics, including transition, pregnancy care, speech and language therapy strategies, and practical case studies.

Our Neuromuscular Care Advisor Conference

Our Neuromuscular Care Advisor Conference was attended by an estimated 80% of the care advisor and clinical nurse specialist workforce in the UK. This year's focus was on social care, assistive technology, psychological upskilling, and palliative care.

"The children's neuromuscular team are honoured to receive the Muscular Dystrophy UK Centre of Excellence Award. This recognises the ongoing care and support provided to children with neuromuscular conditions in Greater Manchester and beyond, and acknowledges the efforts of the team and the support from other speciality teams in the hospital in providing an excellent standard of care to children and families living with neuromuscular conditions."

Dr Imelda Hughes, Consultant Paediatric Neurologist at Royal Manchester Children's Hospital



Photo: Manchester University NHS Foundation Trust

"I enjoyed all the content and variation of those presenting. It was useful to network and share best practice with others from around the UK and hear about different approaches to interventions. The upskilling session was particularly useful."

Neuromuscular Care Advisor Conference attendee.

Our virtual upskilling and networking opportunities

We continued to provide virtual upskilling opportunities to health professionals, expanding our range of webinars to include learning opportunities for non-neuromuscular specialist health professionals. Running a series of six webinars, with a total of 465 health professional attendees, with a further 562 professionals subsequently receiving recordings of the webinars. Across the year, 507 people enrolled on our e-learning modules.

Our regional neuromuscular networks

Regional neuromuscular networks are a critical way in which our community of health professionals and people who use neuromuscular services can be brought together to identify service gaps and challenges in service provision. This ensures specialist and community neuromuscular services are strengthened in local areas. This year we continued to facilitate the work of our five neuromuscular networks and engaged with five NHS-funded neuromuscular networks, supporting in navigating changes to the commissioning system for specialised services and undertaking service scoping exercises, upskilling events, patient information days and network meetings.

Our parliamentary and policy work

Providing support to muscular dystrophy parliamentary groups

We continued to support cross-party groups on muscular dystrophy in the Houses of Parliament, the Scottish Parliament, the Welsh Parliament, and since the restoration of devolved government in Northern Ireland we've worked to reconstitute our Stormont group. Our work with these groups helps to ensure issues affecting people with muscle wasting and weakening conditions are on the political agenda and that they receive the political attention they deserve. We delivered a number of meetings across these groups this year, including launching our All-Party Parliamentary Group on Muscular Dystrophy inquiry report into newborn screening for rare conditions.

Consultation responses

We engaged in a number of Government consultations on issues of importance to our community, including housing and welfare, the closure of railway ticket offices, and disability and mental health strategies. These responses have played a significant role in achieving meaningful change, impacting on the overall quality and outcomes for people living with muscle wasting and weakening conditions.

Our community survey

A central part of our mission is to campaign for people's rights, better understanding, and accessibility. To guide our policy priorities this year we launched a community survey, which received almost 700 responses from people living with a muscle wasting and weakening condition, their family and carers. These responses allowed us to discover more about what our community wants us to prioritise in our campaigning work and to identify the key policy areas in which our community need us to be actively engaged.

We began incorporating these findings into our work this year and will publish a report on the insights gained in 2024/25.

Living well

We understand that living with a muscle wasting and weakening condition can be overwhelming and isolating for individuals and their families. This is especially true if people don't have access to the right information and support to help them live well. We're here to listen and provide information and advice about all aspects of living with a muscle wasting and weakening condition.

Our helpline service

This year 2,752 people contacted our helpline. Our team provided tailored information and emotional support to people living with a condition, their family, carers and friends. Delivering advice and support by phone, email, face-to-face, or through a referral from NHS neuromuscular clinics. The five topics people most contacted us about were alert cards, welfare information requests, emotional support, housing and adaptations advice, and peer support.

Our advocacy service

Through our advocacy service we supported 152 people to express their views and wishes and to challenge decisions made about them in relation to things like access to care, equipment, benefits and education. We supported them to develop self-advocacy skills in the face of these challenges, to communicate their needs and rights. The most support we provided was on Personal Independence Payment (PIP), housing and adaptations, and care packages.

"I was elated when I found out I'd been accepted for the grant. It feels like a real blessing to live in a society that has funds available for people that need it."

Sam, who lives with spinal muscular atrophy, received a grant through a partnership between our grant giving arm the Joseph Patrick Trust and SMArt Moves.

Supporting people through grants

We continued to provide grants for the cost of mobility equipment through our grant giving arm the Joseph Patrick Trust, with 53 people receiving grants this year. We also provided cost-of-living grants to 470 people.

Our tailored therapeutic support groups

This year we successfully partnered with Louise Halling, a professional counsellor and psychotherapist living with limb girdle muscular dystrophy, to run virtual therapeutic support groups. These sessions provided a confidential, supportive space to foster open discussions and build connections. Four therapeutic groups took place over the year.

Our tailored peer support

Our peer support groups continue to flourish. In the past year we've facilitated support groups based on condition, age or circumstances, such as recently receiving a condition diagnosis. We've also worked in partnership with the Teapot Trust, a mental health charity providing art therapy for children and families living with long term health conditions, to pilot a support programme for primary school aged children living with muscle wasting and weakening conditions. Alongside these new groups, we continue to offer one-to-one peer support from our trained peer support volunteers with lived experience.

Muscle Groups – keeping people updated and connected

Our regional Muscle Group meetings provide a safe, welcoming space where people affected by muscle wasting and weakening conditions can share experiences, meet other people in their local community, and learn more about the services we offer. We ran 33 Muscle Group meetings this year across 10 regions of England, and in Scotland, Wales and Northern Ireland. In the past year 315 people have attended their local meeting.

We ran 33 Muscle Group meetings this year across 10 regions of England, and in Scotland, Wales and Northern Ireland.



Photographer: John Sanders

2,752
people contacted our helpline

470
people received a cost-of-living grant

459
people requested our alert cards

315
people attended our regional Muscle Group meetings

162
attendees joined our Scottish Conference, Information Days in Birmingham and Belfast, and our Accessible Golf Day

152
people supported by our advocacy service

108
people joined our tailored support WhatsApp groups

53
people received a Joseph Patrick Trust equipment grant

65
people received peer support from our volunteers

Our virtual information webinars

We held seven virtual information webinars this year, providing condition-specific information and practical and lifestyle talks to help people live well with their condition. Condition management topics included cardiac management, physiotherapy, emotional support, speech and language therapy, and diet and nutrition. Our webinar sessions focused on Becker muscular dystrophy, Charcot-Marie-Tooth disease, Pompe disease, Myasthenia Gravis, Collagen VI, a SMA treatment update, and palliative care.

Our Information Days

We held three in-person Information Days/conferences in England, Northern Ireland and Scotland as well as our first Accessible Golf Day, bringing together a total of 162 people living with muscle wasting and weakening conditions for our Information Days and our Accessible Golf Day. These events provide an opportunity for people to connect with others in the muscle wasting community, share stories, hear from experts to help them live well, meet our team, and to find out more about the advice and support we offer.

Becoming PIF accredited for trusted health information

Following an assessment with the Patient Information Forum (PIF), we were proud to successfully obtain the PIF TICK Quality Mark for Health Information as a producer of trusted information. The PIF TICK logo will feature on our health information going forwards providing assurance that our content is evidence-based, accessible, and produced to the best possible standard.

Our Employability Programme

Our Employability Programme provided individual support to 16 people over the year. This included support in CV and application writing, interview preparation, and guidance in finding suitable jobs, volunteering placements and training opportunities. We also gave talks focusing on employment rights and applying for jobs.

Changing Places toilets

We're proud to continue in our role as co-chair of the Changing Places Consortium, the home of the Changing Places toilet campaign in the UK. This year we continued our partnership work with the Department for Transport (DfT) and the Department for Levelling Up, Housing and Communities (DLUHC) to support the delivery of programmes to install Changing Places toilets (CPts) across England, with a significant commitment from Local Authorities, motorway services operators and train operating companies.

As the Changing Places Consortium approaches its 20th anniversary in 2025, we launched the Changing Places Conversation to help us identify a sustainable future for the continued growth in provision of Changing Places toilets.

In total we registered 324 new toilets in 2023/24.



I started getting strange feelings in my hands in 2010. After being referred to a specialist, they told me I had a protruding disk in my neck. Getting surgery took several years, but I still continued having the same problems. After going back to the consultant, he didn't think the disc had been the problem and referred me for other tests.

Eventually, I had a muscle biopsy and received a letter saying I had a type of muscular dystrophy called inclusion body myositis (IBM). This was six years after my symptoms had started.

Shortly after, we saw that Muscular Dystrophy UK were holding an Information Day. My wife and I attended with the hope of finding out more about the condition as nobody seemed to be able to tell us anything.

Stewart attended our Wales Information day once more this year, many years after he first went to one. He said: **"I've found it very relevant. One or two of the sessions have been absolutely excellent."**

Photographer: Chris Fairweather

Our work in Scotland

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

We continue to provide comprehensive and holistic support to individuals and families living with a muscle wasting and weakening condition in Scotland. To ensure they have access to the right information, care and equipment at the right time to allow them to live well and independently. Our Head of Regional Support, Outreach, and Information who is based in Scotland is the local point of contact for individuals and families in providing advice, information and support. This year we responded to 316 requests for support in Scotland, of which 35 were advocacy cases.

Our Scottish Conference

In March this year, we held our first conference in Scotland since 2018. It took place in Stirling with 65 people from the muscle wasting community attending, along with 13 external speakers. We were also joined by six external organisations who provided information stands. Topics covered included emotional wellbeing and mental health, exercise and fatigue management, self-directed support, housing adaptations, equipment and postural care. As well as sessions on inclusive education and attending university.

Scottish Disability Sports

In April 2023, we worked in partnership with Scottish Disability Sports, Scottish Swimming, Scottish Powerchair Football Association and Scottish Curling to offer a fun-filled afternoon of sport for children living with a muscle wasting and weakening condition. Seventeen families attended.

Scottish Council

Our work in Scotland continues to be developed and guided by our Scottish Council. Scottish Council members are people living with muscle wasting and weakening conditions, family members and professionals. Their role is to represent the views of people affected by muscle wasting and weakening conditions in Scotland. They met three times over the past year and provided extensive support in shaping the content and delivery of our Scottish conference.

Fundraising update

Our Family Funds

Our six Family Funds from Scotland raised a tremendous £10,600 from a variety of innovative fundraising activities this year. This included £6,065 from Team Thomas who had a number of junior and adult runners in events at the Edinburgh Marathon Festival.

"I attended Muscular Dystrophy UK's Scottish conference today; the sessions were all so informative and valuable for me; nothing is ever quite as valuable as connecting with others and feeling less alone as we navigate this journey."

Scottish Conference attendee



Photographer: Julie Broadfoot

Community fundraising activities

The Spirit of Christmas continues to be our stand-out supporter led event, raising £4,800 this year, and a total of £35,000 since it started. There has been an array of supporter led activity that has contributed to our fundraising total, including colour runs, dancing marathons, wedding favours and walking challenges from Ben Nevis to the West Highland Way. Two people from Scotland completed a trek to Everest Base Camp this year raising over £3,000, and a knitting fundraiser raised over £2,000 for our work.

A growth in runs and walks

The biggest growth to our regional fundraising in Scotland came from running and walking, with people taking on events such as the Edinburgh Marathon Festival and Kiltwalks. A fantastic £29,000 was raised, with many fundraisers doubling or tripling their fundraising targets. We continue to promote the Kiltwalk events as our main focus, with an exclusive charity pitstop secured and a drive to increase participation from local community promotion, including free newspaper adverts kindly provided by London Classified.

Our total fundraising in Scotland

Our total fundraising in Regional Development for Scotland was £136,622 – an increase of £19,622 from 2022/23. We received £583,000 in legacies specifically for our work in Scotland.

Research

We continued to support research in Scotland. As part of the 2023 grant round, we're now funding Professor Tom Gillingwater at the University of Edinburgh. Our funding support to Dr Lyndsay Murray of the University of Edinburgh continues, while our grant to Professor Judith Sleeman at the University of St Andrews ended this year.

£719,622
total funds raised to support our work in Scotland

65
people attended our Scottish Conference

£10,600
raised by our Family Funds in Scotland

316
requests for support responded to



Photographer: Vincent White

The difference your support made

Thanks to your amazing generosity, income from donations, gifts, grants, sponsorship, events and campaigns totalled £5.3m this year.

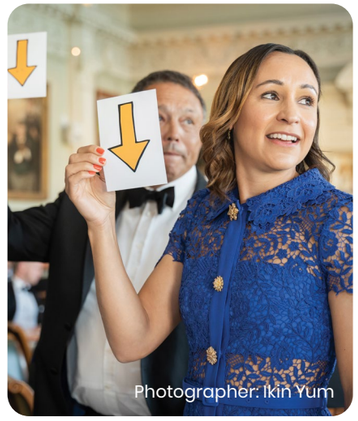
Highlights of this year's fundraising

Our Bidwells 10k Town and Gown running series

This year we welcomed property consultants Bidwells as our title partner for our Oxford and Cambridge running event series. Through this partnership we not only managed to successfully grow the event to attract over 7,500 participants across the two races, and raise over £360,000, the series also became carbon neutral as Bidwells committed to offset the full impact of the event.

Our Celebrity Sports Quiz

For the first time since the Covid pandemic we returned to the prestigious Long Room at Lord's Cricket Ground for our Celebrity Sports Quiz – hosted by our charity President Gabby Logan MBE and her good friend sports presenter and TV personality Kirsty Gallacher. Sporting greats who attended to support us included Jessica Ennis-Hill, Sir Geoffrey Boycott, Monty Panesar and Robin Cousins. Guests on the night enjoyed quizzing with our sports celebrities and raised £88,000.


Photographer: Ikin Yum

Our challenge events

Pedal Paddle Peak 2023

This eighth year of our triple challenge event in the stunning Lake District saw a record 139 participants take part in the 30-mile cycle ride, two-mile canoe paddle, and climb of Helvellyn mountain. Members of our Family Funds, corporate supporters, and people new to the charity, came together to complete the challenge and raise a total of £122,000.

London Marathon 2023

We had 126 runners in the London Marathon 2023, who between them raised a fantastic £323,368. Throughout this reporting period, we also recruited 173 runners, our largest team to date, for London Marathon 2024, which will go on to be our biggest year for fundraising at this event.

Our fundraising year in numbers:

£39,500
raised at the BGC Charity Day thanks to the appearance of our President Gabby Logan MBE, football manager David Moyes and comedian Russell Howard, alongside families from our community

£90,000
raised from our inaugural Double Your Donation campaign that ran for a week in December

£2.9m
raised from 75 individual legacies

£835,373
raised from 7,853 participants signing up to 43 different running events around the country

£427,000
raised at our annual Microscope Ball thanks to the support of the property industry

> **I want to tell you that without these weekends we would not have these friendships or this wonderful support network, thank you to Muscular Dystrophy UK and the team that support us all weekend."**
>
> Family Fund weekend participant

Our Family Funds

Our Family Funds are a special way people in the muscle wasting community can support both those closest to them and a much wider group of people living with muscle wasting and weakening conditions. Our Family Funds are an important part of our community and over the past year they raised an incredible £75,000 by organising their own events and taking part in our challenge events and national fundraising campaigns and appeals.

Congratulations to George's Journey who entered their tenth year as a Family Fund and approached raising over £250,000; a landmark figure also reached by the Hywood's Heroes Family Fund this year.

In 2023, we once more received funding to host a Family Fund Weekend at the fully inclusive Calvert Trust in the Lake District, bringing together our families for a memorable weekend of activity, relaxation, and an opportunity to connect with each other.

Supporter led events

Throughout the UK people from all over the community support our work to change the future of muscle wasting and weakening conditions by fundraising in their own way. Our supporters took part in a huge variety of fundraising campaigns this year, from dress down days as part of our Go Bright campaign to bake sales for Bake a Difference.

We're always blown away by the innovation from the community in finding new ways to fundraise and create their own events throughout the year. **Highlights include:**

The Taylor family from Cumbria, IronWill, delivered a three-day triathlon style event in the Lake District with over 40 people taking part, raising over £50,000 for the Duchenne Breakthrough Research Fund.

Scott Mitchell, also from Cumbria, cycled through every county in England to set a new Guinness World Record, raising over £7,000.

Roger Longshaw from Oxfordshire created My Fee for MD, mowing lawns in his community in return for donations. This idea grew to friends and family completing jobs and taking donations for the charity and has now gone on to raise thousands of pounds.

Up and down the country, supporters organised golf days to raise funds, including our Property Golf Day at Centurion Club, Rollits Golf Day in East Yorkshire, the tenth David Salt Golf Day in Staffordshire, Fighting Back For Jack Golf Day and the Evans Family Golf Day in the West Midlands. Combined these raised more than £110,000.

The twice postponed Source to Sea event spearheaded by Andy Davies from West Sussex took place in April 2023 along the Thames path. An incredible 95 people took part in this accessible event, raising over £26,000.

Fifteen people around the UK jumped out of planes this year to raise an incredible £25,000, including researchers from the John Walton Muscular Dystrophy Research Centre who raised over £4,000.



Photography: Supporter



Team Jed's 24-hour work out

Our longstanding supporter, and this year's President's Award winner for fundraiser of the year, Jed Thirkettle who lives with Ullrich congenital muscular dystrophy (UCMD), completed a hugely impressive 24-hour gym workout. He secured corporate sponsors and partners, extensive press coverage, and raised awareness about UCMD. In total, raising an amazing £20,000 of funds for our work. All at the age of 24.

> **Over the years, everything has been trial and error. However, falling in love with the gym, I wanted to challenge myself. With Mum and Dad fundraising when I was growing up, I knew that when it came to organising my own event, I had to aim big. And the idea snowballed – celebrating 24 years of life with 24 hours in the gym!"**
>
> Jed Thirkettle

Photographer: Olivia Sirley

RHS Chelsea Flower Show

Muscular Dystrophy UK Forest Bathing Garden

In September 2022, we entered the first stage of applying to Project Giving Back (PGB) to have a fully funded garden at the RHS Chelsea Flower Show in 2024.

PGB is a charitable organisation that supports gardens for good causes at the Show. We knew that having a garden would provide us with a unique opportunity to elevate our brand and raise awareness about muscle wasting and weakening conditions by reaching new people.

After being selected from over 200 charity applicants to the short list, in February 2023 we made our pitch with garden designer Ula Maria to the PGB Trustees. In early spring we learnt the exciting news that we'd been selected to have one of nine show gardens.

Our Garden

We were introduced to our brilliant garden designer Ula Maria by our Vice President Alex Wellesley Wesley. Ula grew up in Lithuania and spent long summers in the countryside, which heavily influences her work. She was passionate about our community from the start. She spoke to Martin Hywood, living with limb girdle muscular dystrophy, who told her how lonely he felt after his diagnosis as he sat in his car wondering how his life might change. Ula set about creating a calm and inclusive space bathed in nature to contradict the cold medical spaces that our community so often need to visit.

Ula researched the theme of Forest Bathing, inspired by the ancient Japanese practice of Shinrin-yoku, immersing yourself in nature away from the stresses and strains of everyday life. Being in the forest has proven mental and physical health benefits. Living with a muscle wasting condition can add to the mental load and the garden set out to create an accessible space that would benefit the muscle wasting community.

The final design included a flint wall reminiscent of muscle cells affected by muscular dystrophy and smooth accessible paths and wheelchair height planting for our visitors. This is with over 50 trees to create a forest atmosphere.

Being in the forest has proven mental and physical health benefits.



Photographer: Rebekah Kennington



Illustration: Ula Maria



Photographer: Teri Pengilley

Our President's Award winners



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

Peter and Nancy Andrews Community Achievement Award

Bryan Gould

Bryan is a phenomenal fundraiser and greatly active campaigner. He founded and chairs the Oculopharyngeal muscular dystrophy group and has been a tireless co-chair of the West Midlands Regional Neuromuscular network, as well as leading the way with his independent campaigning against the closure of staffed rail ticket offices.

Fundraiser of the Year Award

Jed Thirkettle

Jed is a truly inspirational fundraiser whose connection to our charity goes back to his childhood as a Family Fund raising money for our work. Jed astounded us this year with his determination to achieve, completing a 24-hour gym workout raising £20,000 for the charity. He is also a valued spokesperson at our fundraising events.

Early Scientist of the Year Award

Meredith James

Meredith has been a considerable influence on the limb girdle muscular dystrophy field and beyond. The work from her PhD, the Development of the North Star for LGMD type muscular dystrophies (NSAD), which she completed in 2023, is currently being used in 12 clinical trials across five individual diseases.

Volunteer of the Year Award

Amanda Hayes

Amanda passionately provides support to so many in the Myasthenia Gravis community, successfully running an online support group for people living with Myasthenia Gravis, speaking at virtual information seminars, and as a Peer Support volunteer. She has also worked with us as a patient expert voice for NICE.

Alexander and Valerie Patrick Award for Carer of the Year

William Jackson

William, when younger, wanted to be a genetic scientist so he could find a cure for his younger brother Louis. Now aged 16 William selflessly takes on a role of providing care and support for his sibling and family.

Richard Attenborough Award for Outstanding Achievement

Professor Francesco Muntoni

Professor Muntoni has made an incredible contribution to the lives of many families within the muscle wasting and weakening community, either directly through his clinic and the numerous presentations he delivers at family-facing events, or indirectly through the hope the research he undertakes brings to people.

Our finances

How we raised our funds

For every £1 we spent:

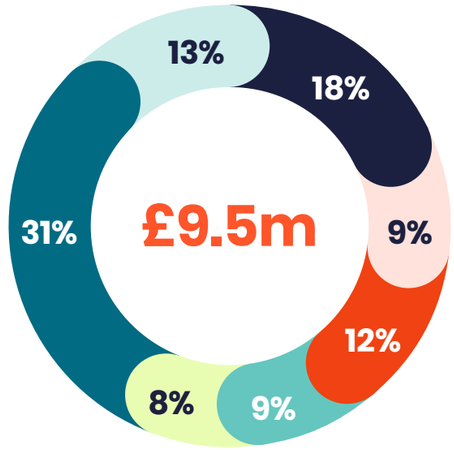


32p is invested in fundraising to ensure we maintain a diverse portfolio to support our community

68p is spent on our charitable activities

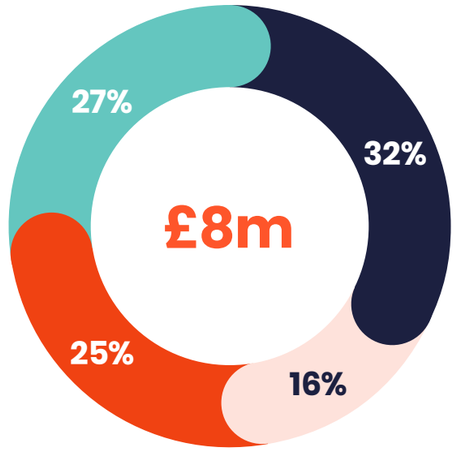
For every £1 we invested in fundraising we raised £3.70





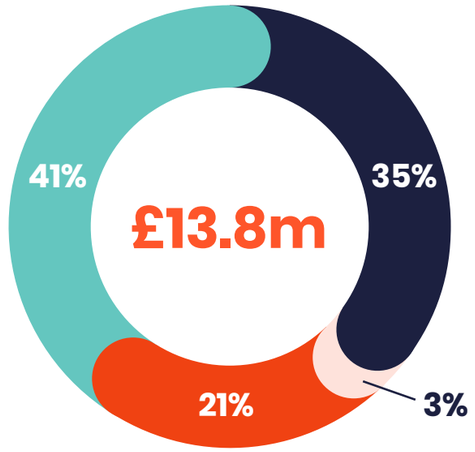
Total income

- **Events and promotions** (£1,726k)
- **Direct marketing** (£824k)
- **Major Donors and Corporate** (£1,106k)
- **Trusts** (£894k)
- **Regional development** (£768k)
- **Legacy** (£2,920k)
- **Other income** (£1,270k)



Total expenditure

- **Fundraising** (£2,596k)
- **Access to specialist care and support** (£1,233k)
- **Independent living** (£2,037k)
- **Medical research** (£2,176k)



Total funds

- **Restricted** (£4,838k)
- **Endowment** (£419k)
- **Designated** (£2,876k)
- **General** (£5,688k)

Our future plans



Going forwards in 2024/25, we will:

- Provide accurate and accessible information, support and signposting, through our national telephone and email helpline service and advocacy support where information provision is not sufficient, and empowerment is needed.
- Connect people affected by muscle wasting and weakening conditions through our national events and virtual seminars, through local groups and through our network of trained peer support volunteers.
- Provide grants to members of our community for essential powered mobility equipment.
- Deliver targeted campaigns on key areas of concern to our community and drive-up UK wide political awareness and support for muscle wasting and weakening conditions.
- Continue as co-chair of the Changing Places Consortium and complete UK Government funded Changing Places programmes.
- Provide unique national physical conferences and virtual training opportunities for specialist and non-specialist health professionals involved in the care of people living with muscle wasting and weakening conditions.
- Provide regional networking, information and intelligence sharing, and upskilling opportunities to health professionals involved in the care of people living with muscle wasting and weakening conditions.
- Map and understand the provision of specialist neuromuscular services across the UK, seek to protect the provision of specialist NHS neuromuscular services and secure additional NHS resource, recognise and disseminate best practice and support neuromuscular services to navigate ongoing healthcare commissioning and delivery reforms
- Help to facilitate access to treatments for muscle wasting and weakening conditions.
- Deliver at least £6m gross fundraising budget.
- Deliver £10m charitable expenditure budget investing our reserves to cover the deficit.
- Invest in a new legacy proposition to maximise the potential of this long-term income stream.
- Invest in a portfolio review of our events and campaigns, which will inform our strategic direction from 2025/26 onwards.
- Launch our new website providing a better user experience and improved navigation.
- Deliver a successful garden at the RHS Chelsea Flower Show 2024, maximising opportunities to reach new people and raise awareness of muscle wasting and weakening conditions.
- Launch a brand campaign to reach people affected by the conditions who aren't currently engaging with the charity.
- Award a grant as part of our partnership with the LifeArc Translational Rare Disease Centre.
- Launch a new call for £1m strategic programmes grants.
- Invest over £500k into the 2024 new research grants programme.
- Continue to engage in a range of research partnerships, including the MAGIC consortium and the LifeArc programmes.
- Award grants as part of our three-year programme to drive innovative research into enhancing the quality of life for people living with muscle wasting and weakening conditions.
- Relaunch our partnership with the Medical Research Council to support clinical fellowships.



Photographer: Kavi Shah

Thank you

Our President
- Gabby Logan MBE

Honorary Life Presidents
- Sue Barker CBE
- Professor Martin Bobrow CBE FRS FMedSci

Our Patrons
- Professor Alan E.H. Emery
- Ian Corner
- Bill Ronald
- Keith Rushton
- Michael Attenborough CBE
- Karen Lewis Attenborough

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

Vice Presidents
- Anil Ahir
- Sophia Bergqvist
- Frances Carey
- Jeremy Champion
- Candida Crewe
- Charity Crewe
- Sebastian Crewe
- Victoria Elliston
- Sir Alex Ferguson CBE
- Andrew Graham
- Bernie Henderson
- Louisa Hill
- Tim Lumsdon
- Simon Knights
- Charles G Manby MBE
- Nicola Manby
- Andy Martin
- Ian Mathieson
- Ann McNeil
- Jeremy D Pelczer
- Julian Pritchard
- Michael A Thirkettle
- Baroness Celia Thomas of Winchester MBE
- Robert Warner
- Alex Wellesley Wesley
- Sir Guy Weston

Our Trustees
- Professor Michael Hanna FMedSci, Chair
- Marcus Brown, Treasurer (until October 2023)
- Ian Gordon, Senior Independent Trustee
- Brigid Sutcliffe
- Charles Scott
- Tanvi Vyas (until October 2023)
- Martin Cardoe
- Joe Gordon, Treasurer (from October 2023)
- Clare O'Hanlon MBE
- Michael Armstrong (until October 2023)
- Michelle Anthony
- Scott Keown (until October 2024)
- Deidre Kelly CBE
- Lord Sharkey
- James Lee (from October 2023)

Senior Leadership Team
- Catherine Woodhead, Chief Executive (until June 2024)
- Wojtek B Trzcinski, Chief Operating Officer / Interim Chief Executive (June 2024-November 2024)
- Dr Kate Adcock, Director of Research and Innovation
- Rob Burley, Director of Care, Communications and Support
- Emma Jones-Parry, Director of Development
- Leanne Thorndyke, Director of Marketing

Key Donors
- Frances Carey
- John Watson & Janis Higgie
- Jeremy and Mary Champion
- Charles and Nicky Manby
- Peter and Frances Meyer
- Mayo Marriott
- Team Jed
- The McAlister Family
- Tony and Monica Moorwood
- Bill and Jacky Ronald
- Charles and Donna Scott
- Sally Whittet and Professor Michael Joy OBE
- The Q Trust
- MAP Nemaline
- Mr & Mrs Graham Williams

Corporate Support
- AirNow Technology
- Bidwells
- BGC Charity Day
- BMW North Oxford
- CeX
- Chimera
- Crocus
- DC Merrett
- Diligencia Group
- Forex Clear
- Mail Metro Media
- Marchmont Investment Management
- Nurture Landscapes
- Orbis
- Premier Paper Group Ltd
- Project Giving Back
- Property Week
- Rosethorn Capital Partners
- Siren
- Tennants Consolidated
- Ula Maria Studio

Trusts and Foundations
- Garfield Weston Foundation
- Hugh Fraser Foundation
- Sir Samuel Scott of Yews Trust
- The Albert Gubay Charitable Foundation
- The Annandale Charitable Trust
- The Christos Lazari Charitable Foundation
- The Cranbury Foundation
- The Frances and Augustus Newman Foundation
- The RS Macdonald Charitable Trust
- The True Colours Trust (supporting Changing Places Toilets)
- The Elizabeth Hardie Ferguson Charitable Trust Fund
- The Edinburgh Trust

Golf Day Committee
- Stephen Rigby

Clay Pigeon Shoot Committee
- John Eaglesham
- Nick Moldon
- Simon Tann

Sports Quiz Committee
- Martin Cardoe
- Rich Cumbers
- Rob Driver
- Lou Hill
- James Pearson
- Ravi Seesurrun
- Vanessa van Blerk

Microscope Ball Committee
- Michelle Anthony, Chair
- David Allen
- Matt Allen
- Jack Beeby
- Guy Bowring
- Lucy Burns
- Adam Cradick
- Rhys Davies
- Fraser Draycott
- Abigail Francis
- Harry Foster
- Charles Howard
- Louise Ioannou
- Scott Keown
- Lizzie Knights
- Jonny Lee
- Tim Lumsdon
- Ben Miller
- Nick Moldon
- Matt Nimmo
- Rich Oliver
- Stephen Rigby
- Simon Tann
- Mark Tatam
- Trish Watson
- Andrew Wedderspoon

The Q Trust Committee
- Sophia Bergqvist
- Candida Crewe
- Charity Crewe
- Victoria Elliston
- Inez Gordon
- Rebecca Jennings
- Nicky Manby
- Alex Wellesley Wesley

Joseph Patrick Trust Grants Panel
- Robert Warner, Chair
- Karen Duckmanton
- Jane Field
- Jane Freebody
- James Lee
- Patricia Lock
- Julian Pritchard
- Kirsty Read

The Welfare Fund of Muscular Dystrophy UK
- Robert Warner, Chair
- Jo Becker
- Karen Duckmanton
- Jane Field
- Jane Freebody
- James Lee
- Patricia Lock
- Julian Pritchard, Vice Chair
- Kirsty Read

Finance Committee
- Marcus Brown, Chair (until October 2023)
- Helene Crutzen
- Ian Mathieson (until March 2023)
- Charles Scott
- Joseph Gordon, Chair (from October 2023)
- Brigid Sutcliffe, Vice Chair (from October 2023)
- Michael Armstrong (resigned October 2023)
- Scott Keown James Lee (joined October 2023)

Appointments and Remuneration Committee
- Professor Mike Hanna, Chair
- Ian Gordon
- Charles Scott
- Brigid Sutcliffe
- Lord Sharkey

Medical Research Committee

- Professor Patrick Chinnery FRCP FMedSci PhD, Chair (until October 2023)
- Dr Gillian Butler-Browne PhD, Vice Chair (until October 2023), Chair (from October 2023)
- Professor Tracey Willis MB CHB MD, Vice Chair (from October 2023)
- Dr Heidi Fuller PhD
- Professor Grainne Gorman MRCP, PhD
- Dr Meredith James PhD
- Dr Jasper Morrow MBChB PhD FRACP (until July 2023)
- Professor Ketan Patel PhD
- Professor Linda Popplewell PhD
- Professor Olivier Pourquie PhD
- Professor Frédéric Relaix PhD
- Professor Laurent Servais MD PhD

Lay Research Panel

- Peter Ashley, Chair (from November 2023)
- Richard Davenport, Vice Chair (until November 2023)
- Alison Kay, Vice Chair (from November 2023)
- Graham Cloke (from December 2023)
- Tammerin du Preez
- Graham Gornall
- Alexa Gummow
- Victoria Houghton
- Corinthia Joseph
- Modupe Joshua
- Hannah Langford
- William Love
- Andy Rose
- Amber Tirimanna
- David Towler
- Roli Roberts (Scientific Advisor)

Services Development Committee

- Professor Deirdre Kelly, Chair
- Dr Chiara Marini-Bettolo
- Dr Jatin Pattni
- Sheila Hawkins
- Lloyd Tingley
- Professor Francesco Muntoni
- Professor Ros Quinlivan
- Carolyn Young
- Tanvi Vyas

Northern Ireland Council

- Claire O'Hanlon, Chair
- Claire Boylan, Secretary

Scottish Council

- Dr Sheonad Macfarlane BSc Med Sci, MB ChB, Chair
- Lindsey Armstrong
- David Gale
- Catherine Gillies
- Allyson Townhill
- Jon Watkins
- Jodie Murphy
- Joe Moan
- Gerry McMenemy
- Elizabeth McHugh
- Fiona Neale

Photographer: Rebekah Kennington

Our policies

Fundraising statement

Our supporters are key to changing the future of muscle wasting and weakening 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 our 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 11 complaints in total in 2023/24. These are included in the following: 0 from 34,222 mailings about our raffles to both warm and cold supporters; 0 complaints from 1,559 guests at our series of special events; 0 complaints from 398 participants at our National Third Party Challenge Events; 9 complaints from 7,671 participants at our own running events (Town & Gown and Pedal, Paddle, Peak), 0 from 403 volunteer fundraising events; 0 from 46,424 pieces of direct mail sent out; 1 complaint from 8,867 pieces of mail sent out about Gifts in Wills; 1 complaint about changes to financial processes in fundraising groups. We have worked together with the individuals who made the last two complaints mentioned to ensure we will learn from our mistakes for the future.

Financial review and policies

Our total income for 2023/24 was £9,508k (2023: £8,221k). The 16% increase in total income this year is a result of rises across the active fundraising income, other income and investment income. Active fundraising income from donations, gifts, grants, and other fundraising activities increased by 37%. The majority of that increase (over £500k) related to the funding received for the RHS Chelsea Flower Show as restricted funds, fully utilised in 2024/25. Legacies income for 2023/24 remained stable at £2,920k (2022: £2,944k), this includes £1.7m legacies accrual based on our best estimates. Investment income was £340k (2023: £169k).

Total other income, including investment and trading, amounted to £1,270k (2023: £863k). The total of £1,228k (2023: £941k) was received in government grants. These included:£382k (2023:£274k) from UK Government Covid Medical Research Charity Support Fund, £740k (2023: £450k) from the Department of Transport and £106k (2023: £217k) from the Department for Leveling Up, Housing and Communities (see Note 2).

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 £600k (13%) from that of the previous year to £5,446k (2023: £4,826k). This increase was reflected across all charitable activities.

Medical research comprised 40% (2023: 41%) of the total charitable expenditure. Access to specialist NHS care and support comprised 23% (2023: 23%), and provision of information, support and opportunities to enable independent living comprised 37% (2023: 36%) of our charitable costs.

The charity ended 2023/24 with a surplus of £1,908k (2023: £1,084k), including £442k net gains (2023: £281k net loss) on investment assets. The surplus included £1.7m 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, assessing 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 to maintain free reserves between £1.65m to £2.2m, based on the current analysis of risk. This has been reviewed in line with 2024/25 budget and the reserves requirement was not increased in the 2023/24.

The free reserves funds balance at 31 March 2024 was £5.7m. It continues to be higher than the target level agreed by the Trustees, partly as a result of high legacy income recognised at the year end. Due to legacy income recognition accounting requirements, we often recognise the income before the actual cash is received. Our legacy accrual (income recognised but not yet received) was £1.7m at 31 March 2024. The timing differences between recognition and receipt of the legacy income creates a challenge for the charity in planning for expending these funds, as we cannot commit them to projects until the funds clear. The legacy accrual represents 50% of the reserves surplus of £3.5m.

In the next two years it is intended that the surplus reserves will be used to accelerate our charitable work in support of those with neuromuscular conditions, by funding a planned two years of deficit budgets, which will enable the charity to increase its investment in research and in development of its charitable activities. It will also allow us to enter the next strategic planning cycle with funds freely available to support our planning for the new strategy which will start early in the 2025/26 financial year, as the current strategy takes us to the end of the 2025 calendar year.

In line with our planning to reduce the surplus on reserves, disclosed in last year's Impact Report, we have made the following commitments totalling £2.5m:

- We have designated £2.15m for two strategic research grants, and we have announced research grant calls for funding starting early in the 2024/25 financial year.
- We have designated £170k to invest in our fundraising, to ensure we have a sustainable and diverse income portfolio and to increase our resilience to changes in external economic factors.

- We have designated £150k towards our data and impact analysis, to ensure our decision making is more data based to respond better to our community's needs.

The remaining designated funds balance represents the residual balance on the IT investment fund, to support some improvements to the information services and the CRM system.

Having reviewed the strategic risks facing the charity and the 2024/25 budget projections, the Board of Trustees considers there are sufficient reserves held on 31 March 2024 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 2023. 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 and the investment managers' performance are reviewed by the Finance Committee on an annual basis.

Ethical considerations

The Charity does not invest directly in tobacco, armaments, high interest rate lending, gambling, adult entertainment, thermal coal and tar sands (defined by companies which derive >10% of their revenue from these).

In 2023/24, Trustees have reviewed the approach of the fund manager towards avoiding offenders in greenhouse gas emissions. It is felt 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 2023/24, 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.

Renumeration 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 vacancies 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 are paid any remuneration or receive other benefits from their charity work. 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, and 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 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 last conducted in 2022/23 with support of an external expert and training provided to Trustees and SLT. The following risks have been identified in 2023/24 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. This includes plans for spending any surplus unrestricted reserves, implemented in 2023/24 with a two to three year ambition to reduce reserves closer to the agreed minimum levels though investments in charitable activities. This has been reflected in the 2024/25 budget and the decision to designate some funds in the 2023/24 financial year.

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. 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 provider to ensure we follow best industry practices to protect the charity from cyber-security threats, including staff training and 24-hour network monitoring services.

e. Providing information that meets our users' needs is essential for their continued support – the charity will continue to review all communications, publications, and the website to ensure they meet our audiences' needs. We continue to diversify our communication channels to ensure we increase our outreach outside our community of over 110,000 people living with a muscle wasting and weakening condition. As a result of this we launched our new refreshed brand in June 2023 and new website in May 2024.

f. Staff recruitment and talent retention continues to pose a 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 have offered staff flexible and agile working conditions that caters for all.

Our prudent approach to risk management proved effective during the Covid-19 pandemic and in 2022/23 during the cost-of-living crisis, the biggest threats to the sector in recent years. We continue to regularly review our approach to risk to ensure it is well balanced and the interests of the Charity are protected.

Grant-making policies

We provide 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 objectives are being met.

We also makes grants for equipment though the Joseph Patrick Trust (JPT) subsidiary. The JPT committee considers applications against approved criteria before approving grants. In 2022/23 the cost-of-living crisis was a key concern for our community; the JPT Committee agreed to offer a one-off cost-of-living grant to people living with muscular dystrophy and associated conditions we support. These grants were approved in March 2023 and 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 subsidiarity, 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 38 to 40.

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 Trust.

Appointment of Trustees

Muscular Dystrophy UK has between seven and 17 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). During the year, three Trustees stepped down completing their terms, one Trustee was re-elected for a second term and three new Trustees were elected. Their appointment was subject to a rigorous review by the Appointment and Remuneration Committee and Board of Trustees, bearing in mind the need for progressive refreshing of the Board's skills and experience. All appointments and resignations were approved by the Company Members with a majority vote at the AGM in October 2023. Two Trustees who have served more than nine years (Professor Hanna, Chair and Ian Gordon, Senior Independent Trustee) were re-elected for a further term in October 2023, within the requirements of the Memorandum and Articles of Association. This decision was approved by more than 70% of all Trustees and supported by Company Members majority at the AGM in 2022. It was considered important to provide strategic leadership continuity following the turbulent years of the Covid pandemic and the cost-of-living crisis. As such, the decision to re-appoint these two Trustees was taken in the best interest of the Charity.

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

In January 2024, we wrote to 265 charity members to ask for their confirmation as charity members, appreciating the breadth of ways people can engage with the charity and their changing needs. We now have a body of 87 charity members, who carefully monitor the charity's progress. The charity members are volunteers drawn from the various stakeholder groups 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 our work. 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 and weakening 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 we should apply these principles and practices during updates in the Board meetings, CEO reports and at the annual Board Away Day. In 2024/25 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 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 our welfare arm, which is its sole corporate Trustee. Constituted on 30 April 1986, with the support of the Patrick family, it provides direct financial assistance in the form of welfare grants to individuals and families living with muscle wasting and weakening conditions, throughout the UK. The consolidated financial statements also include the trading subsidiary, Muscular Dystrophy Group (Trading) Limited (Reg. 893086). We maintain extremely close working relationships with partner charities that also assist those living with muscle wasting conditions.

Statement of Trustees' responsibilities

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

In preparing these financial statements, the directors are required to:

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

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

Provision of information to auditors

So far as each of the directors is aware at the time the report is approved, there is no relevant audit information of which the company's auditors are unaware; and the directors have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information. This report, incorporating the Strategic Report, is approved by the Board and signed on its behalf by:



Professor Michael Hanna
Chair, 17 October 2024

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 2024 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 2024 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

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 2024

	Notes	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2024 £000	Unrestricted Funds £000	Restricted and Endowment Funds £000	Total 2023 £000
Income							
Income from charitable activities							
Donations, gifts and grants	2	3,340	1,131	4,471	2,971	296	3,267
Government grants	2	-	847	847	-	941	941
Legacies	2	2,219	701	2,920	2,949	(5)	2,944
Income from other trading activities	11	67	-	67	206	-	206
Investment income	2, 10	340	-	340	169	-	169
Other income	2	5	858	863	19	675	694
Total income		**5,971**	**3,537**	**9,508**	**6,314**	**1,907**	**8,221**
Expenditure							
Expenditure on raising funds	3	2,135	347	2,482	1,921	13	1,934
Costs from other trading activities	3	114	-	114	96	-	96
		2,249	**347**	**2,596**	**2,017**	**13**	**2,030**
Charitable activities							
Medical research	3, 5	523	1,653	2,176	999	998	1,997
Access to specialist care and support	3	1,180	53	1,233	901	209	1,110
Independent living	3	813	1,224	2,037	565	1,154	1,719
Total – charitable activities		**2,516**	**2,930**	**5,446**	**2,465**	**2,361**	**4,826**
Total expenditure		**4,765**	**3,277**	**8,042**	**4,482**	**2,374**	**6,856**
Net gain/(loss) on investment assets	9	410	32	442	(262)	(19)	(281)
Net movement in funds		**1,616**	**292**	**1,908**	**1,570**	**(486)**	**1,084**
Reconciliation of funds							
Total funds brought forward	15	6,948	4,965	11,913	5,378	5,451	10,829
Total funds carried forward	15	8,564	5,257	13,821	6,948	4,965	11,913

There are no recognised gains or losses other than those disclosed above. All results are derived from continuing activities.
The accompanying notes on pages 56 to 67 form an integral part of the financial statements.

Balance Sheets

As at 31 March 2024
Company Registration Number: 205395

	Notes	Group 2024 £000	Group 2023 £000	Charity 2024 £000	Charity 2023 £000
Fixed Assets					
Tangible Assets	8	370	401	370	401
Investments	9	6,013	5,399	5,767	5,168
Total Fixed Assets		**6,383**	**5,800**	**6,137**	**5,569**
Current Assets					
Stock	12	14	16	-	-
Debtors	13	2,458	1,498	2,517	1,620
Short term investments		1,000	-	1,000	-
Cash at Bank		7,608	8,641	7,494	8,296
Total Current Assets		**11,080**	**10,155**	**11,011**	**9,916**
Creditors falling due within one year	14	(3,642)	(4,042)	(3,417)	(3,796)
Net Current Assets		7,438	6,113	7,594	6,120
Total Assets less current liabilities		**13,821**	**11,913**	**13,731**	**11,689**
Net Assets		**13,821**	**11,913**	**13,731**	**11,689**
The funds of the Charity					
Unrestricted					
- Designated	15	2,876	437	2,876	437
- General	15	5,688	6,511	5,598	6,336
		8,564	6,948	8,474	6,773
Restricted	15	4,838	4,578	4,838	4,529
Endowment	15	419	387	419	387
Total Charity Funds		**13,821**	**11,913**	**13,731**	**11,689**

The Statement of Financial Activities for the year ended 31 March 2024 for the parent charitable company only was a surplus of £2,041K (2023: £996K).

Approved and authorised for issue by the Board of Trustees on 17 October 2024 and signed on its behalf by:

Professor Michael Hanna
Chairman

Joseph Gordon
Treasurer

The accompanying notes on pages 56 to 67 form an integral part of the financial statements.

Statement of Group Cashflows

Year Ended 31 March 2024

	2024 £000	2023 £000
Net cash inflow/(outflow) from operating activities (note a)	**(182)**	**1,069**
Net Cash flow from investing activities	-	-
Dividends from investments	407	159
Purchase of Tangible Fixed Assets	(86)	(196)
Proceeds of sale of Investments	976	3,006
Purchase of Investment	(2,148)	(2,904)
Net Cash provided by investing activities	**(851)**	**65**
Increase/(decrease) in cash and cash equivalents in the year	**(1,033)**	**1,134**
Reconciliation of net cash inflow to movement in net funds		
Increase/(decrease) in cash and cash equivalents in the year (note b)	(1,033)	1,134
Cash and cash equivalents at the beginning of the year	8,641	7,507
Cash and cash equivalents at the end of the year	**7,608**	**8,641**

Notes to cash flow statement

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

Net movement in funds	1,908	1,084
Dividends from investments	(407)	(159)
Investment (gains) / losses	(442)	281
Depreciation	117	117
Decrease / (Increase) in debtors / stock	958	(620)
Increase / (Decrease) in all creditors	(400)	366
Net cash provided by/(used in) operating activities	**182**	**1,069**

	01-Apr-23 £000	Cashflows £000	31-Mar-24 £000
(b) Analysis of changes in net cash funds:			
Cash and cash equivalents	8,641	(1,035)	7,608
Total cash and cash equivalents	**8,641**	**(1,035)**	**7,608**

The accompanying notes on pages 56 to 67 form an integral part of the financial statements.

Notes to the financial statements

For the year ended 31 March 2024

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 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:

i. Entitlement – when Muscular Dystrophy UK has control over the rights to the resource, enabling it to receive the economic benefit.

ii. Probability – when it is probable, more likely than not that the economic benefit will be received.

iii. Measurement – when the monetary value can be measured with sufficient reliability.

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

Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably through estate accounts (or cash receipt) and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is not recognised in the accounts.

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 2023/24 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 and weakening 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 11 of the Corporation Tax Act 2010 or section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains

1. Accounting policies (Cont.)

are applied exclusively to charitable purposes. No tax charge arose in the period.

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

Listed investments

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

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

Unlisted investments

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

Financial instruments

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

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 2024

2. Income

	Unrestricted Funds £000	Restricted Funds £000	Total 2024 £000	Unrestricted Funds £000	Restricted Funds £000	Total 2023 £000
Events and promotions	1,582	144	1,726	1,304	90	1,394
Direct marketing	810	14	824	756	14	770
Major Donors and Corporate	414	692	1,106	412	362	774
Trusts	50	844	894	116	591	707
Regional development	484	284	768	589	180	769
Legacy	2,219	701	2,920	2,949	(5)	2,944
Other income	412	858	1,270	188	675	863
Total income*	**5,971**	**3,537**	**9,508**	**6,314**	**1,907**	**8,221**

** Of this income £1,228k comes from Government Grants (2023: £941k). The government grants included £382k (2023: £274k) from UK Government Covid Medical Research Charity Support Fund included in Trust income above, and £740K (2023: £450k) from the Department of Transport and £106k (2023: £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 2024 £000
Raising Funds				
Expenditure on raising funds	-	2,329	153	2,482
Costs from other Trading Activities	-	109	5	114
Total	**-**	**2,438**	**158**	**2,596**
Charitable Expenditure				
Access to care and independent living				
Access to care	-	1,085	148	1,233
Independent living	1,018	774	245	2,037
Total	**1,018**	**1,859**	**393**	**3,270**
Pursuit of Knowledge				
Medical research	1,578	337	261	2,176
Total Charitable Expenditure	**2,596**	**2,196**	**654**	**5,446**
Total Expenditure	**2,596**	**4,634**	**812**	**8,042**

3. Expenditure (Cont.)

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

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

'Support Costs' comprise of the following:

	2024 £000	2023 £000
Chief Executive and Human Resources	134	150
Finance and insurance	263	243
Office costs	220	377
Information Technology	160	156
Governance	36	29
Total	**813**	**955**

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 departamental running costs.
- 'Governance' includes the annual audit fee and Trustees expenses.

4. Staff costs (Group and Parent Charity)

	2024 £000	2023 £000
Remuneration of Staff		
Wages and Salaries	2,386	2,205
Social Security Costs	239	206
Pensions	127	122
Total	**2,752**	**2,533**

No redundancies were made in the year (2023: 1). The cost of the redundancy payments was nil (2023: £8k).
The monthly average number of employees during the period was 70 (2023: 65), 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 38.
Their total aggregate employment benefits were £469k (2023: £444k).

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

	2024 No.	2023 No.
Earned between the ranges		
£60,000 to £70,000	1	1
£70,001 to £80,000	1	1
£80,001 to £90,000	1	1
£110,001 to £120,000	1	1
Number of staff by activity		
Direct Charitable Expenditure	25	24
Fundraising and Publicity	38	35
Management and Administration	7	6
Total	**70**	**65**

Pension Schemes
There were no outstanding contributions (2023: £0) at the Balance Sheet date.

5. Grant expenditure

	Research Grants *£000*	Welfare Grants *£000*	Total 2024 *£000*	Total 2023 *£000*
Grants awarded in the year	1,785	1,089	2,874	1,957
Grants cancelled in the year	(208)	(71)	(279)	(33)
Total	**1,577**	**1,018**	**2,595**	**1,924**

2023 Comparatives	Research Grants *£000*	Welfare Grants *£000*	Total 2023 *£000*
Grants awarded in the year	1,315	642	1,957
Grants cancelled in the year	(21)	(12)	(33)
Total	**1,294**	**630**	**1,924**

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) totaling £330k and one grant of £97k to University of Oxford (Nemaline myopathy natural history study), there were no institutions in receipt of material research grants (over £80k pa) in 2023/24.

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:

	2024 *£000*	2023 *£000*
Payable between one and five years	1,954	3,003

5. Grant expenditure (Cont.)

Reconciliation of grant funding commitments:

	2024 *£000*	2023 *£000*
Carrying amount at start of year	3,003	2,888
Additions	2,874	1,345
Amounts charged and cancelled in year	(2,764)	(1,230)
Carrying amount at end of year	**3,113**	**3,003**

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.

	2024 *£000*	2023 *£000*
Expiring up to one year	90	72
Expiring between one and five years	522	486
Expiring after more than five years	540	618

7. Net income

Net Income is stated after charging

	2024 *£000*	2023 *£000*
Auditor's remuneration	32	29
Auditor's remuneration - non audit services	4	5
Depreciation	117	117
Operating lease rentals	129	273

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 2023	309	437	16	15	28	805
Additions	17	66	-	-	3	86
Disposals	(200)	(3)	-	-	-	(203)
At 31 Mar 2024	**126**	**500**	**16**	**15**	**31**	**688**
Depreciation 1 Apr 2023	200	188	16	-	-	404
Disposal	(200)	(3)	-	-	-	(203)
Provided for year	11	97	-	-	9	117
At 31 Mar 2024	**11**	**282**	**16**	**-**	**9**	**318**
Net Book Value						
At 31 Mar 2024	**115**	**218**	**-**	**15**	**22**	**370**
At 31 Mar 2024	109	249	-	15	28	401

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 2023	309	434	16	15	28	802
Additions	17	66	-	-	3	86
Disposal	(200)	(3)	-	-	-	(203)
At 31 Mar 2024	**126**	**497**	**16**	**15**	**31**	**685**
Depreciation 1 Apr 2023	200	185	16	-	-	401
Disposal	(200)	(3)	-	-	-	(203)
Provided for year	11	97	-	-	9	117
At 31 Mar 2024	**11**	**279**	**16**	**-**	**9**	**315**
Net Book Value						
At 31 Mar 2024	**115**	**218**	**-**	**15**	**22**	**370**
At 31 Mar 2023	109	249	-	15	28	401

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 2024 £000	Group 2023 £000	Charity 2024 £000	Charity 2023 £000
Market Value at beginning of year	5,399	5,781	5,169	5,387
Acquisitions	1,148	2,904	1,070	2,871
Sales proceeds	(976)	(3,006)	(896)	(2,821)
Total	**5,571**	**5,679**	**5,343**	**5,437**
Gain/(loss) on investment	442	(280)	424	(268)
Market value at end of year	**6,013**	**5,399**	**5,767**	**5,169**
Historical Cost at end of year	**5,409**	**5,186**	**5,165**	**4,992**

Spread of Investments

The investments of Muscular Dystrophy UK are held as follows:

	Group 2024 £000	Group 2023 £000	Charity 2024 £000	Charity 2023 £000
Investments listed on a recognised Stock Exchange and Unit Trusts				
UK and Overseas equities	4,665	3,978	4,477	3,809
UK and Overseas fixed interest	757	678	725	646
Property funds	219	233	210	223
Hedge funds	310	415	293	398
Total	**5,951**	**5,304**	**5,705**	**5,076**
Cash on Deposit awaiting investment		33		30
Unlisted equities	62	62	62	62
Total	**6,013**	**5,399**	**5,767**	**5,168**

Investment management costs for the year were £27k (2023: £26k).

There was no individual investment that constituted more than five percent of the total investment portfolio (at market value) as at the year end. (2023: £nil)

10. Income from investments

	Group 2024 £000	Group 2023 £000	Charity 2024 £000	Charity 2023 £000
UK Equities, UK fixed interest and other	113	81	112	85
Short term Deposit and Bank interest	294	78	286	79
Total	**407**	**159**	**398**	**164**

11. Investments in subsidiary undertakings

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

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

Their net assets and results for the year ended 31 March 2024 are summarised below:

	Muscular Dystrophy Group (Trading) Ltd £000	Joseph Patrick Trust £000
Fixed Assets	-	247
Current Assets	97	68
Current Liabilities	(141)	(181)
Total Net Assets	**(44)**	**134**
Represented by:		
Total Funds	**(44)**	**134**
Total income	67	11
Total expenditure*	(114)	(116)
Investment gains/losses and other B/S movements	-	18
Surplus for the year	**(47)**	**(87)**
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 £14k (2023: £16k).

13. Debtors

	Group 2024 £000	Group 2023 £000	Charity 2024 £000	Charity 2023 £000
Trade debtors	32	-	-	-
Amount due from subsidiary undertakings	(1)	-	97	21
Prepayments and accrued income	2,425	1,491	2,418	1,598
Other debtors	2	7	2	1
Total	**2,458**	**1,498**	**2,517**	**1,620**

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 2024 £000	Group 2023 £000	Charity 2024 £000	Charity 2023 £000
Accruals for grant commitments	3,113	3,003	2,939	2,789
Accruals and Deferred Income	350	573	344	568
Taxation and Social Security	6	58	-	54
Other Creditors	173	408	134	385
Total	**3,642**	**4,042**	**3,417**	**3,796**

15. Funds

	April 2023 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2024 £000
Endowment Fund						
Orchid Ball	387	-	-	-	32	419
Restricted Funds						
Provision of care						
City Bridge Trust / Work experience	4		(4)			-
Scotland	-	634	(31)	-	-	603
Psychological support	29	-	(20)	-	-	9
Volunteering	-	21	(21)	-	-	-
Joseph Patrick Trust - Assistive Technology	49		(6)	-	-	43
Changing Places	2,211	868	(1,194)	-	-	1,885
The Garfield Weston CCS Fund	117	-	(117)	-	-	-
SMA Sreening	-	95	(69)	-	-	26
Chelsea Flower Show	-	605	(321)	-	-	284
Other care	2	17	(16)	-	-	3
Research						
The Patrick Research Fund	100	-	-	-	-	100
Congenital LMNA MD	59	33	2	-	-	94
Q Trust	21	85	(9)	-	-	97
FSHD Research	77	35	(16)	-	-	96
Duchenne Research	167	240	(287)	-	-	120
Ullrich Research	116	63	(38)	-	-	141
Nemaline Research	371	8	(97)	-	-	282
Congenital MD	465	1	(182)	-	-	284
Becker Research Fund	150	6	(82)	-	-	74
SMA Research	14	23	(30)	-	-	7
Limb Girdle research	47	118	-	-	-	165
Other research	579	685	(739)			525
Total Restricted Funds	**4,578**	**3,537**	**(3,277)**	**-**	**-**	**4,838**

15. Funds (Cont.)

	April 2023 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2024 £000
Designated Funds						
IT Investment Fund	36	-	-	-	-	36
Research	-	-	-	2,150	-	2,150
Fundraising	-	-	-	170	-	170
Data Team	-	-	-	150	-	150
Tangible Assets for Charity Use	401	86	(117)	-	-	370
Total Designated Funds	**437**	**86**	**(117)**	**2,470**	**-**	**2,876**
General Fund	6,511	5,885	(4,648)	(2,470)	410	5,688
Total Unrestricted Funds	**6,948**	**5,971**	**4,765**	**-**	**410**	**8,564**
Total Funds	**11,913**	**9,508**	**8,042**	**-**	**442**	**13,821**

2023 Comparatives	April 2022 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2023 £000
Endowment Fund						
Orchid Ball	406	-	-	-	(19)	387
Restricted Funds						
Provision of care						
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 - Assistive Technology	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
Research						
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
Total Restricted Funds	**5,451**	**1,907**	**(2,374)**	**-**	**(19)**	**4,965**

15. Funds (Cont.)

2023 Comparatives	April 2022 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2023 £000
Designated Funds						
IT Investment Fund	96	-	-	(60)	-	36
Tangible Assets for Charity Use	323	136	(118)	60	-	401
Total Designated Funds	**419**	**136**	**(118)**	**-**	**-**	**437**
General Fund	4,959	6,179	(4,355)	-	(262)	6,521
Total Unrestricted Funds	**5,378**	**6,314**	**(4,482)**	**-**	**(262)**	**6,958**
Total Funds	**10,829**	**8,221**	**(6,856)**	**-**	**(281)**	**11,923**

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. This programme terminated in 2023/24.

Scotland - this is used for activities in Scotland across support, policy and research.

Psychological Support - This is used to support our Mental Health Matters work, identifying how Muscular Dystrophy UK can best improve the mental health and wellbeing support available for people affected by muscle wasting and weakening 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 with remaining balance disclosed as unrestricted JPT funds.

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.

SMA Screening – this funds support MDUK involvement in the UK SMA Newborn Screening Alliance, which is working to introduce newborn screening for spinal muscular atrophy (SMA) in the UK.

Chelsea Flower Show – this funds represent restricted income received from the Project Giving Back (PGB) to cover the costs of MDUK garden in May 2024 Chelsea Flower Show. The costs of the garden have been fully covered by this specific grant. PGB gives charitable organisations in the UK the chance to exhibit with a show garden at the RHS Chelsea Flower Show, to promote their causes.

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

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 (final stage expected to be completed in 2024/25).
- Strategic research fund to support two key multiyear projects (Life Arc and a new strategic research call for a multiyear project of approximately £1m) (£2.15m).
- Fundraising (£170k) and the Data Team (£150k) funds to review our fundraising portfolio with a view to improve efficiency and products offered and enable to Data team to improve our impact reporting and data-driven decision making.

Represented by: 2024	Fixed Assets £000	Investments £000	Net Current Assets £000	Total £000
Endowment Funds	-	419	-	419
Restricted Funds	-	-	4,838	4,838
Designated Funds	406	-	2,470	2,876
Unrestricted Funds		6,013	(325)	5,688
Total Funds	**406**	**6,432**	**6,983**	**13,821**

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
Total Funds	**401**	**5,399**	**6,113**	**11,913**

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:

	2024 £000	2023 £000
Residuary	341	694
Reversionary	252	252
All sums are due to Muscular Dystrophy UK.	**593**	**946**

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:

	2024 £000	2023 £000
Donations	5	5
Expenses	5	1

No Trustee received any remuneration during the year (2023: £nil).
There were no other related parties transactions.

MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Registered with FUNDRAISING REGULATOR

OSCR Scottish Charity Regulator www.oscr.org.uk Registered Charity SC039445

Muscular Dystrophy Group of Great Britain and Northern Ireland. Registered charity in England and Wales (205395) and Scotland (SC039445) and a company limited by guarantee without share capital registered with Companies House (705357). Registered office address: 32 Ufford Street, London, England, SE1 8QD

MUSCULAR DYSTROPHY GROUP OF GREAT BRITAIN AND NORTHERN IRELAND

England & Wales - Charity number 205395

Accounts

MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

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.

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.

"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."

Catherine Woodhead
Chief Executive

Professor Michael Hanna
Chair

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

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

Performance Indicator	Our achievements
Provide services and promote opportunities to enable each affected individual to live as independent a life as they wish	**Handled 2,663 requests for support,** a 22% increase on the previous year. **99,103 visits to our website's care and support areas**, a growth of 15 percent on 2021/22. **15,696 people used our online forum** to share experiences and support each other. **169 people supported** through our advocacy service. **24 equipment grants** provided through our JPT programme. **389 bookings,** 196 live attendees and 3,973 online views of our virtual Muscles Matter seminar series. **78 people** attended our two face-to-face information days. Two major resources launched to help people live well with muscle-wasting conditions, accessed 2,615 times. 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. 12 young disabled people supported by our Moving Up programme. **177 Changing Places toilets registered.**
Generate income to continue supporting the community	**£8.2m total income** generated this year, an 11% increase from 2021/22. 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. **£2.9m legacy income**, up from £1.65k in 2021/22.

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

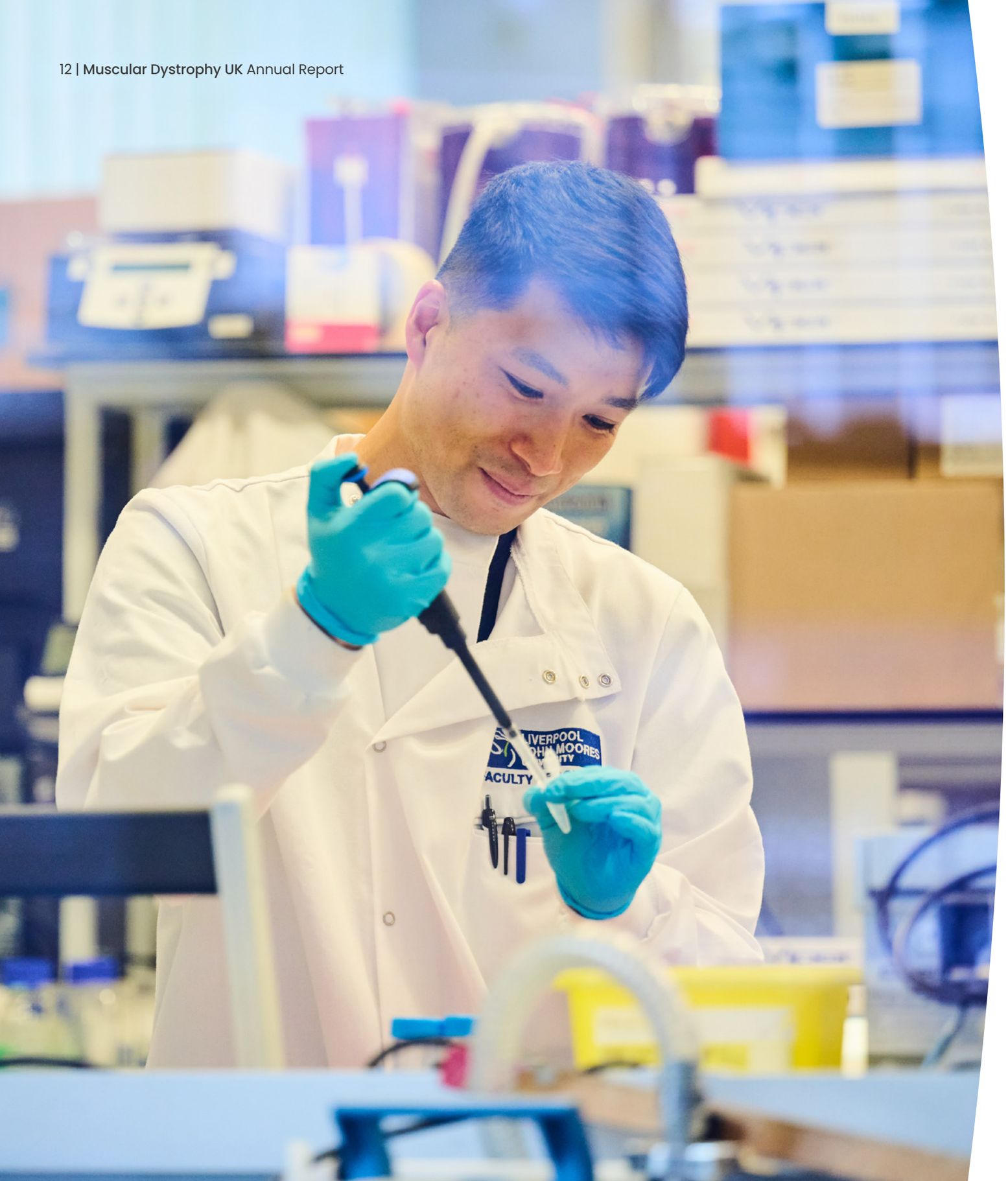
We continue to ensure patients and families can find out about new studies, treatments, and clinical trials for muscle-wasting conditions via email through our Research Line.

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

"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

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 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.

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

UK Prime Minister Rishi Sunak

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:



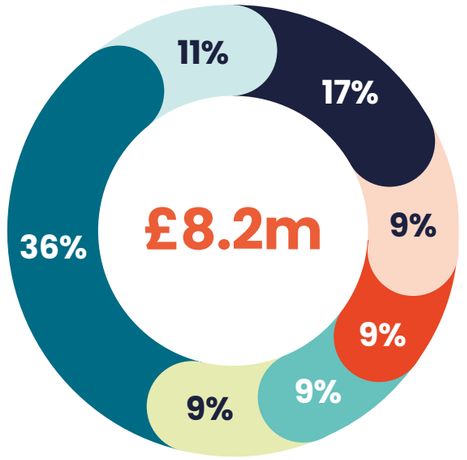
30p Invested in fundraising to ensure we maintain a diverse income portoflio to support our community

70p Charitable activities

For every £1 invested in fundraising we raised £4

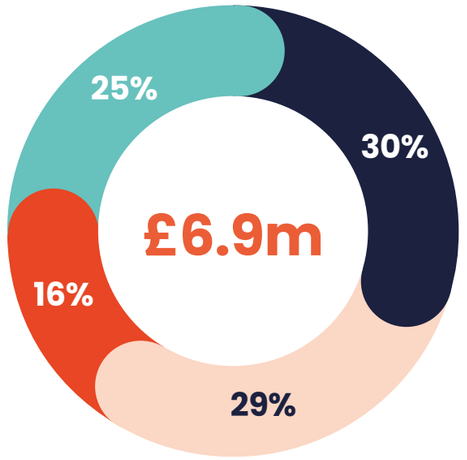


Total income



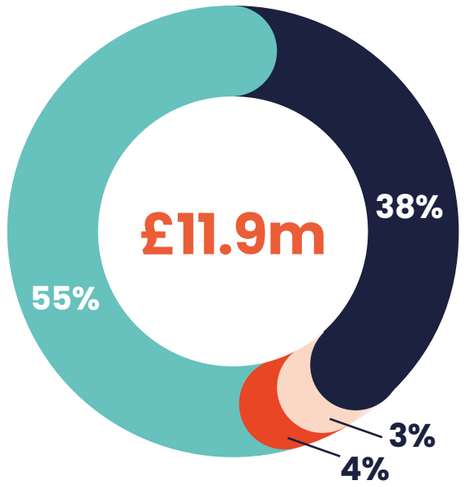
- **Events and promotions** (£1,394k)
- **Direct marketing** (£771k)
- **Major Donors and Corporate** (£773k)
- **Trusts** (£707k)
- **Regional development** (£769k)
- **Legacy** (£2,944k)
- **Other income** (£863k)

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 though 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 iinclusion for the whole community.



Thank yous

Our President
- Gabby Logan MBE

Honorary Life Presidents
- Sue Barker CBE
- Professor Martin Boborw CBE FRS FMedSci

Our Patrons
- Professor Alan E.H. Emery
- Ian Corner
- Bill Ronald
- Keith Rushton
- Michael Attenborough CBE
- Karen Lewis Attenborough

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

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- Alexandra Wellesley Wesley
- Andrew Graham
- Andrew Weir
- Anil Ahir
- Ann McNeil
- Candida Crewe
- Charity Crewe
- Charles G Manby MBE
- Frances Carey
- Sir Guy Weston
- Ian Mathieson
- Jeremy Champion
- Jeremy D Pelczer
- Julian Pritchard
- Louisa Hill
- Matthew Kelly
- Michael Thirkettle
- Nicola Manby
- Sarah E Kelly
- Sebastian Crewe
- Simon Knights
- Sophia Bergqvist
- Victoria Elliston
- Robbie Warner (from October 2022)

Our Trustees
- Professor Michael Hanna FMedSci (Chair)
- Marcus Brown (Treasurer)
- Ian Gordon
- Baroness Celia Thomas of Winchester MBE (until October 2022)
- Brigid Sutcliffe (from October 2022)
- Charles Scott
- Tanvi Vyas
- Martin Cardoe
- Joe Gordon
- Claire O'Hanlon MBE
- Michael Armstrong
- Michelle Anthony
- Scott Keown
- Deidre Kelly CBE
- Lord Sharkey (from March 2023)
- Robert Warner (until October 2022)

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
- Mr & Mrs Graham Williams
- John Watson & Janis Higgie
- Christopher Bruce-Jones
- Jeremy and Mary Champion
- The Duncan Family, Aberdeen
- Charles and Nicky Manby
- Peter and Frances Meyer
- Mayo Marriott
- The McAlister Family
- Tony and Monica Moorwood
- Bill and Jacky Ronald
- Charles and Donna Scott
- Sally Whittet and Professor Michael Joy OBE
- The Q Trust
- MAP Nemaline

Corporate Support
- Bidwells
- BGC Charity Day
- BMW North Oxford
- CeX
- Chimera
- Diligencia Group
- GE Foundation International Grants Fund
- Mail Metro Media
- Marchmont
- Mintel Group
- Tennants Consolidated

Trusts and Foundations
- Clapp Family Charitable Trust
- George & Effie Taylor Charitable Trust
- Garfield Weston Foundation
- Hugh Fraser Foundation
- Sir Samuel Scott of Yews Trust
- The Albert Gubay Charitable Foundation
- The Annandale Charitable Trust
- The Cranbury Foundation
- The Kirby Laing Foundation
- The True Colours Trust

Golf Day Committee
- Stephen Rigby

Clay Pigeon Shoot Committee
- Jon Eaglesham
- Simon Tann
- Nick Moldon

Sports Quiz Committee
- James Pearson
- Louisa Hill
- Martin Cardoe
- Ravi Seesurrun
- Robert Driver
- Rich Cumbers
- Scott Calver
- Vanessa van Blerk

Microscope Ball Committee
- Abigail Francis
- Adam Cradick
- Andrew Wedderspoon
- Charles Howard
- David Allen
- Fraser Draycott
- Guy Bowring
- Harry Foster
- Jack Beeby
- Jonny Lee
- Lizzie Knights
- Louise Ioannou
- Lucy Burns
- Mark Tatam
- Matt Nimmo
- Michelle Anthony (Chair)
- Nick Moldon
- Rhys Davies
- Rich Oliver
- Scott Keown
- Simon Tann
- Stephen Rigby
- Tim Lumsdon
- Trish Watson

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- Charity Crewe
- Candida Crewe
- Emily Reynolds
- Eugenie Teasley
- Inez Gordon
- Nicky Manby
- Rebecca Jennings
- Sophia Bergqvist
- Victoria Elliston

The Young Q Trust Committee
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- Charlie Reynolds
- Emily Reynolds
- Flinty Bane

Joseph Patrick Trust Grants Panel
- Robert Warner (Chair)
- Karen Duckmanton
- Jane Field
- Jane Freebody
- James Lee
- Patricia Lock
- Julian Pritchard
- Kirsty Read

The welfare fund of Muscular Dystrophy UK
- Robert Warner (Chair)
- Jo Becker
- Karen Duckmanton
- Jane Field
- Jane Freebody
- James Lee
- Patricia Lock
- Julian Pritchard (Vice Chair)
- Kirsty Read

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- Ian Gordon (Resigned March 2023)
- Helene Crutzen
- Ian Mathieson
- Charles Scott
- Joseph Gordon
- Brigid Sutcliffe (Joined June 2022)
- Michael Armstrong
- Scott Keown (Joined June 2023)

Appointments and Remuneration Committee
- Professor Mike Hanna (Chair)
- Ian Gordon
- Charles Scott
- Baroness Celia Thomas of Winchester MBE (until October 2022)
- Brigid Sutcliffe
- Lord Sharkey

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- Dr Gillian Butler-Browne PhD (Vice Chair)
- Professor Grainne Gorman MRCP, PhD
- Dr Anna Mayhew PhD
- Dr Jasper Morrow MBChB, PhD, FRACP

- Professor Ketan Patel PhD
- Professor Olivier Pourquie PhD
- Professor Mary Reilly MD, FRCP, FRCPI
- Professor Frédéric Relaix PhD
- Dr Stefan Winblad PhD
- Professor Tracey Willis PhD
- Professor Laurent Servais PhD
- Dr Heidi Fuller PhD
- Professor Linda Popplewell PhD

Lay Research Panel

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- Peter Ashley (Vice-Chair)
- Tammerin du Preez (from December 2022)
- Graham Gornall
- Alexa Gummow
- Victoria Houghton
- Corinthia Joseph
- Modupe Joshua (from December 2022)
- Alison Kay
- Hannah Langford
- William Love (from December 2022)
- Hilary Rattue
- Andy Rose
- Helen Stockdale
- Manoj Thakrar
- David Towler
- Amber Tirimanna (from December 2022)
- Alex Williamson
- Natalie Woodcock (until October 2022)

Services Development Committee

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- Dr Chiara Marini-Bettolo
- Phillippa Farrant
- Sheila Hawkins
- Professor Deirdre Kelly
- Sue Manning
- Professor Francesco Muntoni
- Dr Ros Quinlivan
- Carolyn Young
- Tanvi Vyas

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- Clare Boylan (Secretary)
- Graham Cloke (Treasurer)
- Art Connolly
- Leona Connolly
- Phillip Ellis
- Hayley Ellis
- Suzanne Glover
- Lucy Hare
- Anne Hughes
- Corman McAteer
- Dave McLean
- Jaci McFetridge
- Jim McKeogh
- Kerry McStravog
- Niamh Mullan
- Conor O'Kane
- Mairead Scott
- Catherine Taggart
- Demelza Stuart
- Julie Harvey

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- Michael Armstrong
- Connor Colhoun
- David Davidson
- Claire Eadie
- David Gale
- Catherine Gillies
- 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 though 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 subsidiarity, 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.

Statement of Trustees' responsibilities

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

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

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

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

Provision of information to auditors

So far as each of the directors is aware at the time the report is approved, there is no relevant audit information of which the company's auditors are unaware; and the directors have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

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



Professor 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
Income							
Income from charitable activities							
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
Total income		**6,314**	**1,907**	**8,221**	**4,232**	**2,437**	**6,669**
Expenditure							
Expenditure on raising funds	3	1,921	13	1,934	1,748	-	1,748
Costs from other trading activities	3	96	-	96	80	-	80
		2,017	**13**	**2,030**	**1,828**	**-**	**1,828**
Charitable activities							
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
Total – charitable activities		**2,465**	**2,361**	**4,826**	**2,040**	**1,741**	**3,781**
Total expenditure		**4,482**	**2,374**	**6,856**	**3,868**	**1,741**	**5,609**
Net gain/(loss) on investment assets	9	(262)	(19)	(281)	46	1	47
Net movement in funds		**1,570**	**(486)**	**1,084**	**409**	**698**	**1,107**
Reconciliation of funds							
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
Fixed Assets					
Tangible Assets	8	401	323	401	322
Investments	9	5,399	5,781	5,168	5,387
Total Fixed Assets		**5,800**	**6,104**	**5,569**	**5,709**
Current Assets					
Stock	12	16	13	-	-
Debtors	13	1,498	881	1,620	923
Cash at Bank		8,641	7,507	8,296	7,442
Total Current Assets		**10,155**	**8,401**	**9,916**	**8,365**
Creditors falling due within one year	14	(4,042)	(3,676)	(3,796)	(3,380)
Net Current Assets		6,113	4,725	6,120	4,984
Total Assets less current liabilities		**11,913**	**10,829**	**11,689**	**10,693**
Net Assets		**11,913**	**10,829**	**11,689**	**10,693**
The funds of the Charity					
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
Total Charity Funds		**11,913**	**10,829**	**11,689**	**10,693**

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
Net cash inflow/(outflow) from operating activities (note a)		**1,069**	**479**
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)
Net Cash provided by investing activities		**65**	**(166)**
Increase/(decrease) in cash and cash equivalents in the year		**1,134**	**313**
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
Cash and cash equivalents at the end of the year		**8,641**	**7,507**
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
Net cash provided by/(used in) operating activities		**1,069**	**479**

	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
Total cash and cash equivalents	**7,507**	**1,134**	**8,641**

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:

i. Entitlement – when Muscular Dystrophy UK has control over the rights to the resource, enabling it to receive the economic benefit.

ii. Probability – when it is probable, more likely than not that the economic benefit will be received.

iii. Measurement – when the monetary value can be measured with sufficient reliability.

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

Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably through estate accounts (or cash receipt) and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is not recognised in the accounts.

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 11 of the Corporation Tax Act 2010 or section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes. No tax charge arose in the period.

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
Total income*	**6,314**	**1,907**	**8,221**	**4,321**	**2,438**	**6,669**

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

3. Expenditure (Cont.)

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

'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
Total	**955**	**920**

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 departamental running costs
- 'Governance' includes the annual audit fee and Trustees expenses.

4. Staff costs (Group and Parent Charity)

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

"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
Earned between the ranges		
£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	-
Number of staff by activity		
Direct Charitable Expenditure	24	18
Fundraising and Publicity	35	33
Management and Administration	6	6
Total	**65**	**57**

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)
Total	**1,294**	**630**	**1,924**	**1,273**

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)
Total	**1,236**	**37**	**1,273**

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)
Carrying amount at end of year	**2,790**	**213**	**3,003**

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
At 31 Mar 2023	**309**	**437**	**16**	**15**	**28**	**805**
Depreciation 1 Apr 2022	177	311	24	-	47	560
Disposal	(12)	(205)	(8)	-	(47)	(271)
Provided for year	35	82	-	-	-	117
At 31 Mar 2023	**200**	**188**	**16**	**-**	**-**	**404**
Net Book Value						
At 31 Mar 2023	**109**	**249**	**-**	**15**	**28**	**401**
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
At 31 Mar 2023	**309**	**434**	**16**	**15**	**28**	**802**
Depreciation 1 Apr 2022	177	308	24	-	47	556
Disposal	(12)	(205)	(8)	-	(47)	(272)
Provided for year	35	82	-	-	-	117
At 31 Mar 2023	**200**	**185**	**16**	**-**	**-**	**401**
Net Book Value						
At 31 Mar 2023	**109**	**249**	**-**	**15**	**28**	**401**
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)
	5,679	**5,734**	**5,437**	**5,366**
Realised (loss)/gain on disposals	334	28	325	(2)
Unrealised gain/(loss) on revaluation of Investments	(614)	19	(593)	23
Market value at end of year	**5,399**	**5,781**	**5,168**	**5,387**
Historical Cost at end of year	**5,186**	**4,983**	**4,992**	**4,042**

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
Investments listed on a recognised Stock Exchange and Unit Trusts				
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
	5,304	**5,462**	**5,076**	**5,069**
Cash on Deposit awaiting investment	33	257	31	256
Unlisted equities	62	62	62	62
Total	**5,399**	**5,781**	**5,169**	**5,387**

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
Total	**159**	**151**	**164**	**143**

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)
Total Net Assets	**3**	**221**
Represented by:		
Total Funds	**3**	**221**
Total income	207	131
Total expenditure	(96)	(30)
Investment gains/losses and other B/S movements	-	(13)
Surplus for the year	**111**	**88**
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	-
Total	**1,498**	**881**	**1,620**	**923**

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
Total	**4,042**	**3,676**	**3,796**	**3,380**

15. Funds

	April 2022 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2023 £000
Endowment Fund						
Orchid Ball	406	-	-	-	(19)	387
Restricted Funds						
Provision of care						
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
Research						
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
Total Restricted Funds	**5,451**	**1,907**	**(2,374)**	**-**	**(19)**	**4,965**

15. Funds (Cont.)

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

2022 Comparatives	April 2021 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2022 £000
Endowment Fund						
Orchid Ball	405	-	-	-	1	406
Restricted Funds						
Provision of care						
City Bridge Trust / Work experience	75	60	(53)	-	-	82
Scotland	28	30	(39)	-	-	19
Psychological support	28	-	-	-	-	28
Volunteering	138	-	(78)	-	-	60
Joseph Patrick Trust - 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
Research						
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
Total Restricted Funds	**4,753**	**2,438**	**(1,741)**	**-**	**1**	**5,451**

15. Funds (Cont.)

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

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
Total Funds	**401**	**5,399**	**6,113**	**11,913**

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

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
All sums are due to Muscular Dystrophy UK.	**946**	**1,385**

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.

MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Registered with FUNDRAISING REGULATOR

OSCR Scottish Charity Regulator www.oscr.org.uk Registered Charity SC039445

Muscular Dystrophy Group of Great Britain and Northern Ireland. Registered charity in England and Wales (205395) and Scotland (SC039445) and a company limited by guarantee without share capital registered with Companies House (705357). Registered office address: 32 Ufford Street, London, England, SE1 8QD

MUSCULAR DYSTROPHY GROUP OF GREAT BRITAIN AND NORTHERN IRELAND

England & Wales - Charity number 205395

Accounts

Muscular Dystrophy UK

Fighting muscle-wasting conditions

Annual Report and Financial Statements

Year ended 31 March 2022

www.musculardystrophyuk.org

Registered Charity No. 205395 and Registered Scottish Charity No. SC039445

A company limited by guarantee: 705357

Report of the Board of Trustees 2021/22

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What Muscular Dystrophy UK does – core purpose and activities

Our vision

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

Our mission

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

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

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

Our values

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

Objects of Muscular Dystrophy UK for the Public Benefit

The Charity is established

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

Public Benefit

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

The work of Muscular Dystrophy UK

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

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

We:

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

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

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

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

Achievements and performance against objectives for 2021/22

Overview

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

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

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

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

To help manage the long-term financial impact of the pandemic, we limited the scope of the call for our grant round in 2021/22 and asked researchers for proposals of up to 12 months' duration. Despite working to a different timetable from previous years with the applications arriving in early June and final decisions being made in the winter, we have funded eight innovative projects. These grants cover a range of conditions, namely collagen VI-related disorders, Duchenne muscular dystrophy, facioscapulohumeral muscular dystrophy (FSHD), myotonic dystrophy and congenital myotonic dystrophy. In addition to the project grants, we were delighted to continue our partnership with Spinal Muscular Atrophy UK (SMAUK) to support one four-year PhD studentship in spinal muscular atrophy (SMA) research. Following a series of no-cost extensions to facilitate different working patterns and furlough during the pandemic, several of our pre-existing grants reached their natural end during 2021/22 and, at the end of the year, the charity was funding 31 projects in the UK and through international partnerships.

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

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

Driving change for access to specialist care and support

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

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

MDUK played a key role in securing access to the spinal muscular atrophy (SMA) treatment risdiplam through engagement with both NICE and the Scottish Medicines Consortium (SMC). We worked in partnership with SMA UK as we engaged in the NICE appraisal process to help ensure the treatment became available through an MAA event after publication of a first draft of guidance by NICE that did not recommend the treatment for use on the NHS in England, with MDUK becoming a member of the MAOG. In Scotland we worked with SMA UK to gather the views of the SMA community and represented the patient voice through our joint submission to the SMC. MDUK's Director of Research & Innovation and the Chair of our Scottish Council then gave evidence together to the Patient and Clinical Engagement (PACE) meeting, which helped to secure access to the treatment in Scotland.

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

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

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

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

We aim to ensure that people with any type of neuromuscular condition receive the best possible care and support, from the point of diagnosis and throughout their lives. This involves many different professional roles to identify and meet people's needs. Over the past year, we have secured NHS funding for two new specialist neuromuscular roles; an additional nurse and physiotherapist. We completed specific work on the standards of care for adults with Duchenne muscular dystrophy, which were published in the Journal of Neuromuscular Diseases and launched on World Duchenne Awareness Day. We formed a working group of adults living with Duchenne muscular dystrophy and leading clinicians to convert the standards of care into patient friendly resources, which will be launched in 2022/23.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Changing Places toilets

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

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

This project has been impacted by the COVID-19 pandemic with installations being delayed by lockdowns and a temporary hold put on capital projects across the Motorway Service Area network. However, we continue to work with the partners and rollout has now re-commenced with a programme completion deadline of 30 June 2023. We agreed a new partnership with the DfT to increase provision of these facilities across other areas of the transport network and are currently in discussions with Network Rail, following our insight work highlighting the need for more Changing Places toilets on the rail network.

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

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

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

Scotland

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

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

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

In January 2022, we launched our Scotland specific version of the 'Shining a Light' report, putting forward key recommendations to improve neuromuscular services in the country. We discussed our findings at a Scottish Cross Party Group meeting and with our Scotland Muscle Group and the report publication secured strong media coverage. We used the report's findings and recommendations to feed into the Scottish Cross Party Group on Mental Health's review into mental health inequalities and wrote to Scottish health ministers on the urgent need to improve mental health provision for people with a muscle-wasting condition in Scotland; this has led to dialogue with the neurological conditions' clinical priorities team within the Scottish Government.

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

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

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

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

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

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

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

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

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

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

Plans for 2022/23

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

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

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

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

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

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

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

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

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

particularly important to them:

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

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

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

In 2022/23, we will:

Accelerate Research

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

MDUK will:

- Continue to invest money to deliver high-quality research to understand the underlying causes of muscle-wasting conditions, always making sure our investment has maximum impact. In 2022/23 our grant round is open to proposals covering all conditions and for up to three years' duration for project grants.
- Encourage scientists with new ideas and technologies to come into this area of research. In 2021/22 we saw that this activity pays off because we funded researchers never-before supported by MDUK. We continue to encourage new ideas and collaborations in the field.
- Continue to drive innovation and influence our partners and others to do the same. We hope to continue our partnership with Healx to deliver treatment for FSHD using AI technology. Additionally, we will work in partnership with LifeArc to support a £1m call for translational research into congenital muscular dystrophies.
- Due to the pandemic, many non-COVID-19 related clinical trials have been stalled. By maintaining our investment in the MDUK Oxford Neuromuscular Centre and clinical trial coordinators in Newcastle and London, we have been able to support access to clinical trials.
- Harness the power of genetics for example through our support of fundamental research grants, such as the recent grant to Professor Jennifer Morgan at University College London, who is investigating whether collagen VI genes are important for the proper function of muscle stem cells.
- Continue to facilitate drug development by providing crucial information, through natural history case studies on how a condition progresses with time and how it affects people through our ongoing support of the world's largest natural history study in Duchenne muscular dystrophy known as the NorthStar programme. In addition, we will launch a call for support of a natural history study for nemaline myopathy during 2022/23.
- Increase our understanding of the disease mechanism through our continued support of research projects funded through our annual grant rounds.
- Improving the quality of life by developing evidence-based interventions that improve the quality of life of people affected by a muscle-wasting condition.

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

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

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

MDUK will:

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

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

Fundraising

MDUK will:

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

Fundraising statement

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

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

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

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

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

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

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

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

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

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

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

Financial review and policies

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

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

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

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

Reserves policy

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

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

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

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

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

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

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

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

Investment policy

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

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

Ethical considerations

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

Remuneration policy

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

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

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

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

Risk management

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

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

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

streams using close budget control, clear marketing plans and regular review

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

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

Grant-making policies

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

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

Reference and administrative details

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

Structure, governance and management

Governing document

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

Appointment of Trustees

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

Trustee induction and training

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

Organisation

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

Members

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

Volunteers

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

Charity Governance Code

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

Related parties

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

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

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

Statement of Trustees' responsibilities

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

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

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

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

Provision of information to auditors

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

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

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



Professor M Hanna
Chairman
12 July 2022

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

Opinion

We have audited the financial statements of Muscular Dystrophy Group of Great Britain and Northern Ireland (the 'parent charitable company') and its subsidiaries (the 'group') for the year ended 31 March 2022 which comprise the Consolidated Statement of Financial Activities (incorporating an Income and Expenditure Account), the Group and Parent Charitable Company Balance Sheets, the Statement of Group Cash Flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the group's and the parent charitable company's affairs as at 31 March 2022 and of the group's incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 (as amended) and regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement set out on page 24, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

Auditor's Responsibilities for the audit of the financial statements

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

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

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

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

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

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

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

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

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

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

Our approach was as follows:

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

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

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

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

Use of our report

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

Moore Kingston Smith LLP

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

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

Date: 28 July 2022

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

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

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

BALANCE SHEETS AS AT 31 MARCH 2022
COMPANY REGISTRATION NUMBER 705357
CHARITY REGISTRATION NUMBER 205395/SC039445

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

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

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



Prof M Hanna
Chairman



M Brown
Treasurer

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

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

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

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

1. ACCOUNTING POLICIES

ACCOUNTING CONVENTION

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

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

GOING CONCERN ACCOUNTING POLICIES

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

BASIS OF CONSOLIDATION

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

The subsidiary undertakings included in this consolidated accounts include:

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

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

1. ACCOUNTING POLICIES (cont.)

INCOME

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

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

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

Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably through estate accounts (or cash receipt) and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is not recognised in the accounts.

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

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

EXPENDITURE

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

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

1. ACCOUNTING POLICIES (cont.)

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

Muscular Dystrophy UK awards three types of grant:

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

TAXATION

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

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

LISTED INVESTMENTS

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

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

UNLISTED INVESTMENTS

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

FINANCIAL INSTRUMENTS

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

1. ACCOUNTING POLICIES (cont.)

INTANGIBLE AND TANGIBLE FIXED ASSETS AND DEPRECIATION

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

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

OPERATING LEASES

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

DEBTORS

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

CASH AT BANK AND IN HAND

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

CREDITORS AND PROVISIONS

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

EMPLOYEE BENEFITS

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

PENSIONS

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

1. ACCOUNTING POLICIES (cont.)

ACCOUNTING ESTIMATES AND AREAS OF SIGNIFICANT JUDGMENT

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

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

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

STOCK

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

FUND ACCOUNTING POLICIES

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

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

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

2. INCOME

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

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

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

3. EXPENDITURE

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

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

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

3. EXPENDITURE (cont.)

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

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

These costs have been allocated across the activities on the basis of expenditure incurred for each of the activities.
§ 'Access to care' includes Policy, Communications and training activities. 'Independent living' includes advocacy, care, equipment grants and Changing Places.
§ 'Research' includes the research grants and departamental running costs
§ 'Governance' includes the annual audit fee and Trustees expenses.

4. STAFF COSTS

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

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

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

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

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

4. STAFF COSTS (cont.)

	2022 No	2021 No
Earned between the ranges		
£60,000 to £70,000	1	2
£70,000 to £80,000	2	-
£100,000 to £110,000	1	1

	2022 No	2021 No
Number of staff by activity		
Direct Charitable Expenditure	18	18
Fundraising and Publicity	33	35
Management and Administration	6	6
Total	**57**	**59**

Pension Schemes

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

5. GRANT EXPENDITURE

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

	Research Grants £000	Welfare Grants £000	Total 2021 £000
Grants awarded in the year	1,067	3	1,070
Grants cancelled in the year	(875)	(28)	(903)
Total	**192**	**(25)**	**167**

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

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

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

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

5. GRANT EXPENDITURE (cont.)

	2022 £000	2021 £000
Payable between one and five years	2,371	3,311

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

6. OPERATING LEASE COMMITMENTS

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

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

7. NET INCOME

Net Income is stated after charging

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

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

8. TANGIBLE FIXED ASSETS

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

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

9. INVESTMENTS

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

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

9. INVESTMENTS (cont.)

Spread of Investments

The investments of Muscular Dystrophy UK are held as follows:

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

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

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

10. INCOME FROM INVESTMENTS

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

11. INVESTMENTS IN SUBSIDIARY UNDERTAKINGS

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

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

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

11. INVESTMENTS IN SUBSIDIARY UNDERTAKINGS (cont.)

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

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

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

12. STOCK

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

13. DEBTORS

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

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

14. CREDITORS FALLING DUE WITHIN ONE YEAR

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

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

15. FUNDS

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

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

15. FUNDS (cont.)

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

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

15. FUNDS (cont.)

ENDOWMENT FUND

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

RESTRICTED FUNDS

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

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

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

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

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

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

15. FUNDS (cont.)

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

UNRESTRICTED FUNDS

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

The designation of balances is as follows:

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

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

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

16. LEGACIES

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

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

All sums are due to Muscular Dystrophy UK.

17. STATUS OF CHARITY

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

18. RELATED PARTY TRANSACTIONS

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

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

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

There were no other related parties transactions.

Presidents, Board of Trustees and Committees

President

Gabby Logan MBE

Honorary Life Presidents

Professor George Dickson
Professor Martin Bobrow
Baroness Celia Thomas of Winchester MBE
Sue Barker CBE

Patrons

Michael J Attenborough
Karen E Lewis-Attenborough
Ian Corner
Alan Emery
Bill Ronald
Keith Rushton
Sir Sydney Samuelson CBE

Vice Presidents

Simon Knights
Andy Martin
Matthew Kelly
Jeremy Champion
Sebastian Crewe
Candida Crewe
Sir Guy Weston
Nicola Manby
Jeremy D Pelczer
Sir Alex Ferguson CBE
Sarah E Kelly
Anil Ahir
Michael A Thirkettle
Charity Crewe
Sophia Bergqvist
Julian Pritchard
Andrew J Weir
Andrew Graham
Charles Manby MBE
Frances Carey
Ann McNeil
Alexandra Wellesley Wesley
Victoria Elliston
Ian Mathieson
Louisa Hill

Our Research Vice Presidents

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

Joseph Patrick Trust Grants Panel

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

Joseph Patrick Trust Management Committee

Julian Pritchard (Chair)
Ian Gordon
Robert Warner

Finance Committee

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

Appointments and Remuneration Committee

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

Medical Research Committee

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

Lay Research Committee

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

Services Development Committee

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

Appeal Board

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

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

Northern Ireland Council

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

Scottish Council

Dr Sheonad Macfarlane BSc Med Sci, MB ChB (Chair)
Lindsey Armstrong
Michael Armstrong
Connor Colhoun
David Davidson
Claire Eadie
David Gale
Catherine Gillies
Mairi Leitch
Scott McIntyre
Gill Mitan
Allyson Townhill
Stuart Townhill

Board of Trustees

Professor Michael Hanna FRCP MD MRCP BM BCh FMedSci (Chair)
Marcus Brown (Treasurer)
Michelle Anthony
Michael Armstrong
Martin Cardoe
Ian T Gordon
Joseph Gordon
Sheila Hawkins (until October 2021)
Louisa Hill (until July 2021)
Claire O'Hanlon MBE
Professor Deirdre Kelly CBE (from October 2021)
Scott Keown
Charles Scott
Baroness Celia Thomas of Winchester MBE
Tanvi Vyas
Robert Warner

Senior Leadership Team

Catherine Woodhead, Chief Executive Officer
Dr Kate Adcock, Director of Research and Innovation
Rob Burley, Director of Care, Communications and Support
Emma Jones-Parry, Associate Director of Development
Wojtek B Trzcinski, Director of Finance and Resources

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

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

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

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

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

MUSCULAR DYSTROPHY GROUP OF GREAT BRITAIN AND NORTHERN IRELAND

England & Wales - Charity number 205395

Accounts

Muscular Dystrophy UK

Fighting muscle-wasting conditions

Annual Report and Financial Statements

Year ended 31 March 2021

www.musculardystrophyuk.org

Registered Charity No. 205395 and Registered Scottish Charity No. SC039445

A company limited by guarantee: 705357

Report of the Board of Trustees 2020/21

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What Muscular Dystrophy UK does – core purpose and activities

Our vision

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

Our mission

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

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

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

Our values

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

Objects of Muscular Dystrophy UK for the Public Benefit

The charity is established to promote research into muscle-wasting conditions; to promote the provision of care and treatments to those affected; to assist those who care for individuals affected by such conditions; to promote education and training for affected individuals and to raise the awareness of the public on any matter relating to the charity's objects.

Public Benefit

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

The work of Muscular Dystrophy UK

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

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

We:

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

Over the years, the charity has made important contributions in funding research and developing clinical support, which have led to vital progress such as an early and accurate diagnosis, access to steroid treatments, spinal surgery and respiratory support, which, with improved care, enhance quality of life and life expectancy.

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

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

Achievements and performance against objectives for 2020/21

Overview

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

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

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

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

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

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

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

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

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

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

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

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

What we'll do next

We will continue to Invest to **deliver high-quality research** to understand the underlying causes of muscle-wasting conditions, always making sure our investment aligns with our research strategy and has maximum impact. In 2021/22, we will continue supporting research, including our PhDs, to whom we are already committed to realise the potential of the initial investment. We will also complete a smaller than usual Grant Round that will focus on a limited number of conditions. The Grant Round will also feature the return of our partnership with Spinal Muscular Atrophy UK to support a four-year PhD studentship in SMA research.

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

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

Driving change for access to specialist care and support

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

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

We have been active in the appraisal processes for two other SMA treatments – Risdiplam and the gene therapy, Zolgensma. During 2020/21, Risdiplam became available to eligible patients across the United Kingdom – first through a Compassionate Use Programme and then through an Early Access to Medicines Scheme (EAMS) – ahead of the full assessment process for NHS access taking place in 2021/22. We worked in partnership with patients and other charities to successfully challenge some Trusts and Health Boards that weren't implementing the EAMS.

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

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

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

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

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

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

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

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

We aim to ensure that people with any type of neuromuscular condition receive the best possible care and support, from the point of diagnosis and throughout their lives. This involves many different professional roles to identify and meet people's needs. Over the past year, we secured NHS funding for seven new specialist neuromuscular roles, including consultants, nurses and physiotherapists. This means that since 2013, we have helped secure 109 new specialist neuromuscular roles in the NHS and saved a further 16 from being lost. This represents a total NHS investment of £7.5m per year in specialist services – to help people live well with their condition – that would not otherwise be available to them.

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

We continue to provide support for the cross-party groups on muscular dystrophy in the Houses of Parliament, Scottish Parliament, Welsh Parliament and Northern Ireland Assembly, ensuring that issues affecting people with muscle-wasting conditions receive political attention across the UK. In 2020/21, we successfully adjusted to the impact of the COVID-19 pandemic and delivered a number of virtual meetings of these key groups.

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

Being diagnosed with a muscle-wasting condition means adjusting to a new and unexpected reality. We believe that it is vital that people have easy access to the information and support they need throughout their experience of their condition. That is why we provide personal, free, expert information resources and confidential support. We cover every topic from the latest research, money worries, physical symptoms and emotional well-being. And in 2020/21, we had to rapidly adapt our activity in order to support our community in the face of the COVID-19 pandemic, while navigating the impact of the pandemic on our capacity to deliver those services.

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

As well as providing information and advice to our community, we also ensured that the voice of people with muscle-wasting conditions was heard on key issues, such as treatment decisions, shielding policy and vaccine prioritisation. Again, working in partnership was crucial to this activity. We worked as part of a number of informal and formal collaborations, such as National Voices and the charity sector Shielding and High Risk Coalition. We also joined the cross-government Shielding Working Group, led by the Department for Health and Social Care.

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

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

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

Our advocacy service supports people who may be struggling to get the care and services to which they are entitled. We help by providing advice or intervening on their behalf. For much of the year, we were able to offer only a reduced service, focusing primarily on supporting people to secure Personal Independence Payments (PIP). This was because we redirected our reduced resources to supporting our community through the COVID-19 pandemic.But in January, we were able to resume the full service and by the end of 2020/21, we had supported 250 people through our advocacy service.

As well as supporting people to access financial support, we provide grants to help people living with muscle-wasting conditions meet the costs of powered mobility equipment through our grant-giving arm, the Joseph Patrick Trust (JPT). We weren't able to make any grants in 2020/21 owing to COVID-19, but in February we were delighted to re-open the scheme for applications for a grant round taking place in April 2021.

In addition to providing information and support through our helpline and advocacy services, we had planned to bring people together throughout the year through our normal programme of information and support events, local Muscle Groups and our National Conference. None of these activities was possible because of the impact of COVID-19, but we brought our community together by delivering 'Muscles Matter 2020', our first-ever programme of virtual information and support events. The programme of 14 seminars covered a range of specific muscle-wasting conditions and a number of more general topics relating to living well with a muscle-wasting condition. We received 1,487 bookings from 854 individuals, with a combined 2,388 views on YouTube. We will deliver a 2021 Muscles Matter programme, and establish a virtual model for the first round of Muscle Groups.

We continued to co-chair the Changing Places consortium, which ensures that people are able to access toilet and changing facilities in public places, and promotes their use. We continued to administer a £2m grant programme in partnership with the Department for Transport (DfT) to ensure there is adequate provision of Changing Places toilets in motorway service areas in England. This project has been impacted by the COVID-19 pandemic, but we continue to work with the partners to ensure rollout continues as soon as possible. We agreed a new partnership with the DfT to increase provision of these facilities across other areas of the transport network. We also finalised a new partnership with the Ministry of Housing, Communities and Local Government (MHCLG) to provide insight to help shape a scheme for the distribution of £30m of government funding to install Changing Places toilets in existing buildings in England, and to provide advice and support to Local Authorities in receipt of this funding from 2021/22.

Scotland

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

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

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

Inspired by those who took on the 2.6 challenge, long-term supporter and Scottish Council member, Dave Gayle, set a challenge at the end of April to walk 500 miles. David's fundraising efforts moved many – leading to others joining in and racking up the miles to help reach the 500-mile goal. On 27 May 2020, Dave was delighted to announce the challenge was complete, with a total of 501 miles walked and an incredible £950 raised.

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

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

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

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

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

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

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

Plans for 2021/22

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

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

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

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

There are over 70,000 people living in the UK with over 60 rare and ultra-rare muscle-wasting conditions. The vast majority have no access to any treatments for their conditions. People are living longer today, because of a better understanding about their conditions and, therefore, better specialist care and opportunities to live well for longer.

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

Our core work is to:

- support research to drive the development of effective treatments and cures
- ensure access to specialist NHScare and support
- provide services and promote opportunities to enable individuals and their families to live as independently as possible.
- In addition, we committed ourselves to work for change in four key areas that people with muscle-wasting conditions and their families told us were particularly important to them:
- fast track to treatments
- mental health matters
- advances in technology
- sport, leisure and exercise.

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

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

In 2021/22, we will:

Accelerate research to develop effective treatments and cures:

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

Drive change for access to specialist NHS care:

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

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

Improving quality of life by enabling independent living:

- Support independent living by helping people to live well with their condition by providing information, practical advice, advocacy and support on the phone, online, through specialist information and advocacy officers in the devolved nations, and through our local Muscle Groups. We will continue to deliver our high-quality, accessible support for everyone on the phone, online and, when possible, face to face. We will deliver our virtual Muscles Matter series and resume our Muscle Group meetings – initially virtually.
- Change communities by supporting those who want to take action to change the communities they live in; through our Moving Up project we will continue to support young people to gain access to employment, and by working with our co-chair of the Changing Places consortium Pamis in Scotland, we will improve access to Changing Place toilets.
- Continue to work to remove the barriers that people face to access sport and leisure activities, so they can enjoy the activities that they love and that help them live healthier and more independent lives; we will continue our role as co-chair of the Changing Places consortium and deliver projects with the DfT and MHCLG to help increase the provision of Changing Places toilets in sports and leisure facilities in England; and we will continue to sponsor the Powerchair football leagues with the Wheelchair Football Association and the Scottish Powerchair Football Association.

Fundraising:

- Deliver a £5m gross budget; £4.2m in active fundraising and £930k in legacy, which will result in a net figure of £3.1m. Budget figures reflect a period of cautious consolidation, where an assumption that live events and face-to-face activities will return, producing a growth in income, but caution in that the effects of the pandemic will continue to be felt on the household and corporate purse.
- Review the fundraising portfolio to ensure we have the right activities for our audiences to engage and support wherever they are in their relationship with MDUK, maximising potential and spreading risk, making events COVID-secure where possible and being agile in response to the changing fundraising landscape because of the pandemic.
- Maximise the return on investment through effective deployment of our resources.
- Ensure that fundraising successfully raises awareness of the charity's work and is integrated into our charity communications activities.
- Monitor, evaluate and develop our unrestricted fundraising policy to be integral to our fundraising strategy.

Fundraising statement

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

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

- to deliver best practice rather than compliance
- to never sell or swap donor data
- to never rank donors based on wealth
- not to share data with external agencies for the purposes of wealth screening or finding data you haven't provided to us before
- to enable our audiences to choose which communications they receive and how.

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

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

We know we can beat muscle-wasting conditions more quickly and reach more people with these conditions, by working together. We offer many different opportunities for our fundraisers and donors to engage with us to fulfil our charitable objectives. These include: special and challenge events; corporate partnerships; trusts and foundations; regional and community fundraising activity including Family Funds, Fundraising Groups, Branches and events; individual giving, which includes regular giving, major gifts, mailing campaigns, raffles and a weekly lottery, membership scheme, Christmas cards and online shop sales; Legacy and In-Memory programmes. We conduct our Payroll giving, our gaming programme, legacy administration, the shop fulfilment, printer and mailing houses for external mailings, and the majority of our regional and national challenge events through commercial participation agreements. We carry out internal analysis to ensure the work delivered by the agencies provides best value to the charity, its supporters and users.

We are paid-up members of the Fundraising Regulator (formally Fundraising Standards Board) and subscribe to the fundraising codes of practice. This year, we have attended online virtual webinars where reputable companies have offered free training to those in need, which has allowed staff to remain up-to-date in all areas of fundraising governance and training.

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

Financial review

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

Expenditure on charitable activities was in respect of medical research, access to specialist NHS care and support, and provision of information, support and opportunities to enable independent living. With COVID-19 impacting the charity's operations and delivery, as explained earlier in this report, the charitable expenditure for the year was reduced by 40% to £2,371k compared to the previous financial year (2020: £4,018k). MDUK has preserved any unspent funds as part of its reserves, and will use them to support future charitable activities.

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

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

Reserves policy

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

The recommended free reserves level is calculated annually in advance of the budget process on the basis of the financial impact of the current risks facing the charity. The reserves policy is reviewed annually by the Trustees. The charity seeks to maintain free reserves to manage the risks to which the charity is exposed in the course of its business, including but not limited to safeguarding against volatile voluntary income. The Trustees consider that in order to meet these needs, and to operate effectively, the charity needs reserves of around £1.5-£2.0m, based on the current analysis of risk. This has been reviewed in line with 2021/22 budget review.

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

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

The unrestricted funds balance is substantially higher than the target level agreed by the Trustees. However, in March 2021, the Trustees approved that any surplus in the reserves should be used to underwrite operations and delivery in the 2021/22 and 2022/23 financial years, when the impact of the COVID-19 pandemic is likely to continue and risks to any live fundraising events remain high. It will also support a development of the new strategic plan, when they current strategy comes to an end in 2022.

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

our IT and CRM (database) systems to minimise risks to the data system, lower longer-term costs, and mobilise the staff to work in the new post-COVID-19 environment. This would enable the charity to review in a year's time its premises' needs, which would lead to a long-term cost reduction when our contract with the landlord comes to an end.
The higher level of total reserves (free and designated) than outlined in the policy played a substantial role in providing the charity with additional security when faced with the COVID-19 pandemic.

Investment policy

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

Remuneration policy

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

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

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

None of the Trustees is paid any remuneration or receives any other benefits from their work for the charity. Details of reimbursed expenses to Trustees can be found in Note 17.

Ethical considerations

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

Risk management

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

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

a. maintaining income levels is essential to the charity's financial sustainability – the charity continues to monitor the risks associated with its diverse voluntary income streams using close budget control, clear marketing plans and regular review

b. needing to hold a sufficient level of unrestricted funds to provide a buffer against loss of income or unplanned expenditure – during the COVID-19 pandemic, the charity has reviewed these fortnightly, then monthly, and the charity will return to keeping these funds under quarterly review when appropriate

c. the impact of a stock market crash on the value of the investment portfolio, mitigated by taking the advice of professional investment managers

d. data protection: given GDPR, fines and attacks on data, this is a very real risk to the charity; leading experts in the field have been advising us and we continue to work proactively to address this issue

e. providing information that meets the needs of our users is essential for their continued support of the charity – the charity is reviewing all communications, publications and the website to ensure they meet the needs of all of our audiences.

Our risk management policy proved effective during the COVID-19 pandemic. The charity reacted to the potential impact of the pandemic in March 2020 by forming a special Board Emergency Sub-committee, who worked with the SLT on reducing the impact of the pandemic, including an initially estimated £2.8m income drop against the original budget. Together, they:

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

Grant-making policies

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

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

Going concern

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

Reference and administrative details

Muscular Dystrophy UK is a charitable company limited by guarantee. It is registered as a charity (Number 205395) in England and Wales and (Number SCO39445) in Scotland. The details of the Patron, the President, Honorary Life Presidents, Vice Presidents, Committees, senior leadership team and advisors are set out on pages 49 to 53.

Structure, governance and management

Governing document

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

Appointment of Trustees

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

Trustee induction and training

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

Organisation

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

Members

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

Volunteers

Volunteers are central to the work of MDUK. We rely on voluntary help in all aspects of the work of the charity. Volunteers work in the office, get involved in fundraising, provide their advice and guidance on many committees, provide support to individuals and families with

muscle-wasting conditions, and get involved with campaigning and media work. All these efforts help the charity achieve its aims and objectives and we would wish to thank them all for their hard work and support.

Charity Governance Code

This code is a practical tool to help charities and their trustees develop high standards of governance. In 2018/19, the Board reviewed the code (which was refreshed in 2020, with reference to Equality, Diversity and Inclusion principle and Integrity principle). We continue to work together on how these principles and practices should be applied at MDUK.

Related parties

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

The consolidated financial statements also include the Trading subsidiary, Muscular Dystrophy Group (Trading) Limited of the Muscular Dystrophy Group of Great Britain and Northern Ireland. MDUK maintains extremely close working relationships with partner charities that also assist those living with muscle-wasting conditions.

Provision of information to auditors

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

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

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

STATEMENT OF TRUSTEES' RESPONSIBILITIES

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

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

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

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

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



Professor M Hanna
Chairman
20 July 2021

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

Opinion

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

In our opinion, the financial statements:

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

Basis for opinion

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

Conclusions relating to going concern

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

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

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

Other information

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

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

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

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

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

Auditor's responsibilities for the audit of the financial statements

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

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

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

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

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

instances of non-compliance with laws and regulation and fraud;

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

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

Use of our report

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



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

Date: 22nd July 2021

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

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

There are no recognised gains or losses other than those disclosed above. All results are derived from continuing activities. The accompanying notes on pages 33 to 48 form an integral part of the financial statements.

BALANCE SHEETS AS AT 31 MARCH 2021
COMPANY REGISTRATION NUMBER 705357

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

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

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





M Hanna
Chairman

M Brown
Treasurer

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

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

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

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

1. ACCOUNTING POLICIES

ACCOUNTING CONVENTION

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

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

GOING CONCERN ACCOUNTING POLICIES

The charitable company's level of free reserves available at the year end, were considered adequate resources to continue in operational existence for the foreseeable future, even with the continued impact of the Covid-19 pandemic. The pandemic caused the Trustees to review the positions of the Charity and its subsidiaries in 2020/21 financial year; revised budgets were prepared in August 2020 and adopted, understandable reductions were made to the revenues, there were also reductions in costs, all of which resulted in protecting the reserves and net surplus for the year. In March 2021, new financial year budgets were prepared, taking into consideration continued Covid-19 restrictions in 2021/22, and the likely effects on some streams of fundraising. The budgets and cash flows were reviewed in July 2021 and the Trustees have considered forecasts covering twelve months period until July 2022. Accordingly, the financial statements have been prepared on a going concern basis and the Trustees do not anticipate any material uncertainties.

BASIS OF CONSOLIDATION

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

The subsidiary undertakings included in this consolidated accounts include:

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

1. ACCOUNTING POLICIES (cont.)

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

INCOME

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

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

Income received for a specific purpose is treated as restricted funds.

Where income is received subject to donor-imposed conditions that specify a future time period in which the expenditure should take place, such income is deferred and recognised as a liability.

It is released as income in the accounting period in which Muscular Dystrophy UK is allowed to expend the resource.

Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably through estate accounts (or cash receipt) and the charity has been notified of the executor's intention to make a distribution. Where legacies have been notified to the charity or the charity is aware of the granting of probate, and the criteria for income recognition have not been met, then the legacy is not recognised in the accounts.
Government grant income paid under the Coronavirus Job Retention Scheme (CJRS) has been recognised in the Statement of Financial Activities in the period to which the underlying furloughed staff costs relate to.

EXPENDITURE

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

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

1. ACCOUNTING POLICIES (cont.)

Governance costs have been allocated in line with cost of administration and include those costs associated with meeting the constitutional and statutory requirements of the charity and include audit fees and costs linked to the strategic management of the charity.

Muscular Dystrophy UK awards three types of grant:

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

TAXATION

Muscular Dystrophy Group of Great Britain and Northern Ireland and the Joseph Patrick Trust are registered charities with the meaning of para 1 schedule 6 Finance Act 2010. Accordingly, they are exempt from taxation in respect of income or capital gains within categories covered by Chapter 3 of Part 11 of the Corporation Tax Act 2010 or section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes. No tax charge arose in the period. Muscular Dystrophy Group (Trading) Limited used to donate by way of Gift Aid all taxable profits to the parent charity. In November 2020 a deed of covenant was signed between the trading company and parent charity, which now guides this arrangment.

LISTED INVESTMENTS

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

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

UNLISTED INVESTMENTS

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

FINANCIAL INSTRUMENTS

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

1. ACCOUNTING POLICIES (cont.)

TANGIBLE FIXED ASSETS AND DEPRECIATION

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

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

OPERATING LEASES

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

DEBTORS

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

CASH AT BANK AND IN HAND

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

CREDITORS AND PROVISIONS

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

EMPLOYEE BENEFITS

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

PENSIONS

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

1. ACCOUNTING POLICIES (cont.)

ACCOUNTING ESTIMATES AND AREAS OF SIGNIFICANT JUDGMENT

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

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

- Estimating the useful economic life of tangible fixed assets
- Estimating the probability of the receipt of legacy income and the amount to be received

STOCK

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

FUND ACCOUNTING POLICIES

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

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

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

2. INCOME

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

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

3. EXPENDITURE

	Direct Costs			
	Grants £000	Other £000	Support Costs £000	2021 £000
Raising Funds				
Expenditure on raising funds	-	973	163	1,136
Costs from other Trading Activities	-	49	18	67
Total	-	**1,022**	**181**	**1,203**
Charitable Expenditure				
Access to care and independent living				
Access to care	-	962	302	1,264
Independent living	-25	360	105	440
Total	-25	1,322	407	1,704
Pursuit of Knowledge				
Medical research	192	316	159	667
Total Charitable Expenditure	**167**	**1,638**	**567**	**2,371**
Total Expenditure	**167**	**2,660**	**748**	**3,574**

	Direct Costs		Support	
	Grants £000	Other £000	Costs £000	2020 £000
Raising Funds				
Expenditure on raising funds	-	1,981	230	2,211
Costs from other Trading Activities	-	111	10	121
Total	**-**	**2,092**	**240**	**2,332**

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

3. EXPENDITURE (cont.)

Charitable Expenditure				
Access to care and independent living				
Access to care	-	1,350	309	1,659
Independent living	223	717	215	1,155
Total	223	2,067	524	2,814
Pursuit of Knowledge				
Medical research	495	486	223	1,204
Total Charitable Expenditure	**718**	**2,553**	**747**	**4,018**
Total Expenditure	**718**	**4,645**	**987**	**6,350**

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

'Support Costs' comprise of the following :

			2021	2020
			£000	£000
Chief Executive and Human Resources			96	114
Finance and insurance			238	311
Office costs			271	397
Information Technology			121	141
Governance			22	24
Total			**748**	**987**

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

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

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

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

4. STAFF COSTS (Group and Parent Charity)

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

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

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

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

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

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

	2021 No	2020 No
Earned between the ranges		
£60,000 to £70,000	2	-
£70,000 to £80,000	-	3
£100,000 to £110,000	1	1

	2021 No	2020 No
Number of staff by activity		
Direct Charitable Expenditure	18	41
Fundraising and Publicity	35	38
Management and Administration	6	7
Total	**59**	**86**

Pension Schemes

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

5. GRANT EXPENDITURE

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

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

With the exception of welfare grants that are paid to individuals, all grants are paid to institutions. A list of grants to institutions is available from the registered office.

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

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

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

5. GRANT EXPENDITURE (cont.)

	2021 £000	2020 £000
Payable between one and five years	3,311	3,066

Reconciliation of grant funding commitments :

	Research 2021 £000	JPT 2021 £000	Total 2021 £000
Carrying amount at start of year	4,309	352	4,661
Additions	1,067	3	1,070
Amounts charged and cancelled in year	(2,436)	(83)	(2,519)
Carrying amount at end of year	**2,940**	**272**	**3,212**

6. OPERATING LEASE COMMITMENTS

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

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

7. NET INCOME

Net Income is stated after charging

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

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

8. TANGIBLE FIXED ASSETS

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

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

9. INVESTMENTS

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

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

9. INVESTMENTS cont.

Spread of Investments
The investments of Muscular Dystrophy UK are held as follows:

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

The unlisted equity investment has been valued at its likely realisable value.
Investment management costs for the year were £28k (2019/20: £28k).

There was no individual investment that constituted more than five percent of the total investment portfolio (at market value) as at the year end. (2019 : £nil)

10. INCOME FROM INVESTMENTS

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

11. INVESTMENTS IN SUBSIDIARY UNDERTAKINGS

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

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

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

11. INVESTMENTS IN SUBSIDIARY UNDERTAKINGS cont.

	Muscular Dystrophy Group (Trading) Ltd £000	Joseph Patrick Trust £000
Fixed Assets	2	370
Current Assets	52	4
Current Liabilities	(51)	(306)
Total Net Assets	**3**	**68**
Represented by:		
Total Funds	**3**	**68**
Total income	101	66
Total expenditure*	(64)	12
Surplus for the year	**37**	**78**
Country of Registration	England	England
Number of fully paid £1 ordinary shares	100	-
Voting rights owned by Muscular Dystrophy UK	100%	100%

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

12. STOCK

The stock held in Muscular Dystrophy Group (Trading) Ltd represents new goods available for sale valued at £11k (2019/20 : £13k).

13. DEBTORS

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

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

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

14. CREDITORS FALLING DUE WITHIN ONE YEAR

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

15. FUNDS

	April 2020 £000	Income £000	Expendi-ture £000	Movement between funds* £000	Invest-ment gains £000	March 2021 £000
Endowment Fund						
Orchid Ball	353	-	-	-	52	405
Restricted Funds						
Provision of care						
City Bridge Trust / Work experience	52	57	(34)	-	-	75
Comic relief	24	-	-	(24)	-	-
Psychological support	117	-	(1)	(88)	-	28
Powerchair football	19	(19)	-	-	-	(0)
Joseph Patrick Trust - Assistive Technology	30	-	-	-	-	30
Changing Places	1,961	881	(262)	-	-	2,580
Other care	212	267	(190)	(64)	-	225
Research						
The Patrick Research Fund	307	-	(8)	-	-	299
Oxford Neuromuscular Centre	328	54	(8)	-	-	374
Q Trust Fellowship	250	3	(250)	-	-	3
Walton Fund	119	-	-	(119)	-	-
Duchenne Research	297	100	(359)	-	-	38
Ullrich Research	106	24	-	-	-	130
Nemaline Research	145	9	-	-	-	154
Congenital MD	(35)	30	-	-	-	(5)
Becker Research Fund	72	11	-	-	-	83
Other research	252	157	(75)	-	-	334
Total Restricted and Endowment Funds	**4,609**	**1,574**	**(1,187)**	**(295)**	**52**	**4,753**
Designated Funds						
Research	1,172	-	-	(1,172)	-	-
Clinical	229	-	-	(229)	-	-
IT Investment Fund	-	-	-	250	-	250
Tangible Assets for Charity Use	190	58	(58)	-	-	189
Total Designated Funds	**1,591**	**58**	**(58)**	**(1,151)**	-	**439**

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

15. FUNDS cont.

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

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

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

15. FUNDS cont.

ENDOWMENT FUND

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

RESTRICTED FUNDS

The Joseph Patrick Trust is a restricted trust within Muscular Dystrophy UK as explained in Note 11. Its assets are restricted to 'provide welfare, relief and support to those living with muscle-wasting conditions'.

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

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

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

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

UNRESTRICTED FUNDS

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

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

The designation of balances is as follows:

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

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

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

15. FUNDS cont.

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

16. LEGACIES

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

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

All sums are due to Muscular Dystrophy UK.

17. STATUS OF CHARITY

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

18. RELATED PARTY TRANSACTIONS

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

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

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

Presidents, Board of Trustees and Committees

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

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

President

Gabby Logan MBE

Honorary Life Presidents

Professor Martin Bobrow CBE FRS FMed Sci
Sue Barker CBE
Baroness Celia Thomas of Winchester MBE

Patrons

Professor Alan Emery
Ian Corner
Bill Ronald
Sir Sydney Samuelson CBE
Keith Rushton

Vice Presidents

Anil Ahir
The Hon. Michael Attenborough CBE
Karen Attenborough
Sophia Bergqvist
Frances Carey
Jeremy Champion
Candida Crewe
Charity Crewe
Sebastian Crewe
Victoria Elliston
Sir Alex Ferguson CBE
Andrew Graham
Matthew Kelly
Sarah Kelly
Simon Knights
Charles Manby

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

Our Research Vice Presidents

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

Joseph Patrick Trust Grants Panel

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

Joseph Patrick Trust Management Committee

Julian Pritchard (Chair)
Ian T Gordon
Robert Warner

Finance Committee

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

Appointments and Remuneration Committee

Professor Mike Hanna FRCP MD MRCP BM BCh FMedSci (Chair)
Ian T Gordon
Richard Price (until March 2021)
Charles Scott (from March 2021)
Baroness Celia Thomas of Winchester MBE

Medical Research Committee

Professor Hugh Willison MBBS PhD FRSE FMedSci (Chair)
Dr Gillian Butler-Browne
Professor Thomas Gillingwater MBA PhD
Dr Anna Mayhew PhD
Dr Jasper Morrow MBChB PhD FRACP
Professor Olivier Pourquie PhD
Professor Mary Reilly MD FRCP FRCPI FMedSci
Professor Frédéric Relaix
Professor Ulrike Schara MD PhD
Professor Dominic Wells MA VetMB PhD MRCVS FHEA FS (Deputy Chair)
Dr Stefan Winblad

Lay Research Committee

Alex Williamson (Chair until 31 March 2020)
Richard Davenport (Vice Chair until 31 March 2020; Chair from 1 April 2020)
Peter Ashley (Vice Chair from 1 April 2020)
Andrew Graham
Corinthia Joseph
Alison Kay PhD
Giovanna de Kock
Stephen Meech (until 31 March 2021)
Hilary Rattue
Roli Roberts PhD (Scientific advisor)
Andy Rose
Helen Stockdale
Manoj Thakrar
Natalie Woodcock

Services Development Committee

Baroness Celia Thomas of Winchester MBE (Chair)
Philip Anderson
Dr Chiara Marini-Bettolo
Phillippa Farrant
Sheila Hawkins
Dr David Hilton-Jones
Professor Deirdre Kelly

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

Appeal Board

The Appeal Board is a group of senior volunteers, who meet quarterly to help raise funds and awareness through their extended networks.
Martin Cardoe (Chair)
Alex Elberg
Joseph Gordon
Martin Hywood
Tim Lumsdon
Charles Scott

Northern Ireland Council

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

Scottish Council

Dr Sheonad Macfarlane BSc Med Sci MB ChB (Chair)
Lindsey Armstrong
Michael Armstrong
Connor Colhoun
David Davidson
Claire Eadie
David Gale
Catherine Gillies
Mairi Leitch
Scott McIntyre

Gill Mitan
Allyson Townhill
Stuart Townhill

Emergency Committee

Owing to the impact of the COVID-19 pandemic on the charity, an Emergency Committee was set up for a finite period, with the CEO and Finance Director.
Professor Michael Hanna FRCP MD MRCP BM BCh FMedSci (Chair)
Marcus Brown (Treasurer)
Ian T Gordon
Joseph Gordon
Ian Mathieson
Richard Price
Charles Scott

Board of Trustees

Professor Michael Hanna FRCP MD MRCP BM BCh FMedSci (Chair)
Marcus Brown (Treasurer)
Michael Armstrong
Martin Cardoe
Ian T Gordon
Joseph Gordon
Sheila Hawkins
Louisa Hill
Claire O'Hanlon
Richard Price (until March 2021)
Charles Scott
Baroness Celia Thomas of Winchester MBE
Tanvi Vyas
Robert Warner

Senior Leadership Team

Catherine Woodhead, Chief Executive Officer
Dr Kate Adcock, Director of Research and Innovation
Rob Burley, Director of Campaigns, Care and Support
Emma Jones-Parry, Associate Director of Development
Stephen Mooney, Director of Communications and Marketing
Wojtek B Trzcinski, Director of Finance and Resources

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

We are hugely grateful to our enthusiastic and generous committee members, whose support and tireless commitment meant that this year they worked with us on virtual campaigns, set and smashed fundraising targets despite not being able to organise and attend live events. Thank you to the Microscope Ball Committee, Sports Quiz Committee, The Q Trust, The Clay Pigeon Shoot Committee and the Appeal Board.

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

MDUK relies almost entirely on voluntary donations and legacies to fund our core work. This year, because of the pandemic, we received £106k as part of the government's emergency funding to the sector (3% of our fundraising income).

As part of our role as co-chair of the Changing Places Consortium, our Campaigns, Care and Support team has received grant funding from the DfT and the MHCLG to support projects that will see significant increased provision of Changing Places toilets in England. Our DfT partnership involves the distribution of grants for installations in motorway service areas and across the transport network; and our partnership with MHCLG involves our providing information and advice to Local Authorities that are in receipt of funding to increase provision in existing buildings. These partnerships as co-chair of the Changing Places Consortium represent £2,580k (54%) of the restricted funds in our 2020/21 accounts.

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