

Annual Report 2024/25

Together we are stronger



Contents

A message from our Chair and Chief Executive	4
Zoe and Archie's story	6
About us	7
The year in numbers	8
Looking back on what we achieved	9
Our research advances	12
Driving change for access to specialist care and support	16
Living well	20
Our work in Scotland	24
The difference your support made	26
RHS Chelsea Flower Show success	30
Our President's Award winners	33
Our finances	34
Our future plans	36
Thank you	38
Our policies	42
Governance, structure and management	46
Independent auditor's report	48
Financial statements and notes	52





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

speaking 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	<ul style="list-style-type: none"> Awarded a grant of £1.15m to Professor Patrick Chinnery at the University of Cambridge
Launch a new call for £1m strategic programmes grant	<ul style="list-style-type: none"> Awarded a grant of £1m to Professor Mary Reilly at University College London
Invest over £500,000 into the 2024 new research grants programme	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Awarded two new grants as part of this scheme
Relaunch our partnership with the Medical Research Council to support clinical fellowships	<ul style="list-style-type: none"> This scheme is now live
Deliver at least £6m gross fundraising budget	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Successfully launched our <i>Change the Story</i> legacy campaign in March 2025
Invest in a portfolio review of our events and campaigns to inform our strategic direction from 2025/26 onwards	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Launched <i>Missing People. Missing Support</i> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Participated in eight treatment appraisals this year
Deliver £10m charitable expenditure budget investing our reserves to cover the deficit	<ul style="list-style-type: none"> Spent total of £10.1m on work supporting our community
Launch our new website providing a better user experience and improved navigation	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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.”

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.



Photographer: Jo Ritchie

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.

Our role in treatment recommendations 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



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

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*

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



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.



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 Zipline 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

£94,000

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

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 and zip slides to personal physical challenges, our community raised over £264,000 to support our vital work. Here are some examples of their inspirational fundraising.

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 Facioscapulo-humeral 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 £94,000 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, 60 supporters from our Family Fund network came together at the Bartonsdale 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.



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

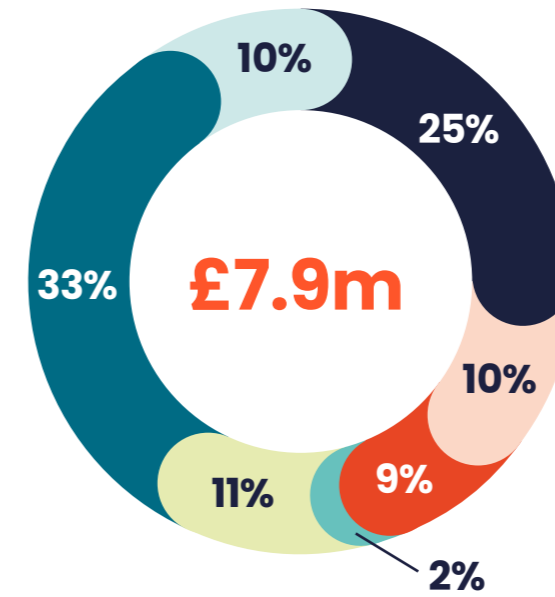
68p

is spent on our charitable activities

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

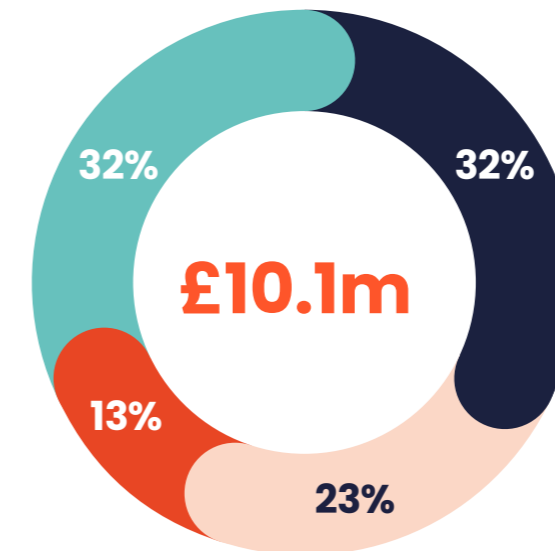


Total income



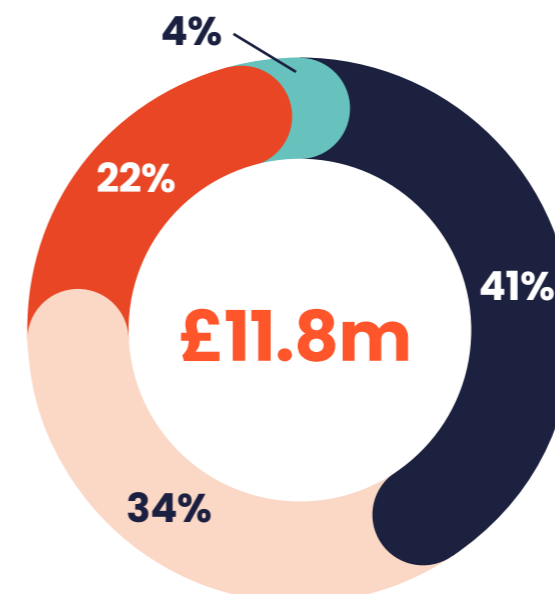
- Events and promotions (£2m)
- Individual giving (£802,000)
- Major Donors and Corporate (£678,000)
- Trusts (£193,000)
- Regional development (£873,000)
- Legacy (£2.6m)
- Other income (£821,000)

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

Our President

- Gabby Logan MBE

Honorary Life Presidents

- Sue Barker CBE
- Professor Martin Bobrow CBE FRS FMedSci

Our Patrons

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

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
- Marcus Brown
- Frances Carey
- Jeremy Champion
- Candida Crewe
- Charity Crewe
- Sebastian Crewe
- Victoria Elliston
- Sir Alex Ferguson CBE
- Bernie Henderson
- Louisa Hill
- Tim Lumsdon
- Simon Knights
- Charles G Manby MBE
- Nicola Manby
- 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
- Tanvi Vyas MBE

Our Trustees

- Professor Michael Hanna FMedSci, Chair
- Michelle Anthony
- Martin Cardoe
- Chloe Docker (from July 2024)
- Ian Gordon
- Joe Gordon, Treasurer
- Scott Keown (until October 2024)
- Professor Deidre Kelly CBE
- James Lee
- Gerry McMenemy
- Clare O'Hanlon MBE
- Charles Scott
- Lord Sharkey
- Brigid Sutcliffe

Senior Leadership Team

- Andrew Fletcher, Chief Executive (from November 2024)
- 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
- Charles and Nicky Manby
- 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
- Sally Whittet and Professor Michael Joy OBE

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
- Rosethorn Capital Partners
- 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 Eglwys 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 Seesurrin
- 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 Nirmalanathan
- 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



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.

Remuneration 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 subsidiary, Muscular Dystrophy Group (Trading) Limited, registered with the Companies House (Reg. 893086) and unincorporated charitable subsidiary, Joseph Patrick Trust, registered with the Charity Commission (Reg. 294475).

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

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

Investment Managers: 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							
<i>Income from charitable activities</i>							
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
<i>Charitable activities</i>							
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
<i>Net gain/(loss) on investment assets</i>	9	112	(4)	109	410	32	442
<i>Transfer between funds</i>		-	-	-	-	-	-
Net movement in funds		237	(2,308)	(2,071)	1,616	292	1,908
<i>Reconciliation of funds</i>							
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:

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

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

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

Services in kind are valued at the lower of their market value and equivalent market cost were these to be purchased directly by the charity. The Trustees consider that all services in kind received in 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 II of the Corporation Tax Act 2010 or section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains

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				
<i>Access to care and independent living</i>				
Access to care	-	1,101	181	1,282
Independent living	1,887	896	458	3,241
Total	1,887	1,997	639	4,523
<i>Pursuit of Knowledge</i>				
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				
<i>Access to care and independent living</i>				
Access to care	-	1,085	148	1,233
Independent living	1,018	774	245	2,037
Total	1,018	1,859	393	3,270
<i>Pursuit of knowledge</i>				
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 departmental 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 University 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						
<i>Provision of care</i>						
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						
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						
<i>Provision of care</i>						
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.

FSHD 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



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