

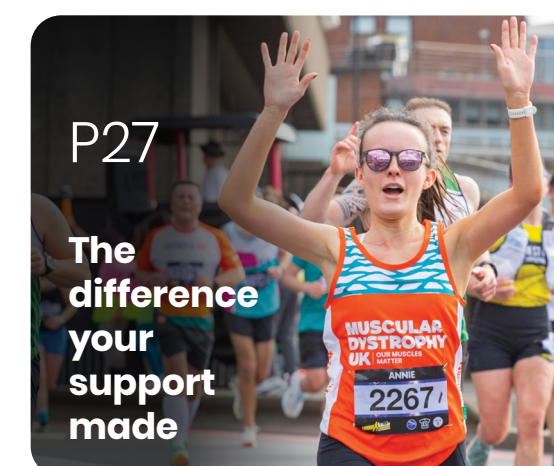
Annual Report 2023/24

Together we are stronger



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1 in 600

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

A message from our Chair and Chief Executive



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

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

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

This year we celebrated our successful five-year partnership with Oxford University in the MDUK Oxford Neuromuscular Centre, set up in 2019. During the past five years our partnership has transformed the clinical trial landscape in Oxford from almost no trials in 2019 to over 20 either in progress or being set up by end of 2023. This is all thanks to our community

of fundraisers and donors and the £1.2m investment we've been able to make in the centre during this time.

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

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

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

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

This year, our direct activities expanded to include targeted mental health support, with both psychological and counselling programmes for people living with a condition. Our GriefChat support function

reminds us that December, particularly Christmas, can be a time to gather with loved ones and remember those we've lost. This is why we appreciate the work of the Northern Ireland Council, who continue to lead our Belfast annual Spirit of Christmas event.

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

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



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

Wojtek Trzcinski
Chief Operating Officer
and Interim Chief Executive

Professor Michael Hanna
Chair

Naomi's story

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



Photographer: Rose Dedman

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

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

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

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



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

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

About us

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

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

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

Our mission

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

Our values

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

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

Objects of Muscular Dystrophy UK for the Public Benefit

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

We work:

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

Public Benefit

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

The year in numbers



We funded 11 new research projects totalling **£1.3m**.



Nearly **3,000** people were supported through our helpline.



Over **150** people were supported through our advocacy service.



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



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



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



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



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



Nearly **500** healthcare professionals attended our six upskilling webinars.



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

Looking back on what we achieved

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

Performance indicator	Our achievements
Award successful grants in our £1m joint fund with LifeArc to accelerate projects to develop new treatments for congenital muscular dystrophy.	<ul style="list-style-type: none">We awarded joint funded grants with LifeArc and will be making a formal announcement when contracts have been signed.
Launch a new £1.15m programme to pump-prime strategic research.	<ul style="list-style-type: none">We agreed to contribute £1.15m over five years in a partnership with the LifeArc Centre for Rare Mitochondrial Diseases. This followed LifeArc's £40m grant call for Translational Rare Disease Centres in which we announced we would contribute this sum to any successful centres addressing muscle wasting and weakening conditions.
Invest £500k into the 2023/24 new research grants programme.	<ul style="list-style-type: none">We invested over £500k into new research grants.
Launch a £90k three-year programme to drive innovative research into enhancing the quality of life for people living with muscle wasting and weakening conditions.	<ul style="list-style-type: none">We finalised the work for this in 2023/24 and the programme was officially launched April 2024.
Engage in a range of partnerships to begin new projects, including Horizon Europe and UKRI funded grant Next-generation models and genetic therapies for rare neuromuscular diseases, the nemaline myopathy natural history study at the University of Oxford, and a jointly funded project with the Myotubular Trust.	<ul style="list-style-type: none">We're actively involved in the Next-generation models and genetic therapies for rare neuromuscular diseases (the MAGIC consortium).The nemaline myopathy natural history study is in its final stages of approval with the regulatory authorities and should begin recruiting patients in 2024.We've committed to providing up to £60k towards a three-year partnership with the Myotubular Trust to fund a project to understand liver disease in people with X-linked myotubular myopathy.

This year’s achievements and performance measured against our 2023/24 objectives – continued



Performance indicator	Our achievements
Engage with the largest number of neuromuscular centres and patient viewpoints through our neuromuscular services audit and Centres of Excellence Awards.	<ul style="list-style-type: none">• We engaged with 27 centres through our audit of neuromuscular services and Centres of Excellence Awards process and awarded 24 Centres of Excellence and Pursing Excellence awards.
Continue to ensure that neuromuscular services and the needs of our community are represented in decisions about future provision as commissioning reforms continue, new treatments become available and the needs of our community evolve.	<ul style="list-style-type: none">• We provided health professionals with e-learning modules and upskilling webinars.• We carried out our role as a member of the NHSE Specialised Services Stakeholder Forum and a core member of the England Rare Disease Action Plan Patient Advisory Group.
Launch two new initiatives through our Mental Health Matters work to provide psychological support to our community, with the aim of providing increased access to support from a specialist neuromuscular psychiatrist or receiving targeted counselling support.	<ul style="list-style-type: none">• Our Mental Health Matters steering group, chaired by a neuromuscular clinical psychologist, met twice this year to shape support for our community.• We launched four therapeutic support groups, facilitated by a counsellor with lived experience of a muscle wasting and weakening condition.
Contribute to virtual and physical support events for both people living with muscle wasting and weakening conditions and professionals who support them.	<ul style="list-style-type: none">• We held Information Days in Northern Ireland and England, a Scottish Conference, and accessible golf day, along with seven virtual information webinars.
Provide support to neuromuscular services and fellow charities at their events.	<ul style="list-style-type: none">• We managed and facilitated five Muscular Dystrophy UK Regional Neuromuscular Networks.• We attended seven external events supporting other charities and neuromuscular services.
Deliver an Allied Health Professionals conference, a Care Adviser conference and two Information Days in England and Northern Ireland, before the return of the Scottish Conference in March 2024.	<ul style="list-style-type: none">• We held two health professional conferences, two Information Days and a Scottish Conference.
Continue to evolve our local Muscle Groups, with virtual events providing condition specific information and support.	<ul style="list-style-type: none">• We held 33 Muscle Group meetings and delivered seven virtual information webinars.
Continue to fight for access to treatments and for support services to be resourced for their roll-out. Engaging in the NICE and SMC appraisal processes for new treatments through to campaigning for SMA to be added to the NHS newborn screening programme on the newborn screening list.	<ul style="list-style-type: none">• We took part in 10 treatment appraisal processes. Two culminated in recommendations the treatment should be made available as an NHS treatment option; one was withdrawn part way through the appraisal process by the manufacturer; and seven continue into 2024/25.• We continued our role as co-secretariat of the UK SMA Newborn Screening Alliance, the work of which contributed to the securing of ‘in-service evaluation’ (pilot) of newborn screening by the NHS Newborn Screening Committee.

This year’s achievements and performance measured against our 2023/24 objectives – continued

Performance indicator	Our achievements
Complete our role in supporting the roll-out of the Department for Levelling Up, Housing and Communities (DLUHC) £30m Changing Places fund and the Department for Transport (DfT) Motorway Service Area Changing Places programme.	<ul style="list-style-type: none">• We successfully helped register a total of 324 Changing places toilets under the Changing Places scheme this year. 252 of these were part of the DLUHC and DfT programmes.
Deliver £6.6m gross budget through active fundraising (£4.2m), legacies (£1.6m) and other income (£772k), which will result in net figure of £4.4m available for our charitable activities. Invest in our legacy team to maximise the potential of this long-term income stream.	<ul style="list-style-type: none">• Delivered a gross budget of £9.5m through active fundraising (£5.3m), legacies (£2.9m) and other income (£1.3m), which has resulted in a net figure of £6.9m available for our charitable activities. Work is being done on a new legacy proposition to ensure we maximise on the potential of this long-term income stream.
Maximise return on our investment through effective deployment of resources and continued monitoring and improvement where possible of return on investment, maintaining at least 2.7 ratio or above.	<ul style="list-style-type: none">• We have continued to maintain a fundraising cost to income ratio above 2.7. In 2023/24 for every £1 we spent on fundraising we raised £3.70.
Work towards our Patient Information Forum (PIF) accreditation – a signal that we are a trusted information creator through our updated factsheets and alerts cards. A standard our community requires.	<ul style="list-style-type: none">• We were successfully awarded PIF Tick accreditation.
Reduce our overhead costs to 15% of total costs as a result of moving to smaller office.	<ul style="list-style-type: none">• Our support costs in 2023/24 financial year were £812k, which represents 10% of our total expenditure of £8,042k.
Launch our refreshed brand to reach more of the 110,000 people living with one of 60 muscle wasting and weakening conditions.	<ul style="list-style-type: none">• We launched our new brand in July 2023 and continued to roll it out throughout 2023/24.
Continue working on reducing our surplus reserves though careful investment planning alongside the existing strategy.	<ul style="list-style-type: none">• We have designated £2.1m of our free funds for the two strategic research calls. Both of which were announced in early 2024/25.
Remain committed to responsible leadership in the sector, with a continued focus on our team’s wellbeing, our impact on the environment, and equality, diversity, and inclusion for the whole community.	<ul style="list-style-type: none">• We continued to focus on our team’s wellbeing, our impact on the environment, and equality, diversity, and inclusion for the whole community by carrying out various initiatives. These included: wellbeing champion mental health first aiders group, financial wellbeing webinars and wellbeing resources, our EDI working group, and offsetting the carbon emissions from the 2023 Oxford 10k, making it our first carbon neutral Town and Gown event.

Our research advances

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

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



Photographer: Teri Pengilley



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

Our 2023 grant awards

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

The European Neuromuscular Centre

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

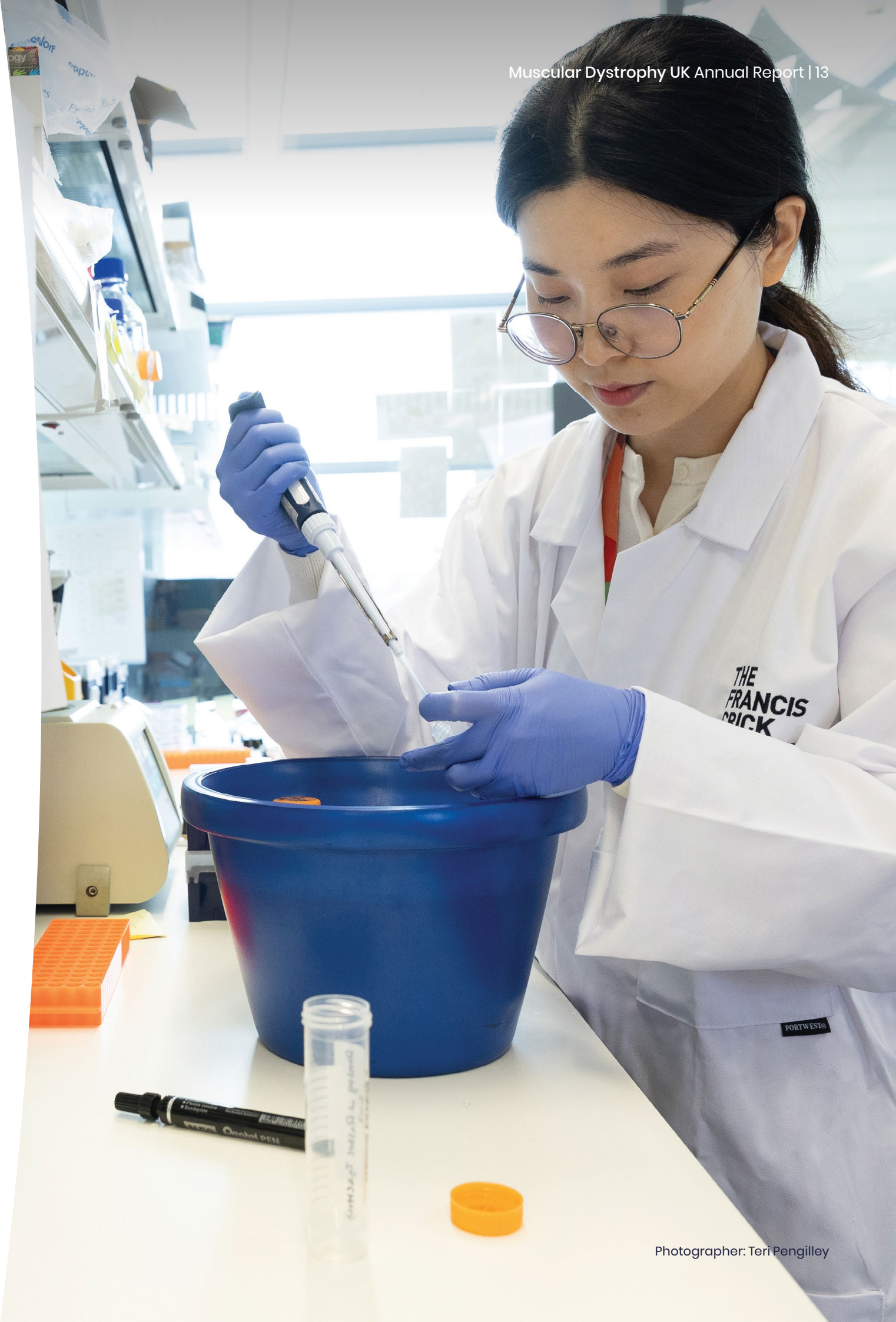
Our Research Line

Through our research line, we continued to ensure patients and families could

access information about new research studies, treatments, and clinical trials for muscle wasting and weakening conditions.

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

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



Photographer: Teri Pengilley

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

Medical Research Charities Early-Career Researcher Fund

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



Photographer: Teri Pengilly

Highlights of our research funding

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

The role of periostin in Duchenne muscular dystrophy

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

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

We use skeletal muscles to move our bodies. They are made up of long fibres supported by an intricate range of other cells. Recreating this intricate system in the laboratory is invaluable to

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

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

We funded research looking at whether a self-management support programme called Neuromuscular Bridges could successfully be used in neuromuscular specialist centres. The programme focuses on building patients’ confidence and includes special training for healthcare



£1.2m

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

£382,000

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

11

new grants worth over £1.3m awarded this year

43

active research projects

professionals. As part of his PhD studies, Dr Laurence Lee, supervised by Dr Gita Ramdharry, found the programme was helpful to clinicians and people living with muscle wasting and weakening conditions.

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

Professor Linda Popplewell, Professor of Genetic Medicine at Teesside University

Driving change for access to specialist care and support

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

Our role in treatment recommendations and appraisals

This year we continued to be active in 10 muscle wasting or weakening treatment appraisal processes with the National Institute for Health and Care Excellence (NICE) and Scottish Medicines Consortium (SMC). These appraisals result in recommendations as to whether a treatment should be made available on the NHS. As a formal stakeholder, we ensure the experience

of our community is fully represented, submitting evidence on their behalf and supporting people to deliver in-person evidence in appraisal committee meetings. This year we were selected as the formal Patient Expert for the NICE appraisal of Duchenne muscular dystrophy treatment vamorolone, which meant we also took part in an appraisal committee meeting.



Photographer: Jo Ritchie



10
treatment appraisal processes participated in

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

155
attendees at our Allied Health Professional virtual conference

507
enrolments on our e-learning modules

465
attendees for our six health professional upskilling webinars



Photographer: Jo Ritchie

Connecting and upskilling health professionals

24 Centres of Excellence or Pursuing Excellence awarded

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

Our health professional conferences

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

Our Allied Health Professionals Conference

We expanded our traditional Physiotherapy Conference into an Allied Health Professionals Conference, responding to requests from health professionals in other disciplines wishing to deepen their understanding of the

multidisciplinary care of people living with muscle wasting and weakening conditions. The event was very well attended, with 155 participants hearing about a wide range of topics, including transition, pregnancy care, speech and language therapy strategies, and practical case studies.

Our Neuromuscular Care Advisor Conference

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



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

Neuromuscular Care Advisor Conference attendee.

Our virtual upskilling and networking opportunities

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

Our regional neuromuscular networks

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

Our parliamentary and policy work

Providing support to muscular dystrophy parliamentary groups

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

Consultation responses

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

Our community survey

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

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



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

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



Photo: Manchester University NHS Foundation Trust

Living well

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

Our helpline service

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

Our advocacy service

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



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

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

Supporting people through grants

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

Our tailored therapeutic support groups

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

Our tailored peer support

Our peer support groups continue to flourish. In the past year we've facilitated support groups based on condition, age or circumstances, such as recently receiving a condition diagnosis. We've also worked in

partnership with the Teapot Trust, a mental health charity providing art therapy for children and families living with long term health conditions, to pilot a support programme for primary school aged children living with muscle wasting and weakening conditions. Alongside these new groups, we continue to offer one-to-one peer support from our trained peer support volunteers with lived experience.

Muscle Groups – keeping people updated and connected

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

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



Photographer: John Sanders



2,752

people contacted our helpline

470

people received a cost-of-living grant

459

people requested our alert cards

315

people attended our regional Muscle Group meetings

162

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

152

people supported by our advocacy service

108

people joined our tailored support WhatsApp groups

53

people received a Joseph Patrick Trust equipment grant

65

people received peer support from our volunteers

Our virtual information webinars

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

Our Information Days

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

Becoming PIF accredited for trusted health information

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

Our Employability Programme

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

Changing Places toilets

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

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

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



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

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

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

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

Our work in Scotland

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

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

Our Scottish Conference

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

Scottish Disability Sports

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

Scottish Council

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

Fundraising update

Our Family Funds

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



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

Scottish Conference attendee

Community fundraising activities

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

A growth in runs and walks

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



Photographer: Julie Broadfoot

Our total fundraising in Scotland

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

Research

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

£719,622

total funds raised to support our work in Scotland

65

people attended our Scottish Conference

£10,600

raised by our Family Funds in Scotland

316

requests for support responded to



Photographer: Vincent White

The difference your support made

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



Highlights of this year's fundraising

Our Bidwells 10k Town and Gown running series

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

Our Celebrity Sports Quiz

For the first time since the Covid pandemic we returned to the prestigious Long Room at Lord's Cricket Ground for our Celebrity Sports Quiz – hosted by our charity President Gabby Logan MBE and her good

friend sports presenter and TV personality Kirsty Gallacher. Sporting greats who attended to support us included Jessica Ennis-Hill, Sir Geoffrey Boycott, Monty Panesar and Robin Cousins. Guests on the night enjoyed quizzing with our sports celebrities and raised £88,000.



Photographer: Ikin Yum

Our challenge events

Pedal Paddle Peak 2023

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

London Marathon 2023

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

Our fundraising year in numbers:

£39,500

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

£90,000

raised from our inaugural Double Your Donation campaign that ran for a week in December

£2.9m

raised from 75 individual legacies

£835,373

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

£427,000

raised at our annual Microscope Ball thanks to the support of the property industry



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

Family Fund weekend participant

Our Family Funds

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

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

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

Supporter led events

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

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

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

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

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

Up and down the country, supporters organised golf days

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

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

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



Photography: Supporter

Team Jed's 24-hour work out

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

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

Jed Thirkettle

Photographer: Olivia Sirley

RHS Chelsea Flower Show

Muscular Dystrophy UK Forest Bathing Garden

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

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

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

Our Garden

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

Ula researched the theme of Forest Bathing, inspired by the ancient Japanese practice of Shinrin-yoku, immersing yourself in nature away from the stresses and strains of everyday life. Being in the forest has

proven mental and physical health benefits. Living with a muscle wasting condition can add to the mental load and the garden set out to create an accessible space that would benefit the muscle wasting community.

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

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



Photographer: Rebekah Kennington



Illustration: Ula Maria

Our President's Award winners



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

**Peter and Nancy Andrews
Community Achievement Award**

Bryan Gould

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

Fundraiser of the Year Award

Jed Thirkettle

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

Early Scientist of the Year Award

Meredith James

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

Volunteer of the Year Award

Amanda Hayes

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

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

William Jackson

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

**Richard Attenborough Award
for Outstanding Achievement**

Professor Francesco Muntoni

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

Our finances

How we raised our funds

For every **£1** we spent:



32p

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

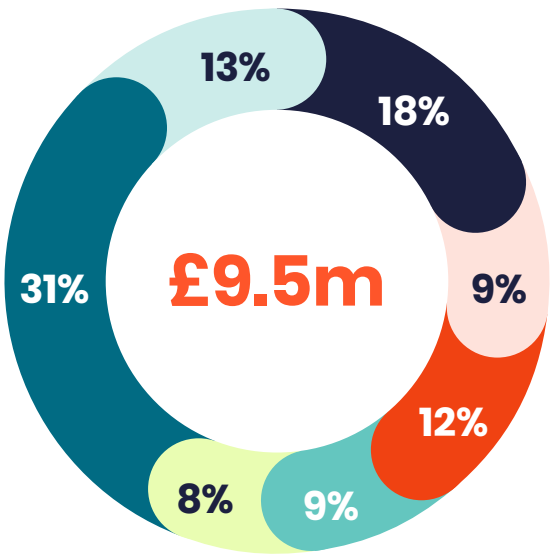
68p

is spent on our charitable activities

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

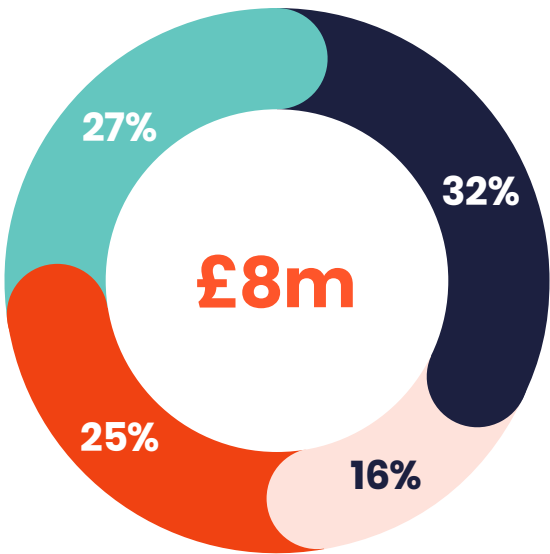


Total income



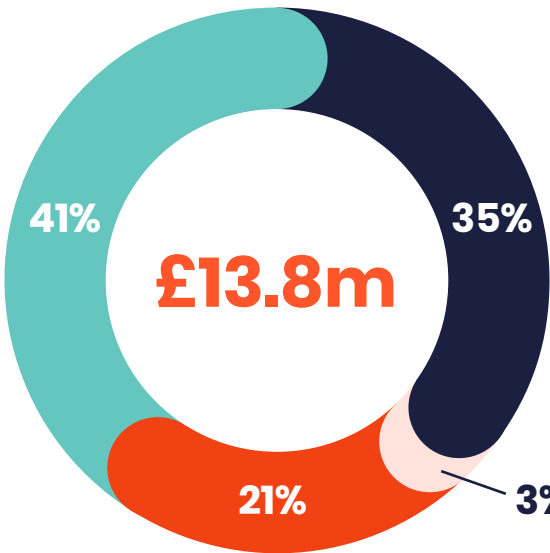
- Events and promotions** (£1,726k)
- Direct marketing** (£824k)
- Major Donors and Corporate** (£1,106k)
- Trusts** (£894k)
- Regional development** (£768k)
- Legacy** (£2,920k)
- Other income** (£1,270k)

Total expenditure



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

Total funds



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

Our future plans



Going forwards in 2024/25, we will:

- Provide accurate and accessible information, support and signposting, through our national telephone and email helpline service and advocacy support where information provision is not sufficient, and empowerment is needed.
- Connect people affected by muscle wasting and weakening conditions through our national events and virtual seminars, through local groups and through our network of trained peer support volunteers.
- Provide grants to members of our community for essential powered mobility equipment.
- Deliver targeted campaigns on key areas of concern to our community and drive-up UK wide political awareness and support for muscle wasting and weakening conditions.
- Continue as co-chair of the Changing Places Consortium and complete UK Government funded Changing Places programmes.
- Provide unique national physical conferences and virtual training opportunities for specialist and non-specialist health professionals involved in the care of people living with muscle wasting and weakening conditions.
- Provide regional networking, information and intelligence sharing, and upskilling opportunities to health professionals involved in the care of people living with muscle wasting and weakening conditions.
- Map and understand the provision of specialist neuromuscular services across the UK, seek to protect the provision of specialist NHS neuromuscular services and secure additional NHS resource, recognise and disseminate best practice and support neuromuscular services to navigate ongoing healthcare commissioning and delivery reforms
- Help to facilitate access to treatments for muscle wasting and weakening conditions.
- Deliver at least £6m gross fundraising budget.
- Deliver £10m charitable expenditure budget investing our reserves to cover the deficit.
- Invest in a new legacy proposition to maximise the potential of this long-term income stream.
- Invest in a portfolio review of our events and campaigns, which will inform our strategic direction from 2025/26 onwards.

- Launch our new website providing a better user experience and improved navigation.
- Deliver a successful garden at the RHS Chelsea Flower Show 2024, maximising opportunities to reach new people and raise awareness of muscle wasting and weakening conditions.
- Launch a brand campaign to reach people affected by the conditions who aren't currently engaging with the charity.
- Award a grant as part of our partnership with the LifeArc Translational Rare Disease Centre.
- Launch a new call for £1m strategic programmes grants.
- Invest over £500k into the 2024 new research grants programme.
- Continue to engage in a range of research partnerships, including the MAGIC consortium and the LifeArc programmes.
- Award grants as part of our three-year programme to drive innovative research into enhancing the quality of life for people living with muscle wasting and weakening conditions.
- Relaunch our partnership with the Medical Research Council to support clinical fellowships.



Photographer: Kavi Shah

Thank you

Our President

- Gabby Logan MBE

Honorary Life Presidents

- Sue Barker CBE
- Professor Martin Bobrow CBE FRS FMedSci

Our Patrons

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

Research Vice Presidents

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

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- Sophia Bergqvist
- Frances Carey
- Jeremy Champion

- Candida Crewe
- Charity Crewe
- Sebastian Crewe
- Victoria Elliston
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- Andrew Graham
- Bernie Henderson
- Louisa Hill
- Tim Lumsdon
- Simon Knights
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- Nicola Manby
- Andy Martin
- Ian Mathieson
- Ann McNeil
- Jeremy D Pelczer
- Julian Pritchard
- Michael A Thirkettle
- Baroness Celia Thomas of Winchester MBE
- Robert Warner
- Alex Wellesley Wesley
- Sir Guy Weston

Our Trustees

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

Senior Leadership Team

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

Key Donors

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

Corporate Support

- AirNow Technology
- Bidwells
- BGC Charity Day
- BMW North Oxford
- CeX
- Chimera
- Crocus
- DC Merrett

- Diligencia Group
- Forex Clear
- Mail Metro Media
- Marchmont Investment Management
- Nurture Landscapes
- Orbis
- Premier Paper Group Ltd
- Project Giving Back
- Property Week
- Rosethorn Capital Partners
- Siren
- Tennants Consolidated
- Ula Maria Studio

Trusts and Foundations

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

Golf Day Committee

- Stephen Rigby

Clay Pigeon Shoot Committee

- John Eaglesham
- Nick Moldon
- Simon Tann

Sports Quiz Committee

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

Microscope Ball Committee

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

The Q Trust Committee

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- Candida Crewe
- Charity Crewe
- Victoria Elliston
- Inez Gordon
- Rebecca Jennings
- Nicky Manby
- Alex Wellesley Wesley

Joseph Patrick Trust Grants Panel

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- Jane Field
- Jane Freebody
- James Lee
- Patricia Lock
- Julian Pritchard
- Kirsty Read

The Welfare Fund of Muscular Dystrophy UK

- Robert Warner, Chair
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- Karen Duckmanton
- Jane Field
- Jane Freebody
- James Lee
- Patricia Lock
- Julian Pritchard, Vice Chair
- Kirsty Read

Finance Committee

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

Appointments and Remuneration Committee

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

Medical Research Committee

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

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

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- Dr Jatin Pattni
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- Professor Francesco Muntoni
- Professor Ros Quinlivan
- Carolyn Young
- Tanvi Vyas

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

Scottish Council

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



Photographer: Rebekah Kennington

Our policies

Fundraising statement

Our supporters are key to changing the future of muscle wasting and weakening conditions, and in observing and promoting a consistently high standard of fundraising. We regularly monitor our practices to identify training requirements and set policy priorities for our fundraising. We work to ensure a culture of honesty, integrity and respect with the public, as well as transparency of process to our donors about our cause and the way that their donation will be used. We also recognise how important it is to manage our supporters' data compliantly, with both care and integrity. Our statement of fundraising best practice, underlies our commitment to the following personal information practices:

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

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

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

We offer many different opportunities for our fundraisers and donors to engage with us to allow us to fulfil our charitable objectives. These include special and challenge events; corporate partnerships; trusts and foundations; regional and community fundraising activities, including Family Funds; fundraising groups, branches and events; individual giving, which includes regular giving, major gifts, appeals, raffles and a weekly lottery, membership scheme; Christmas cards and online shop sales; legacy and in-memory programmes.

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

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

training as well as seminars and events by relevant providers.

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

Financial review and policies

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

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

Expenditure on charitable activities was in respect of medical research, access to specialist NHS care and support, and the provision of information, support, and opportunities to enable independent living. The total charitable expenditure has increased by over £600k (13%) from that of the previous year to £5,446k (2023: £4,826k). This increase was reflected across all charitable activities.

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

The charity ended 2023/24 with a surplus of £1,908k (2023: £1,084k), including £442k net gains (2023: £281k net loss) on investment assets. The surplus included £1.7m estimated accrual for legacy income, which we are expecting to receive in the future years when the legal matters relating to the estates are finalised.

Reserves policy

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

The recommended free reserves level is revised annually as part of the budget process, assessing the financial impact of the current risks facing the charity. The reserves policy is reviewed annually by the Trustees. The charity seeks to maintain free reserves to manage the risks to which the charity is exposed in the course of its business, including but not limited to safeguarding against volatile voluntary income. The Trustees consider that to meet these needs, and to operate effectively, the charity needs to maintain free reserves between £1.65m to £2.2m, based on the current analysis of risk. This has been reviewed in line with 2024/25 budget and the reserves requirement was not increased in the 2023/24.

The free reserves funds balance at 31 March 2024 was £5.7m. It continues to be higher than the target level agreed by the Trustees, partly as a result of high legacy income recognised at the year end. Due to legacy income recognition accounting requirements, we often recognise the income before the actual cash is received. Our legacy accrual (income recognised

but not yet received) was £1.7m at 31 March 2024. The timing differences between recognition and receipt of the legacy income creates a challenge for the charity in planning for expending these funds, as we cannot commit them to projects until the funds clear. The legacy accrual represents 50% of the reserves surplus of £3.5m.

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

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

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

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

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

Having reviewed the strategic risks facing the charity and the 2024/25 budget projections, the Board of Trustees considers there are sufficient reserves held on 31 March 2024 to manage those risks effectively. Accordingly, they continue to adopt the 'going concern' basis in preparing the Annual Report and Accounts.

Investment policy

The overall objectives are to create sufficient income and capital growth to enable the charity to carry out its purposes consistently year by year with due and proper consideration for future needs and the maintenance of, and if possible, the enhancement of, the value of the invested funds while they are retained. Both capital and income may be used at any time for the furtherance of the charity's aims. The objectives are to be achieved by investing prudently in a broad range of fixed interest securities and equities, which are quoted on a Recognised Investment Exchange, and Unit Trusts and OEICs (open-ended investment companies), which are authorised under the Financial Services and Markets Act 2023. There should be no direct investment in the following: derivative contracts, including futures and options; commodities and derivatives thereof, contracts for differences or structured products. The investment policy and the investment managers'

performance are reviewed by the Finance Committee on an annual basis.

Ethical considerations

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

In 2023/24, Trustees have reviewed the approach of the fund manager towards avoiding offenders in greenhouse gas emissions. It is felt their approach continues to be sufficient. Trustees reserve the right to exclude companies or industry sectors that carry out activities contrary to the aims of the charity, or from holding particular investments that damage the charity's reputation. Trustees expect the fund manager to have considered the suitability of investments of the same kind as any particular investment proposed or retained.

In 2023/24, Trustees and the Senior Leadership Team (SLT) confirmed that the fund manager was not investing in Russian businesses following the Russian invasion of Ukraine in February 2022.

Remuneration policy

Salaries of the Chief Executive and the SLT are set by the Board's Appointments and Remuneration Committee, taking into account the performance of the charity overall, external comparisons, and the needs of the charity in the longer term. The Board's Appointments and Remunerations Committee reviews the performance of the CEO and the SLT annually. The charity pays above the London Living Wage for all posts. We advertise vacancies on our website and seek applicants

from both our current staff and externally. No member of the SLT has a car supplied by the charity, and all staff members (and Trustees) travel on standard fares on charity business. None of the Trustees are paid any remuneration or receive other benefits from their charity work. Details of reimbursed expenses to Trustees can be found in Note 18.

Risk management

The Trustees continue to support formal risk management procedures, to assess business risks and implement strategies to minimise risk. Risks have been identified and classified in terms of their potential impact and likelihood, and the processes in place to manage them. The comprehensive risk management strategy is based upon a detailed risk register, which is subject to regular scrutiny and review. Risks are reviewed against the strategic aims of the charity and evaluated against controls in place. Action plans to minimise or remove risk where possible are in place and kept under review. A detailed risk approach review was last conducted in 2022/23 with support of an external expert and training provided to Trustees and SLT. The following risks have been identified in 2023/24 as the most significant for the charity's financial sustainability:

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

strategic growth, as well as enable the organisation to be flexible to respond to the community needs when/if required. This includes plans for spending any surplus unrestricted reserves, implemented in 2023/24 with a two to three year ambition to reduce reserves closer to the agreed minimum levels though investments in charitable activities. This has been reflected in the 2024/25 budget and the decision to designate some funds in the 2023/24 financial year.

- c. The impact of a stock market crash** on the value of the investment portfolio, mitigated by taking the advice of professional investment managers and long-term investment strategy and maintaining higher than expected reserves to protect the charity against external economic factors.
- d. Data protection breach:** given GDPR, fines and attacks on data, this is a very real risk to the charity; leading professionals have been advising us and we continue to work proactively to address this. We have upgraded our database and data storage environment (cloud) to ensure we take advantage of the latest available technologies. We work closely with our external IT provider to ensure we follow best industry practices to protect the charity from cyber-security threats, including staff training and 24-hour network monitoring services.
- e. Providing information** that meets our users' needs is essential for their continued support – the charity will continue to review all communications, publications, and the website to ensure they meet our

audiences' needs. We continue to diversify our communication channels to ensure we increase our outreach outside our community of over 110,000 people living with a muscle wasting and weakening condition. As a result of this we launched our new refreshed brand in June 2023 and new website in May 2024.

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

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

Grant-making policies

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

We also makes grants for equipment though the Joseph Patrick Trust (JPT) subsidiary. The JPT committee considers applications against approved criteria before approving grants.

In 2022/23 the cost-of-living crisis was a key concern for our community; the JPT Committee agreed to offer a one-off cost-of-living grant to people living with muscular dystrophy and associated conditions we support. These grants were approved in March 2023 and paid out from April 2023. The volume of demand for the grants created technical and administrative challenges that resulted in two complaints being received and handled.

Reference and administrative details

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

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

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

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

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

The details of the President, Patrons, Honorary Life Presidents, Vice Presidents, Trustees, Committees, SLT and advisors are set out on pages 38 to 40.

Structure, governance and management

Governing document

The Muscular Dystrophy Group of Great Britain and Northern Ireland, operating as Muscular Dystrophy UK, is a company limited by guarantee governed by its Memorandum and Articles of Association, dated 2 September 1961 and as amended on 12 October 2019, to allow for current arrangements and charity law best practice. Muscular Dystrophy UK is registered as a charity with the Charity Commission and the Office of the Scottish Charity Regulator. Anybody over the age of 18 who supports and promotes the objectives of the charity can become a member, excluding current staff. Muscular Dystrophy UK has a wholly owned trading subsidiary, Muscular Dystrophy Group (Trading) Ltd. and not-for-profit grants giving subsidiary, Joseph Patrick Trust.

Appointment of Trustees

Muscular Dystrophy UK has between seven and 17 Trustees. The selection, appointment, retirement and duties of Trustees are described in detail in the Memorandum and Articles of Association (article 29–44 et al). During the year, three Trustees stepped down completing their terms, one Trustee was re-elected for a second term and three new Trustees were elected. Their appointment was subject to a rigorous review by the Appointment and Remuneration Committee and Board of Trustees, bearing in mind the need for progressive refreshing of the Board's skills and experience. All appointments and resignations were approved by the Company

Members with a majority vote at the AGM in October 2023. Two Trustees who have served more than nine years (Professor Hanna, Chair and Ian Gordon, Senior Independent Trustee) were re-elected for a further term in October 2023, within the requirements of the Memorandum and Articles of Association. This decision was approved by more than 70% of all Trustees and supported by Company Members majority at the AGM in 2022. It was considered important to provide strategic leadership continuity following the turbulent years of the Covid pandemic and the cost-of-living crisis. As such, the decision to re-appoint these two Trustees was taken in the best interest of the Charity.

Trustee induction and training

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

Organisation

The Board of Trustees is ultimately responsible for the management of MDUK. The Board meets quarterly, and there are standing committees covering key areas of activity: research (Medical Research Committee, MRC, and Lay Research Panel, LRP), care

(Services Development Committee, SDC), finance and fundraising (Finance Committee), Marketing (Content Advisory Group, CAG) and appointments (Appointments and Remuneration Committee). A Chief Executive, with delegated authority, is appointed by and is accountable to the Trustees for managing the day-to-day operations of MDUK and the delivery of operational plans.

Members

In January 2024, we wrote to 265 charity members to ask for their confirmation as charity members, appreciating the breadth of ways people can engage with the charity and their changing needs. We now have a body of 87 charity members, who carefully monitor the charity's progress. The charity members are volunteers drawn from the various stakeholder groups the charity represents: individuals, family members, scientists, doctors, MPs, Lords and others. Trustees are members. If you are keen on following the charity's work and would be interested in becoming a member, please contact the charity.

Volunteers

Volunteers are central to our work. We rely on voluntary help in all aspects of the work of the charity. Volunteers work in the office, get involved in fundraising, provide their advice and guidance on many committees, provide support to individuals and families with muscle wasting and weakening conditions, and get involved with campaigning and media work. All these efforts help the

charity achieve its aims and objectives and we would like to thank them all for their hard work and support.

Charity Governance Code

This code is a practical tool to help charities and their trustees develop high standards of governance. The Board is reminded of the code, and we continually work together on how we should apply these principles and practices during updates in the Board meetings, CEO reports and at the annual Board Away Day. In 2024/25 the Trustees engaged in workshops about the organisational purpose, vision, and values; were regularly updated on the culture of the organisation; supported on the updated risk management plans; and engaged in committees. These committees and the Board of Trustees are annually reviewed and updated to ensure they are an effective team with a balance of skills, experience, and backgrounds to make informed decisions, and to ensure that no one individual has undue power or influence.

Related parties

The Joseph Patrick Trust (JPT), an unincorporated charity, (Reg. 294475), is our welfare arm, which is its sole corporate Trustee. Constituted on 30 April 1986, with the support of the Patrick family, it provides direct financial assistance in the form of welfare grants to individuals and families living with muscle wasting and weakening conditions, throughout the UK. The consolidated financial statements also include the trading subsidiary, Muscular Dystrophy Group (Trading) Limited (Reg. 893086). We maintain extremely close working relationships with partner charities that also assist those living with muscle wasting conditions.

Statement of Trustees' responsibilities

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

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

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the Charities SORP.
- Make judgments and accounting estimates that are reasonable and prudent.
- State whether applicable UK accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements.
- Prepare the financial statements on the going

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

Provision of information to auditors

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



Professor Michael Hanna
Chair, 17 October 2024

Independent auditor's report

Opinion

We have audited the financial statements of Muscular Dystrophy Group of Great Britain and Northern Ireland (the 'parent charitable company') and its subsidiaries (the 'group') for the year ended 31 March 2024 which comprise the Consolidated Statement of Financial Activities (incorporating an Income and Expenditure Account), the Group and Parent Charitable Company Balance Sheets, the Statement of Group Cash Flows and notes to the financial statements, including significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the group's and the parent charitable company's affairs as of 31 March 2024 and of the group's incoming resources and application of resources, including its income and expenditure, for the year then ended.
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and

- have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 (as amended) and regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

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

Conclusions relating to going concern

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

Based on the work we have performed, we have not identified any material uncertainties relating to events

or conditions that, individually or collectively, may cast significant doubt on the group's and parent charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

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

Other Information

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

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements, or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements themselves.

If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

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

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

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

Responsibilities of the Trustees

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

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

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

Auditor's Responsibilities for the audit of the financial statements

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

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

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

We also:

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

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

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

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

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

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect

of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below.

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

Our approach was as follows:

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

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

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

Use of our report

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

Moore Kingston Smith LLP

Andrew Stickland
Senior Statutory Auditor

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

9 Appold Street,
London EC2A 2AP

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

Financial statements and notes

Consolidated Statement of Financial Activities (Incorporating an Income and Expenditure Account)

For the year ended 31 March 2024

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

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

Balance Sheets

As at 31 March 2024
Company Registration Number: 205395

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

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

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

Professor Michael Hanna
Chairman

Joseph Gordon
Treasurer

Statement of Group Cashflows

Year Ended 31 March 2024

	2024 £000	2023 £000
Net cash inflow/(outflow) from operating activities (note a)	(182)	1,069
Net Cash flow from investing activities	-	-
Dividends from investments	407	159
Purchase of Tangible Fixed Assets	(86)	(196)
Proceeds of sale of Investments	976	3,006
Purchase of Investment	(2,148)	(2,904)
Net Cash provided by investing activities	(851)	65
Increase/(decrease) in cash and cash equivalents in the year	(1,033)	1,134
<i>Reconciliation of net cash inflow to movement in net funds</i>		
Increase/(decrease) in cash and cash equivalents in the year (note b)	(1,033)	1,134
Cash and cash equivalents at the beginning of the year	8,641	7,507
Cash and cash equivalents at the end of the year	7,608	8,641
Notes to cash flow statement		
<i>(a) Reconciliation of net movement in funds to net cash flow from operating activities:</i>		
Net movement in funds	1,908	1,084
Dividends from investments	(407)	(159)
Investment (gains) / losses	(442)	281
Depreciation	117	117
Decrease / (Increase) in debtors / stock	958	(620)
Increase / (Decrease) in all creditors	(400)	366
Net cash provided by/(used in) operating activities	182	1,069

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

Notes to the financial statements

For the year ended 31 March 2024

Policies

1. Accounting policies

Accounting convention

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

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

Going concern accounting policies

The charitable company’s level of free reserves available at the year end, were considered adequate resources to continue in operational existence for the foreseeable future, even with continuous impact of the cost-of-living crisis. The budgets and cash flows for 2023/24 were reviewed in September 2023 and the Trustees have considered cash forecasts covering the twelve month period until October 2024. Accordingly, the financial statements have been prepared on a going concern basis and the trustees do not anticipate any material uncertainties.

Basis of consolidation

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

- Muscular Dystrophy Group (Trading) Limited (registered company number 00893086).

- The Joseph Patrick Trust (JPT), an unincorporated charity, (registered charity number 294475).

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

Income

Income is recognised in the SOFA when the effect of the transaction results in an increase in the charity’s assets. This will be dependent on three factors:

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

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

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

Services in kind are valued at the lower of their market value and equivalent market cost were these to be purchased directly by the charity. The Trustees consider that all services in kind received in 2023/24 do not meet recognition criteria outlined in module

6 of the charity SORP 2019. Therefore, no estimates for these services were included in this set of accounts.

Expenditure

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

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

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

Muscular Dystrophy UK awards three types of grants:

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

Taxation

Muscular Dystrophy Group of Great Britain and Northern Ireland and the Joseph Patrick Trust are registered charities with the meaning of para 1 schedule 6 Finance Act 2010. Accordingly, they are exempt from taxation in respect of income or capital gains within categories covered by Chapter 3 of Part 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. Cash at bank and in hand is defined as all cash held in instant access bank accounts and used as working capital. Financial liabilities held at amortised cost comprise all creditors except social security and other taxes.

Intangible and tangible fixed assets and depreciation

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

Leasehold premises: over length of lease
Motor Vehicles: over three years
All other assets: over four years.

Operating leases

The charity provides for operating leases on property on an actual cost basis. Rent-free periods on property are apportioned over the life of the lease. Any rent-free period is to offset the additional costs incurred by moving into new premises and reflects the inducement offered in that period by the landlord to let the property.

Debtors

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

Cash at bank and in hand

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

Creditors and provisions

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

Employee benefits

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

Pensions

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

Accounting estimates and areas of significant judgment

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

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

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

Stock

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

Fund accounting policies

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

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

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

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

Notes to the financial statements

For the year ended 31 March 2024

2. Income

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

* Of this income £1,228k comes from Government Grants (2023: £941k). The government grants included £382k (2023: £274k) from UK Government Covid Medical Research Charity Support Fund included in Trust income above, and £740K (2023: £450k) from the Department of Transport and £106k (2023: £217k) from the Department for Levelling Up, Housing and Communities included in Other income figure.

3. Expenditure

	Grants £000	Other £000	Support Costs £000	Total 2024 £000
Raising Funds				
Expenditure on raising funds	-	2,329	153	2,482
Costs from other Trading Activities	-	109	5	114
Total	-	2,438	158	2,596
Charitable Expenditure				
<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

3. Expenditure (Cont.)

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

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

‘Support Costs’ comprise of the following:

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

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

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

4. Staff costs (Group and Parent Charity)

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

No redundancies were made in the year (2023: 1). The cost of the redundancy payments was nil (2023: £8k). The monthly average number of employees during the period was 70 (2023: 65), of whom there were the following higher paid employees as detailed below.

Details of the Key Management Personnel, which consists of the Senior Management Team, can be found on page 38. Their total aggregate employment benefits were £469k (2023: £444k).

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

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

Pension Schemes

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

5. Grant expenditure

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

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

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

Apart from the two strategic grants at University College London (North Star Project) totaling £330k and one grant of £97k to University of Oxford (Nemaline myopathy natural history study), there were no institutions in receipt of material research grants (over £80k pa) in 2023/24.

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

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

5. Grant expenditure (Cont.)

Reconciliation of grant funding commitments:

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

6. Operating lease commitments

Muscular Dystrophy UK is committed to the following minimum lease commitments under a non-cancellable operating lease on its headquarters and office equipment.

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

7. Net income

Net Income is stated after charging

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

8. Tangible fixed assets

Group	Leasehold premises £000	Computer equipment £000	Motor Cars £000	Other assets £000	Other equipment £000	Total £000
Cost at 1 Apr 2023	309	437	16	15	28	805
Additions	17	66	–	–	3	86
Disposals	(200)	(3)	–	–	–	(203)
At 31 Mar 2024	126	500	16	15	31	688
Depreciation 1 Apr 2023	200	188	16	–	–	404
Disposal	(200)	(3)	–	–	–	(203)
Provided for year	11	97	–	–	9	117
At 31 Mar 2024	11	282	16	–	9	318
Net Book Value						
At 31 Mar 2024	115	218	–	15	22	370
At 31 Mar 2024	109	249	–	15	28	401

8. Tangible fixed assets (Cont.)

Parent Charity	Leasehold premises £000	Computer equipment £000	Motor Cars £000	Other assets £000	Other equipment £000	Total £000
Cost at 1 Apr 2023	309	434	16	15	28	802
Additions	17	66	-	-	3	86
Disposal	(200)	(3)	-	-	-	(203)
At 31 Mar 2024	126	497	16	15	31	685
Depreciation 1 Apr 2023	200	185	16	-	-	401
Disposal	(200)	(3)	-	-	-	(203)
Provided for year	11	97	-	-	9	117
At 31 Mar 2024	11	279	16	-	9	315
Net Book Value						
At 31 Mar 2024	115	218	-	15	22	370
At 31 Mar 2023	109	249	-	15	28	401

All tangible fixed assets are used in the promotion of Muscular Dystrophy UK’s work; none is held for investment. Included in Other Assets are three portraits especially commissioned by the charity; they are held at a cost of £15k. In the opinion of the Trustees, they are worth not less than this valuation and as such no depreciation is charged.

9. Investments

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

Spread of Investments

The investments of Muscular Dystrophy UK are held as follows:

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

Investment management costs for the year were £27k (2023: £26k). There was no individual investment that constituted more than five percent of the total investment portfolio (at market value) as at the year end. (2023: £nil)

10. Income from investments

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

11. Investments in subsidiary undertakings

- The accounts of Muscular Dystrophy UK (i.e. ‘charity’ accounts) incorporate the results of the following entity on a line-by-line basis:
- Joseph Patrick Trust, a separately registered charity, 294475, which makes grants towards welfare equipment. Muscular Dystrophy UK is the sole corporate Trustee.
 - Muscular Dystrophy Group (Trading) Limited, 893086, which undertakes trading activities on behalf of the charity and covenants all profits to the charity. Muscular Dystrophy UK is the sole shareholder.
 - They are both registered at 32 Ufford Street, London, SE1 8QD.

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

	Muscular Dystrophy Group (Trading) Ltd £000	Joseph Patrick Trust £000
Fixed Assets	-	247
Current Assets	97	68
Current Liabilities	(141)	(181)
Total Net Assets	(44)	134
Represented by:		
Total Funds	(44)	134
Total income	67	11
Total expenditure*	(114)	(116)
Investment gains/losses and other B/S movements	-	18
Surplus for the year	(47)	(87)
Country of Registration	England	England
Number of fully paid £1 ordinary shares	100	-
Voting rights owned by Muscular Dystrophy UK	100%	100%

12. Stock

The stock held in Muscular Dystrophy Group (Trading) Ltd represents new goods available for sale valued at £14k (2023: £16k).

13. Debtors

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

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

14. Creditors falling due within one year

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

15. Funds

	April 2023 £000	Income £000	Expenditure £000	Movement between funds £000	Investment gains £000	March 2024 £000
Endowment Fund						
Orchid Ball	387	-	-	-	32	419
Restricted Funds						
<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 Sreening	-	95	(69)	-	-	26
Chelsea Flower Show	-	605	(321)	-	-	284
Other care	2	17	(16)	-	-	3
Research						
The Patrick Research Fund	100	-	-	-	-	100
Congenital LMNA MD	59	33	2	-	-	94
Q Trust	21	85	(9)	-	-	97
FSHD Research	77	35	(16)	-	-	96
Duchenne Research	167	240	(287)	-	-	120
Ullrich Research	116	63	(38)	-	-	141
Nemaline Research	371	8	(97)	-	-	282
Congenital MD	465	1	(182)	-	-	284
Becker Research Fund	150	6	(82)	-	-	74
SMA Research	14	23	(30)	-	-	7
Limb Girdle research	47	118	-	-	-	165
Other research	579	685	(739)			525
Total Restricted Funds	4,578	3,537	(3,277)	-	-	4,838

15. Funds (Cont.)

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

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

15. Funds (Cont.)

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

Endowment Fund

The Orchid Ball Fund is an endowed fund, the income from which (shown separately) is restricted in the first instance to research and welfare in Scotland. Any unused income in a financial period is then directed to funding research.

Restricted Fund

City Bridge Trust / Work experience – this is funding received from the City Bridge Trust to support young disabled people in the London area to access work experience and develop their employability skills. This programme terminated in 2023/24.

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

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

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

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

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

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

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

SMA Screening – this funds support MDUK involvement in the UK SMA Newborn Screening Alliance, which is working

to introduce newborn screening for spinal muscular atrophy (SMA) in the UK.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Unrestricted Funds

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

The designation of balances is as follows:

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

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

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

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

16. Legacies

The charity is entitled to a share in a number of estates which it monitors closely. The following sums have not been reflected in these financial statements in accordance with the accounting policies set out in Note 1. The potential values of these estates to the charity at the balance sheet date are as follows:

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

17. Status of charity

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

18. Related party transactions

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

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

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



Muscular Dystrophy 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