MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Impact Report 2023/24

Together we are stronger

Contents

1 in 600

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

Photographer: Rebekah Kennington

Front cover photographer: Rose Dedman

A message from our Chair and Chief Executive

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

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

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

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

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

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

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

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

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

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

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

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 be granted Frankie's full entitlement again, which is a huge relief."

About us

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

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

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

Our mission

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

Our values

- **Stronger together.** We believe in the power of community. That the whole is greater than the sum of its parts. Because the more of us who come together, the greater the impact we'll make.
- **Forward thinking.** We're here for everyone. Whoever you are. Wherever you're from. You are our sole focus. We set ourselves clear targets and measure our impact.
- **Here for you.** We're here for everyone, but we know support isn't one-size-fits-all. We take the time to listen to every individual, so we can tailor our support to you.
- **Never Stop.** We've already made advances that would have been unthinkable just 10 years ago, and we are determined to go even further and faster.

Objects of Muscular Dystrophy UK for the Public Benefit

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

We work:

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

Public Benefit

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

The year in numbers

We funded 11 new research projects totalling £1.3m.

Nearly 3,000 people were supported through our helpline.

Over 150 people were supported through our advocacy service.

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

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

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

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

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

Nearly 500 healthcare professionals attended our six upskilling webinars.

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

Looking back on what we achieved

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

Performance indicator	Our achievements
Award successful grants in our £1m joint fund with LifeArc to accelerate projects to develop new treatments for congenital muscular dystrophy.	• We awarded joint funded grants with LifeArc and will be making a formal announcement when contracts have been signed.
Launch a new £1.15m programme to pump-prime strategic research.	• We agreed to contribute £1.15m over five years in a partnership with the LifeArc Centre for Rare Mitochondrial Diseases. This followed LifeArc's £40m grant call for Translational Rare Disease Centres in which we announced we would contribute this sum to any successful centres addressing muscle wasting and weakening conditions.
Invest £500k into the 2023/24 new research grants programme.	• We invested over £500k into new research grants.
Launch a £90k three-year programme to drive innovative research into enhancing the quality of life for people living with muscle wasting and weakening conditions.	• We finalised the work for this in 2023/24 and the programme was officially launched April 2024.
Engage in a range of partnerships to begin new projects, including Horizon Europe and UKRI funded grant *Next-generation models and genetic therapies for rare neuromuscular diseases*, the nemaline myopathy natural history study at the University of Oxford, and a jointly funded project with the Myotubular Trust.	• We're actively involved in the Next-generation models and genetic therapies for rare neuromuscular diseases (the MAGIC consortium). • The nemaline myopathy natural history study is in its final stages of approval with the regulatory authorities and should begin recruiting patients in 2024. • We've committed to providing up to £60k towards a three-year partnership with the Myotubular Trust to fund a project to understand liver disease in people with X-linked myotubular myopathy.

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

Performance indicator	Our achievements
Engage with the largest number of neuromuscular centres and patient viewpoints through our neuromuscular services audit and Centres of Excellence Awards.	• We engaged with 27 centres through our audit of neuromuscular services and Centres of Excellence Awards process and awarded 24 Centres of Excellence and Pursing Excellence awards.
Continue to ensure that neuromuscular services and the needs of our community are represented in decisions about future provision as commissioning reforms continue, new treatments become available and the needs of our community evolve.	• We provided health professionals with e-learning modules and upskilling webinars. • We carried out our role as a member of the NHSE Specialised Services Stakeholder Forum and a core member of the England Rare Disease Action Plan Patient Advisory Group.
Launch two new initiatives through our Mental Health Matters work to provide psychological support to our community, with the aim of providing increased access to support from a specialist neuromuscular psychiatrist or receiving targeted counselling support.	• Our Mental Health Matters steering group, chaired by a neuromuscular clinical psychologist, met twice this year to shape support for our community. • We launched four therapeutic support groups, facilitated by a counsellor with lived experience of a muscle wasting and weakening condition.
Contribute to virtual and physical support events for both people living with muscle wasting and weakening conditions and professionals who support them.	• We held Information Days in Northern Ireland and England, a Scottish Conference, and accessible golf day, along with seven virtual information webinars.
Provide support to neuromuscular services and fellow charities at their events.	• We managed and facilitated five Muscular Dystrophy UK Regional Neuromuscular Networks. • We attended seven external events supporting other charities and neuromuscular services.
Deliver an Allied Health Professionals conference, a Care Adviser conference and two Information Days in England and Northern Ireland, before the return of the Scottish Conference in March 2024.	• We held two health professional conferences, two Information Days and a Scottish Conference.
Continue to evolve our local Muscle Groups, with virtual events providing condition specific information and support.	• We held 33 Muscle Group meetings and delivered seven virtual information webinars.
Continue to fight for access to treatments and for support services to be resourced for their roll-out. Engaging in the NICE and SMC appraisal processes for new treatments through to campaigning for SMA to be added to the NHS newborn screening programme on the newborn screening list.	• We took part in 10 treatment appraisal processes. Two culminated in recommendations the treatment should be made available as an NHS treatment option; one was withdrawn part way through the appraisal process by the manufacturer; and seven continue into 2024/25. • We continued our role as co-secretariat of the UK SMA Newborn Screening Alliance, the work of which contributed to the securing of 'in-service evaluation' (pilot) of newborn screening by the NHS Newborn Screening Committee.

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

Performance indicator	Our achievements
Complete our role in supporting the roll-out of the Department for Levelling Up, Housing and Communities (DLUHC) £30m Changing Places fund and the Department for Transport (DfT) Motorway Service Area Changing Places programme.	• We successfully helped register a total of 324 Changing places toilets under the Changing Places scheme this year. 252 of these were part of the DLUHC and DfT programmes.
Deliver £6.6m gross budget through active fundraising (£4.2m), legacies (£1.6m) and other income (£772k), which will result in net figure of £4.4m available for our charitable activities. Invest in our legacy team to maximise the potential of this long-term income stream.	• Delivered a gross budget of £9.5m through active fundraising (£5.3m), legacies, (£2.9m) and other income (£1.3m), which has resulted in a net figure of £6.9m available for our charitable activities. Work is being done on a new legacy proposition to ensure we maximise on the potential of this long-term income stream.
Maximise return on our investment through effective deployment of resources and continued monitoring and improvement where possible of return on investment, maintaining at least 2.7 ratio or above.	• We have continued to maintain a fundraising cost to income ratio above 2.7. In 2023/24 for every £1 we spent on fundraising we raised £3.70.
Work towards our Patient Information Forum (PIF) accreditation - a signal that we are a trusted information creator through our updated factsheets and alerts cards. A standard our community requires.	• We were successfully awarded PIF Tick accreditation.
Reduce our overhead costs to 15% of total costs as a result of moving to smaller office.	• Our support costs in 2023/24 financial year were £812k, which represents 10% of our total expenditure of £8,042k.
Launch our refreshed brand to reach more of the 110,000 people living with one of 60 muscle wasting and weakening conditions.	• We launched our new brand in July 2023 and continued to roll it out throughout 2023/24.
Continue working on reducing our surplus reserves though careful investment planning alongside the existing strategy.	• We have designated £2.1m of our free funds for the two strategic research calls. Both of which were announced in early 2024/25.
Remain committed to responsible leadership in the sector, with a continued focus on our team's wellbeing, our impact on the environment, and equality, diversity, and inclusion for the whole community.	• We continued to focus on our team's wellbeing, our impact on the environment, and equality, diversity, and inclusion for the whole community by carrying out various initiatives. These included: wellbeing champion mental health first aiders group, financial wellbeing webinars and wellbeing resources, our EDI working group, and offsetting the carbon emissions from the 2023 Oxford 10k, making it our first carbon neutral Town and Gown event.

Our research advances

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

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

Photographer: Teri Pengilley

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

Our 2023 grant awards

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

The European Neuromuscular Centre

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

Our Research Line

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

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

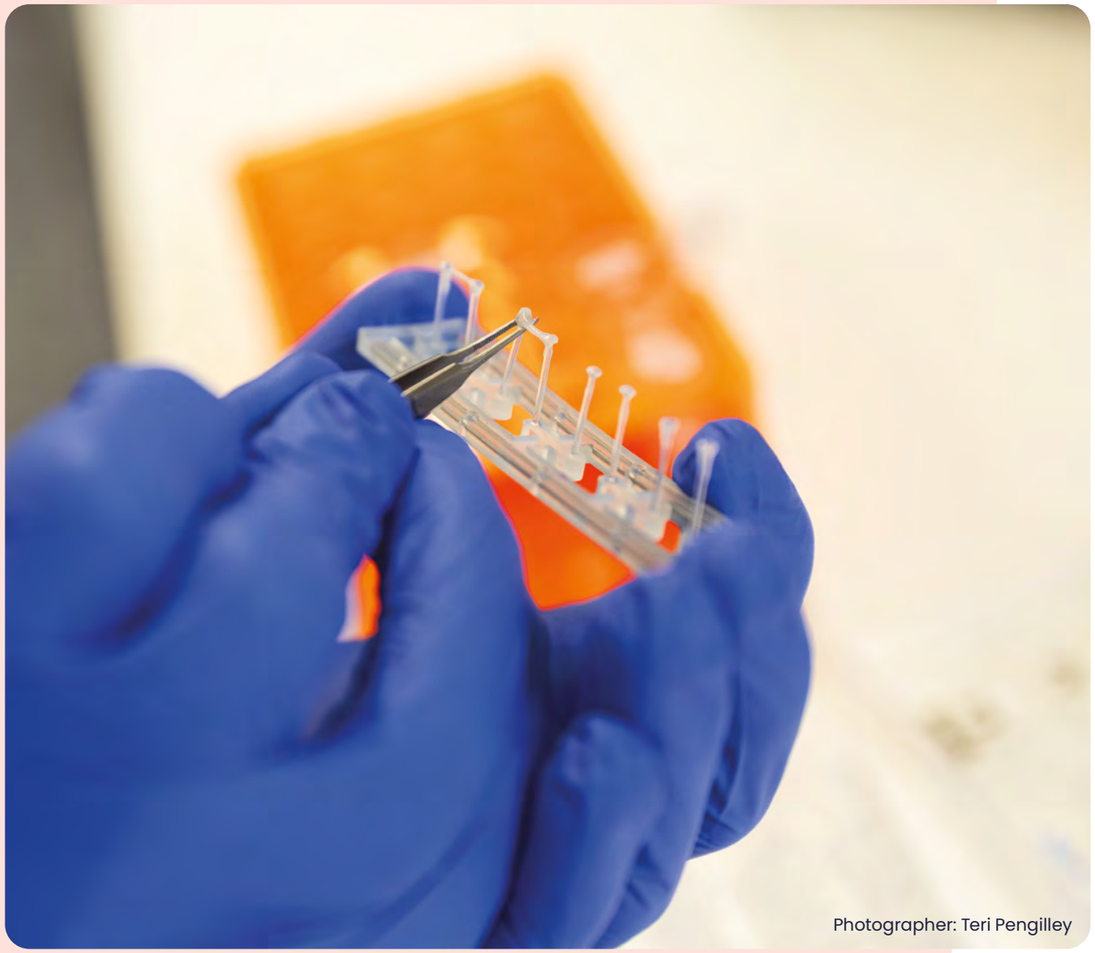
In January 2019, we partnered with the University of Oxford to form the MDUK Oxford Neuromuscular Centre to drive forward the development of new therapies and increase clinical trial capacity for muscle wasting and weakening conditions. This year we celebrated the fifth anniversary of the Centre with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

Photographer: Teri Pengilley

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

Medical Research Charities Early-Career Researcher Fund

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



Photographer: Teri Pengilley

Highlights of our research funding

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

The role of periostin in Duchenne muscular dystrophy

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

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

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

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

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

£1.2m

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

£382,000

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

11

new grants worth over £1.3m awarded this year

43

active research projects

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

Driving change for access to specialist care and support

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

Our role in treatment recommendations and appraisals

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

Photographer: Jo Ritchie

10
treatment appraisal processes participated in

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

155
attendees at our Allied Health Professional virtual conference

507
enrolments on our e-learning modules

465
attendees for our six health professional upskilling webinars

Photographer: Jo Ritchie

Connecting and upskilling health professionals

24 Centres of Excellence or Pursuing Excellence awarded

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

Our health professional conferences

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

Our Allied Health Professionals Conference

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

Our Neuromuscular Care Advisor Conference

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

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

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

Photo: Manchester University NHS Foundation Trust

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

Neuromuscular Care Advisor Conference attendee.

Our virtual upskilling and networking opportunities

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

Our regional neuromuscular networks

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

Our parliamentary and policy work

Providing support to muscular dystrophy parliamentary groups

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

Consultation responses

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

Our community survey

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

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

Living well

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

Our helpline service

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

Our advocacy service

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

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

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

Supporting people through grants

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

Our tailored therapeutic support groups

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

Our tailored peer support

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

Muscle Groups – keeping people updated and connected

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

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

Photographer: John Sanders

2,752
people contacted our helpline

470
people received a cost-of-living grant

459
people requested our alert cards

315
people attended our regional Muscle Group meetings

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

152
people supported by our advocacy service

108
people joined our tailored support WhatsApp groups

53
people received a Joseph Patrick Trust equipment grant

65
people received peer support from our volunteers

Our virtual information webinars

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

Our Information Days

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

Becoming PIF accredited for trusted health information

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

Our Employability Programme

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

Changing Places toilets

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

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

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

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

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

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

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

Photographer: Chris Fairweather

Our work in Scotland

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

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

Our Scottish Conference

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

Scottish Disability Sports

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

Scottish Council

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

Fundraising update

Our Family Funds

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

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

Scottish Conference attendee

Photographer: Julie Broadfoot

Community fundraising activities

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

A growth in runs and walks

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

Our total fundraising in Scotland

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

Research

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

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

65
people attended our Scottish Conference

£10,600
raised by our Family Funds in Scotland

316
requests for support responded to

Photographer: Vincent White

The difference your support made

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

Highlights of this year's fundraising

Our Bidwells 10k Town and Gown running series

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

Our Celebrity Sports Quiz

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


Photographer: Ikin Yum

Our challenge events

Pedal Paddle Peak 2023

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

London Marathon 2023

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

Our fundraising year in numbers:

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

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

£2.9m
raised from 75 individual legacies

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

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

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

Our Family Funds

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

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

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

Supporter led events

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

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

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

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

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

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

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

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

Photographer: Olivia Sirley

Team Jed's 24-hour work out

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

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

Photographer: Olivia Sirley

RHS Chelsea Flower Show

Muscular Dystrophy UK Forest Bathing Garden

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

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

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

Our Garden

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

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

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

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

Photographer: Rebekah Kennington

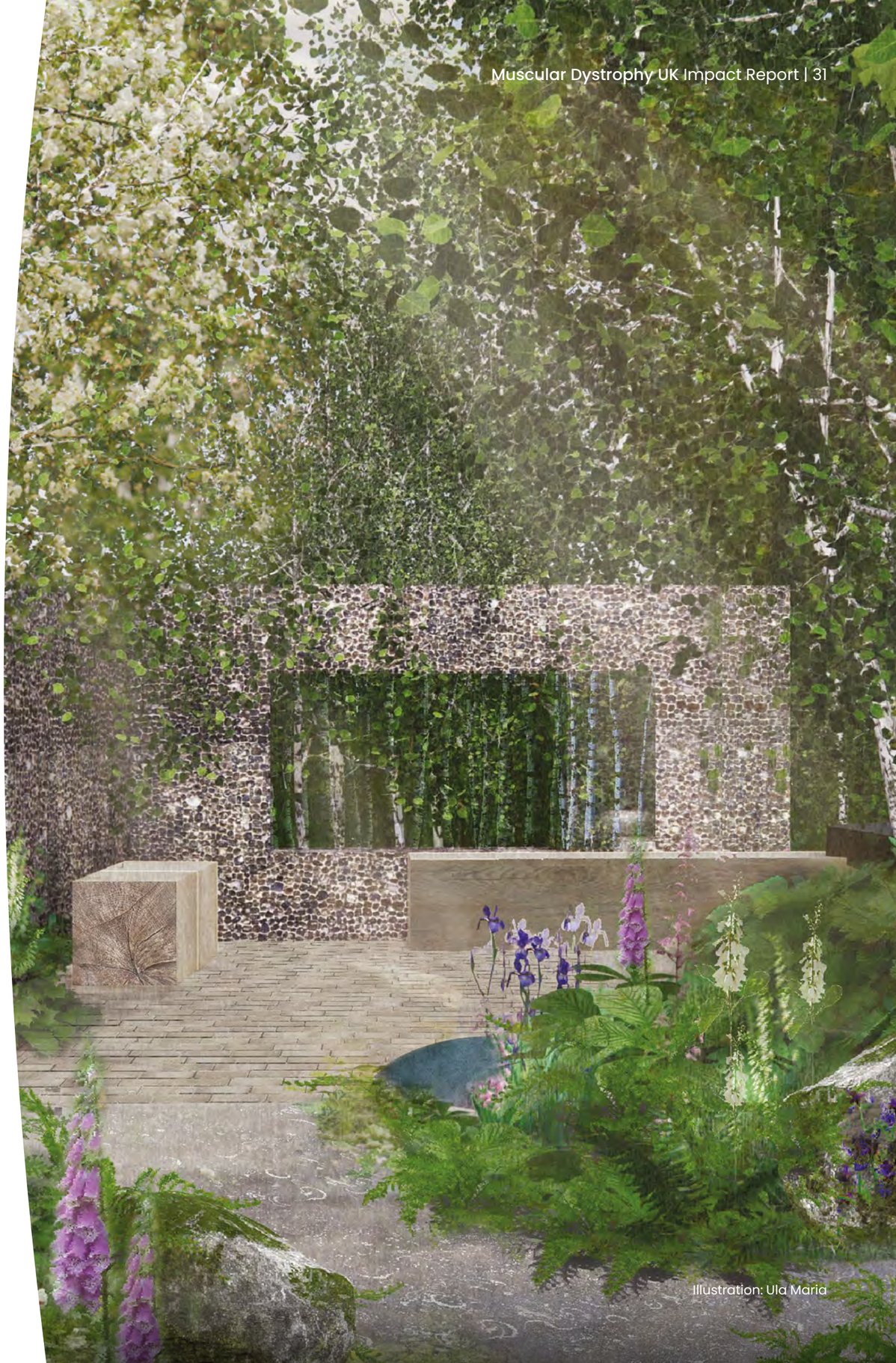


Illustration: Ula Maria

Photographer: Teri Pengilley

Our President's Award winners

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

Peter and Nancy Andrews Community Achievement Award

Bryan Gould

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

Fundraiser of the Year Award

Jed Thirkettle

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

Early Scientist of the Year Award

Meredith James

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

Volunteer of the Year Award

Amanda Hayes

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

Alexander and Valerie Patrick Award for Carer of the Year

William Jackson

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

Richard Attenborough Award for Outstanding Achievement

Professor Francesco Muntoni

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

Our finances

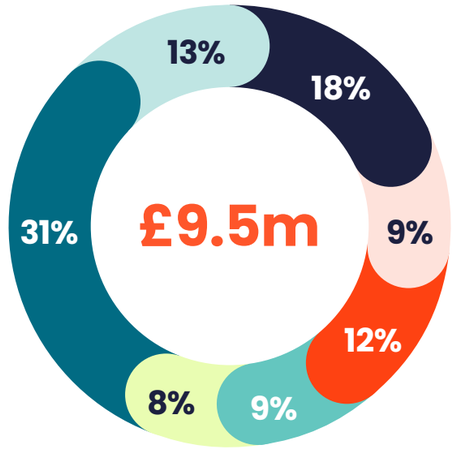
How we raised our funds

For every £1 we spent:

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

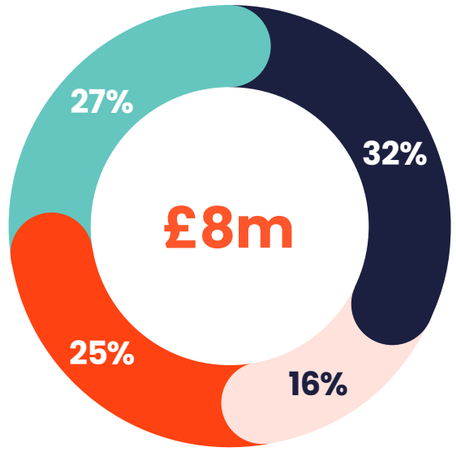
68p is spent on our charitable activities

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



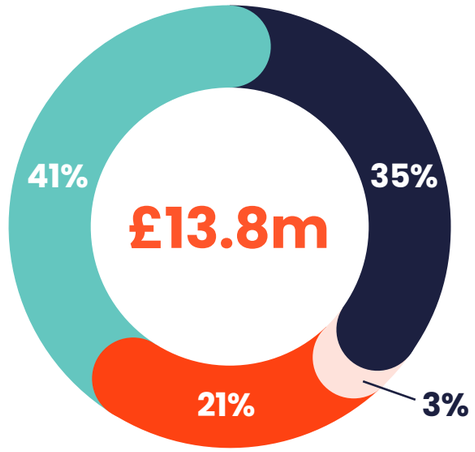
Total income

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



Total expenditure

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



Total funds

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

Our future plans

Going forwards in 2024/25, we will:

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

Photographer: Kavi Shah

Thank you

Our President
- Gabby Logan MBE

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

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- Ian Corner
- Bill Ronald
- Keith Rushton
- Michael Attenborough CBE
- Karen Lewis Attenborough

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- 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
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- Jeremy and Mary Champion
- Charles and Nicky Manby
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- Mayo Marriott
- Team Jed
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- Tony and Monica Moorwood
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- Sally Whittet and Professor Michael Joy OBE
- The Q Trust
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Corporate Support
- AirNow Technology
- Bidwells
- BGC Charity Day
- BMW North Oxford
- CeX
- Chimera
- Crocus
- DC Merrett
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- Forex Clear
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- Property Week
- Rosethorn Capital Partners
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- 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

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- John Eaglesham
- Nick Moldon
- Simon Tann

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- Rob Driver
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- Guy Bowring
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- Fraser Draycott
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- Michael Armstrong (resigned October 2023)
- Scott Keown James Lee (joined October 2023)

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- Dr Heidi Fuller PhD
- Professor Grainne Gorman MRCP, PhD
- Dr Meredith James PhD
- Dr Jasper Morrow MBChB PhD FRACP (until July 2023)
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- Corinthia Joseph
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- William Love
- Andy Rose
- Amber Tirimanna
- David Towler
- Roli Roberts (Scientific Advisor)

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- Tanvi Vyas

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- Claire Boylan, Secretary

Scottish Council

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- David Gale
- Catherine Gillies
- Allyson Townhill
- Jon Watkins
- Jodie Murphy
- Joe Moan
- Gerry McMenemy
- Elizabeth McHugh
- Fiona Neale

Photographer: Rebekah Kennington

Together we can change the future of muscle wasting conditions.

Photographer: Jo Ritchie

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