MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Impact Report 2024/25

Together we are stronger



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Front cover and opposite photographer: Chris O'Donovan



A message from our Chair and Chief Executive

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

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

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

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

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

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

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

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

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

Thank you for your support.



Andy Fletcher
Chief Executive



Professor Michael Hanna
Chair

Zoe and Archie's story

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

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

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

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



Photographer: Chris O'Donovan

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

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

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

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

About us

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

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

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

Our mission

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

Our values

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

Objects of Muscular Dystrophy UK for the Public Benefit

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

We work to:

- Promote research
- Promote the provision of care and treatment
- Assist those who care for persons affected by the conditions
- Provide education and training to persons affected
- Raise public awareness on any matter relating to the Charity's objects

Public Benefit

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

The year in numbers

£1.7m
committed to 12 new research projects

£7.9m
raised this year

£2.15m
committed in strategic research grants

More than 260
healthcare professionals attended our upskilling webinars

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

Nearly 3,500
people supported through our helpline

More than 460
people joined our WhatsApp communities

Nearly 80
Trusts and Foundations supported our work this year

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

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

Looking back on what we achieved

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

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

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

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

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

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

Our research advances

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

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

Our grant awards this year

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

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

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

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

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

Celebrating 20 years of the NorthStar programme

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

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

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

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

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

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

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



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

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

Photographer: Chris O'Donovan

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

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

New centre to accelerate mitochondrial disease treatments

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

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

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

Partnerships to drive forward new treatments for congenital muscular dystrophy

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

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

Professor Haiyan Zhou, funding recipient

Research to support people living well with muscle wasting conditions

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

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

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

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

John, living with Pompe disease

Highlights of our research funding

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



Photographer: Jo Ritchie

Speeding up diagnosis

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

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

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

Samantha Fitzsimmon, Project Manager, John Walton Muscular Dystrophy Centre

Finding potential new treatments for CMT

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

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

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

Working towards a less invasive test for muscle wasting conditions

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

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

Over £1.5m
invested into the NorthStar programme over the past 20 years

£1.15m
invested in a new strategic award for mitochondrial disease research

£1m
invested in a new strategic award for Charcot-Marie-Tooth disease

12
new grants worth over £1.7m committed this year

43
active research projects

£19,000
invested in a new grant scheme for improving quality of life

Over 100
people contacted our research line

Driving change for access to specialist care and support

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



1
new treatment approved for NHS use

8
treatment assessments participated in

711
enrolments to our e-learning module

177
attendees at our two conferences

266
attendees at our three healthcare professional upskilling webinars

Our role in treatment recommend-ations and appraisals

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

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

Connecting and upskilling healthcare professionals

Our healthcare professional conferences

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

Our Neuromuscular Care Advisor Conference

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



Photographer: Teri Pengilley

Our Allied Health Professional Conference

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

Upskilling webinars

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

Centre of Excellence awards

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

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

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

Webinar participant

Our policy and parliamentary work

Community survey - setting out priorities

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

Reporting on the financial insecurity of our community

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



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

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

Photographer: Jo Ritchie

Living well

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

Our helpline service

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

Our advocacy service

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

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

Lauren, living with SMA type 1



Photographer: Jo Ritchie

Mobility equipment grants

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

Our tailored therapeutic support groups

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

Our tailored peer support

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

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

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

3,392
people supported through our helpline

Over 130
people supported through our advocacy service

More than 200
people attended our information days across the UK

462
people joined our WhatsApp communities

447
people attended our Muscle Groups

109
referrals supported by our peer volunteers

62
peer volunteers in our volunteer network

131
people provided with a wheelchair and other equipment grants

Muscle Groups – keeping people updated and connected

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

Our webinars

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

Our Information Days

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

PIF accredited for trusted health information

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

Our Employability Programme

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

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

Information Day participant

Photographer: Chris Fairweather/Huw Evans Agency

Our work in Scotland

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

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

Our support services

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

Scottish disability sports

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

Neuromuscular physiotherapist sessions

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

Missing People. Missing Support report

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

Scotland Information Day

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

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



Photographer: Phil Wilkinson

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

£143,813
total funds raised

£12,000
raised through Kiltwalk by 32 participants

Fundraising update

Family Funds

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

Community fundraising activities

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

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

Our total fundraising in Scotland

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

Research

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

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

The difference your support made

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

Highlights of this year's fundraising

Climbing Mount Kilimanjaro to raise funds

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

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

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

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

Celebrating our Microscope Ball's 40th anniversary

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

Our running events are booming

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

76

Trusts and Foundations supported our work this year

£1.2m

raised across 41 different running events

£176,000

raised from our 43 Family Funds

Over £500,000

raised at the 40th Anniversary Microscope Ball

£245,500

raised at a sellout Bidwells Oxford Town and Gown 10k

£101,000

raised by 15 supporters climbing Mount Kilimanjaro

£80,000

raised in just three days through Double your Donation

£74,157

raised from activities related to our RHS Chelsea Flower Show Garden



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

Simon, who climbed Mount Kilimanjaro

Photographer: Cathey Cullum/Muscular Dystrophy UK

Strength to strength – our Pedal Paddle Peak triple challenge events

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

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

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

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

London Marathon 2024 – A record-breaking year

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

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



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



Photographer: Tom McNally

Supporters fundraising their way

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

Eight marathons in eight weeks

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

Three peaks in memory

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

Cycling across Europe

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

Coast to coast for Josie

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

Golf days – driving strong support

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

Star-studded comedy night

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

Our Family Funds

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

Welcome Tahira's Team

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

Our Family Fund Weekend

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


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

Photographer: Jo Ritchie

RHS Chelsea Flower Show success

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



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

Maximising the opportunity

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

Raising awareness with non-neuromuscular healthcare professionals

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

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

Photographer for both: Rebekah Kennington

Connecting with the muscle wasting community

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

Immeasurable impact, exceeding expectations

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





Photographer for both: Rebekah Kennington

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

Community attendee

Our President's Award winners

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

Peter and Nancy Andrews Community Achievement Award

Liz Keenan

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

Early Career Scientist of the Year Award

Dr Ami Ketley

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

Fundraiser of the Year Award

Tom Penzer Adams

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

Volunteer of the Year Award

Phil Grant

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

Alexander and Valerie Patrick Award for Carer of the Year

Isabel Spragg

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

Richard Attenborough Award for Outstanding Achievement

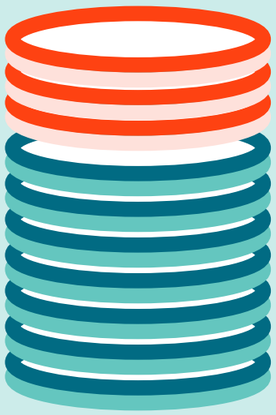
Sheila Hawkins

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

Our finances

How we raised our funds

For every £1 we spent:

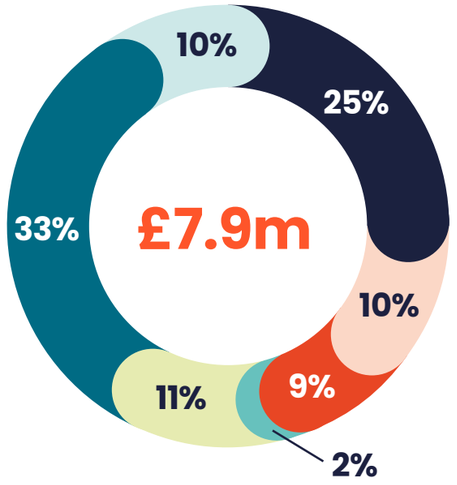


32p is invested in fundraising to ensure we maintain a diverse portfolio to support our community

68p is spent on our charitable activities

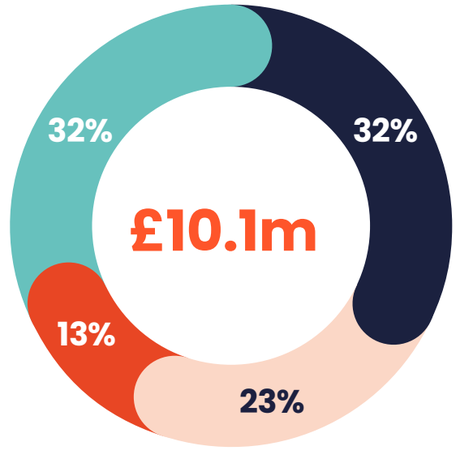
For every £1 we invested in fundraising we raised £2.50
(total income / fundraising costs)





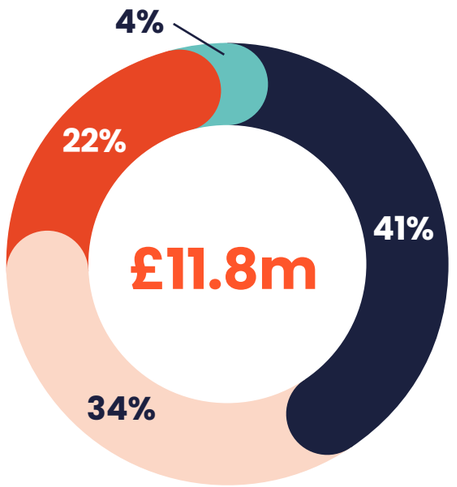
Total income

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



Total expenditure

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



Total funds

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

Our future plans

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

We will be focusing on four strategic goals:



Strategic goal one
Transforming diagnosis

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

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

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

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



Strategic goal two
No one faces their journey alone

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

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

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

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



Strategic goal three
New treatments, universal support

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

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

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

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



Strategic goal four
Living life to the full

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

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

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

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

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

Andy Fletcher, Chief Executive

Thank you

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Photographer: Chris O'Donovan

Together we can make a difference.



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