

Impact Report 2022/23

Together we are stronger





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A message from our Chair and Chief Executive



Welcome to our Impact Report. A year in which we have rallied our community so that everyone with a muscle-wasting and weakening condition can get the healthcare, support and treatments needed to feel stronger, both mentally and physically.

The Covid-19 pandemic required fast paced, difficult decisions which continued into 2022/23. These hard decisions, a clear focus and the amazing support of our community have allowed us to successfully return to a full grants round for new research projects this year, bringing our total live research grants to 43 projects and our current commitments to £6m. This support also helped us to deliver more assistance to our community, with an increased demand coming through our helpline phone and email service - greater than during the initial Covid-19 period.

The main area for which people come to us continues to be access to welfare and financial support, particularly in navigating the PIP system. We provide information, advice, and advocacy support in this area and in the year ahead we will be increasing our policy capacity around this to tackle decision-makers about

issues that our community experience. The investment to do this will come from our unrestricted reserves, which we have built up through careful planning and the excellent delivery of activities like the Microscope Ball, along with all the collections at shops and stations, cakes sales, marathon to three-kilometre runs, people skydiving and numerous other community fundraising activities. There are also those kind enough to leave a gift in their Will, who will be able to see an ongoing legacy supporting our community both today and tomorrow.

Other planned investments for 2023/24 include an increase in research commitments; more effective communications, so we can reach a greater number of the 110,000 people who need our support; and a continued drive to collaborate with our colleagues in the NHS to provide localised specialist support and access to new treatments.

This year saw the completion of the access journey in England for the first treatment in our field, Translarna, for some people living with Duchenne muscular dystrophy, when NICE recommended it as an NHS treatment option. Since we began the push for this treatment in 2016, great strides have been made in treatment development, by the end of this reporting year we were working on access to 12 treatments for five different conditions. But more must be done, and we are pleased to be investing in further funding partnerships.

As a responsible leader we continue to evolve our work to address wider issues of climate change, racism, equality, diversity, and inclusion, so we can help create a safer, better society. This year we launched our equality, diversity and inclusion (EDI) strategy and worked closely with our EDI ambassador to give our community a voice across many platforms.



Catherine Woodhead
Chief Executive

We have already made great advances that would have been unthinkable just 10 years ago, and we are determined to go even further and faster. Our community makes us stronger and that's why we worked together to refresh our organisational strategy this year. Bringing together individuals, families and carers, scientists, health professionals, supporters, volunteers, donors and everyone who is close to us across England, Scotland, Northern Ireland and Wales.

Thank you to our dedicated community for graciously giving your time and money throughout the year. And to the scientists, healthcare professionals, our dedicated President, trustees, and staff team – thank you! The support from everyone has helped us to make every day count for people living with muscle-wasting and weakening conditions. We are all unique individuals. Together we are stronger.



Professor Michael Hanna
Chair



Thank you to our dedicated community for graciously giving your time and money throughout the year. And to the scientists, healthcare professionals, our dedicated President, trustees, and staff team."

Tiffany's story

Tiffany shares her journey so far, and why being an Equality, Diversity and Inclusion Ambassador is so important to her.

"My son Roman, aged three, lives with the very rare muscle-wasting condition LMNA-CMD. He was diagnosed at the age of one. Getting the news was hard to take for myself and his dad as we didn't previously know anything about muscle-wasting conditions.

"Despite all the challenges he faces, Roman is a boy who is full of life. He doesn't let anything hold him back and amazes everyone who meets him.

"We now have a lot more knowledge and are finding our feet. But it can be a very lonely world, and none of our friends and family have been through an experience like ours. This inspired me to write a children's book to help people learn more about the support Roman needs with his condition, in a way that is easy to understand. It's also really important to have more storybooks with Black representation.

"Given that muscle-wasting conditions are so rare, we want Roman to know there are other children, adults and families in the Black community who understand what he is going through. That is why it is so important for us to raise our voice to ensure that Roman feels part of a muscle-wasting community that better represents Black people and their families.

"I've been appointed as an ambassador for Muscular Dystrophy UK, and I'm excited to say I'll be specifically focused on connecting, representing and expanding the Black muscle-wasting community. I'm also really pleased that the charity has recently created an EDI working group and is working to improve its diversity.

I hope that in my role I can use my voice to make a difference, making life more inclusive for Roman and other Black families affected by neuromuscular conditions."



I've been appointed as an ambassador for Muscular Dystrophy UK, and I'm excited to say I'll be specifically focused on connecting, representing and expanding the Black muscle-wasting community."



About us

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

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

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

Our mission

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

Our values

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

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

Objects of Muscular Dystrophy UK for the Public Benefit

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

We do it:

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

Public Benefit

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

The year in numbers

 £1.3m

awarded for research including 14 new grants, bringing the live portfolio to 43 active research grants being supported, with a total cost commitment of £6m

 £8.2m

income generated

 2,663

people living with, or affected by, a muscle-wasting condition supported through our phone and email support service

 10

treatment appraisals on which we were active, with two treatments recommended by NICE for NHS use

 99,103

visits to the care and support sections of our website

 15,696

unique page views to our online forum allowing people to share experiences and support each other

 3,973

online views of our muscles matter seminars

 1,857

views of the Standards of Care for Adults with Duchenne muscular dystrophy videos

 470

attendees at our Allied Health Professional upskilling webinars

 80

participants at our Physiotherapy Conference

Looking back on what we achieved

This year's achievements and performance measured against our 2021/22 objectives.

| Performance Indicator | Our achievements |
|---|--|
| Fund high-quality research to find effective treatments, and ultimately identify cures for all muscle-wasting conditions | <p>Funded 14 new research projects, including three three-year project grants; seven two-year project grants; two 12-month grants; and two four-year PhD studentships.</p> <p>This included providing a further two year's funding for both the paediatric and adult NorthStar networks.</p> <p>Supported LifeArc in its review of proposals to accelerate research projects to develop new treatments for congenital muscular dystrophy.</p> <p>Launched our annual grant round, for which the outcome will be announced in late autumn 2023.</p> |
| Ensure everyone has access to specialist NHS care from a multidisciplinary team | <p>Engaged in ten treatment appraisal processes for muscle-wasting and weakening conditions.</p> <p>Two treatments recommended by NICE for muscle-wasting and weakening conditions.</p> <p>80 attendees at our Physiotherapy Conference.</p> <p>42 attendees at our Care Advisor Conference.</p> <p>470 attendees at Allied Health Professional upskilling webinars.</p> <p>20-50 monthly enrolments on our e-learning modules.</p> <p>Five MDUK Regional Neuromuscular Networks managed.</p> <p>Two policy reports on commissioning reforms published.</p> <p>33 neuromuscular centres submitted an Expression of Interest to our audit of neuromuscular services and Centres of Excellence awards.</p> <p>Four cross-party parliament and assembly groups on muscular dystrophy run across the UK.</p> |

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

| Performance Indicator | Our achievements |
|--|---|
| <p>Provide services and promote opportunities to enable each affected individual to live as independent a life as they wish</p> | <p>Handled 2,663 requests for support, a 22% increase on the previous year.</p> <p>99,103 visits to our website’s care and support areas, a growth of 15 percent on 2021/22.</p> <p>15,696 people used our online forum to share experiences and support each other.</p> <p>169 people supported through our advocacy service.</p> <p>24 equipment grants provided through our JPT programme.</p> <p>389 bookings, 196 live attendees and 3,973 online views of our virtual Muscles Matter seminar series.</p> <p>78 people attended our two face-to-face information days.</p> <p>Two major resources launched to help people live well with muscle-wasting conditions, accessed 2,615 times.</p> <p>Major report launched into the Cost of Living with a Muscle Wasting Condition, which was mentioned in the House of Commons by two Members of Parliament.</p> <p>12 young disabled people supported by our Moving Up programme.</p> <p>177 Changing Places toilets registered.</p> |
| <p>Generate income to continue supporting the community</p> | <p>£8.2m total income generated this year, an 11% increase from 2021/22.</p> <p>Merged two teams with a view to cementing the fundraising strategies of both teams to maximise income from supporters, while establishing a firm foundation for future sustainability.</p> <p>£2.9m legacy income, up from £1.65k in 2021/22.</p> |

Our research advances

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

Our three-year research strategy, ‘Transforming lives through research’, remains the driving force for our research activity. We continue to support high-quality research that deepens our understanding of neuromuscular conditions and support studies into ultra-rare conditions.

Our grant awards

This year, we were delighted to award grants to researchers with no prior history with the charity demonstrating our continued journey to encourage new researchers into the neuromuscular research field.

Our application process was opened further than the previous year, to include project grants and PhD studentships in any of the neuromuscular conditions supported by us. This resulted in a wide variety of very strong research proposals, which were subjected to a rigorous selection process. Of the grants we funded, two cover research relevant to a wide range of muscle-wasting conditions. While the others address the following

conditions: Charcot-Marie-Tooth disease (CMT), congenital muscular dystrophies (including LAMA2-RD, Collagen-VI and INPP5K-related), congenital myasthenic syndromes (CMS), Duchenne muscular dystrophy, mitochondrial myopathy, and spinal muscular atrophy (SMA).

It is the first time in several years that we have supported new research into CMT, CMS and mitochondrial myopathy. Some of the other projects build on work we’ve previously funded.

The European neuromuscular centre

We continue to be an executive member of the European Neuromuscular Centre (ENMC). A network of neuromuscular research charities from across Europe who bring experts together to tackle challenges found in the field of neuromuscular research. The ENMC returned to hosting in-person workshops this year following a Covid-19 hiatus. As with previous years, many of these included UK clinicians, researchers and patient

representatives and could not have happened without our financial support.

Our Research Line

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

Supporting the PREFER project

This year saw the end of the six-year PREFER project for which we provided support. The project outlined the importance of using patient preferences in medical decision-making alongside clinical results from the drug development stage through to marketing. Following this six-year project PREFER published recommendations for pharmaceutical companies, developers, regulatory bodies, and other involved parties, towards a more personal approach to drug discovery and medical product marketing, factoring in patient considerations alongside evidence-based data.



“Improving lives today and transforming lives in the future.”



Highlights of our research funding

Research projects take time to deliver impact. Here are some highlights from grants that were active in 2022/23 that we awarded in previous years:

Research into causes of muscle weakening in SMA

We funded research carried out by Dr Melissa Bowerman's team, including PhD student Emma Sutton, at the University of Keele, investigating the mechanisms that drive skeletal muscle wasting. This has revealed a new cause of muscle weakening in spinal muscular atrophy (SMA) during early muscle development. These findings could eventually enhance existing treatments for SMA and similar conditions. SMA is a genetically inherited neuromuscular condition which causes progressive muscle weakness and loss of movement due to muscle wasting. It can affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing.

Research to help predict the severity and progression of Duchenne muscular dystrophy

We provided partial funding to researchers led by Professor Francesco Muntoni at University College London whose research made progress in helping to understand why the severity of Duchenne muscular dystrophy symptoms varies between boys. This could have major implications for clinical prognosis and future research in treatments. Duchenne muscular dystrophy is a muscle-wasting condition caused by a lack of protein called dystrophin.

Research to better understand the cause of myotonic dystrophy type 1

We funded research by Dr Judith Sleeman at the University of St Andrews which culminated in findings that have linked myotonic dystrophy type 1 to an issue with the mechanism that controls stress response in cells in the body. This better understanding of the root cause behind the condition will in time lead to more targeted and effective therapies and treatments. Myotonic dystrophy is a genetic condition that causes progressive muscle weakness and wasting.

Research targeting the cell's energy system as a potential treatment for FSHD

We funded research carried out by Professor Peter Zammit and his team at King's College London to investigate how the known genetic causes of FSHD translate into its symptoms, focusing on metabolism and mitochondria. The project successfully identified potentially novel therapies for treating FSHD, which could alleviate symptoms and be combined with other effective treatment options. Facioscapulohumeral muscular dystrophy (FSHD) is the third most common inherited muscular dystrophy, whilst it doesn't shorten lives, it drastically impacts on the quality of life.

Driving change for access to specialist care and support

It has been an active and successful year for our work around securing access to treatments for muscle-wasting and weakening conditions. At the same time, we have continued to support health professionals involved in the care of our community and have sought to ensure that NHS neuromuscular services received appropriate attention from commissioners and decision makers – particularly as the Integrated Care System model and other health service commissioning changes began to be rolled-out.



10

NICE treatment appraisals in which we were active

2

treatments recommended for use by the NHS

42

attendees at our Care Advisor conference focusing on the mental health and wellbeing of our community

20-50

people per month enrolled on our e-learning modules



Our role in treatment recommendations and appraisals



We have been leading the fight for access to Translarna.”

Duchenne muscular dystrophy

It was a major milestone in January 2023 when the National Institute for Health and Care Excellence (NICE) recommended **Translarna** (also called **ataluren**) as a treatment option for Duchenne muscular dystrophy which is a result of a ‘nonsense mutation’ in the dystrophin gene. We have been leading the fight for access to Translarna since 2016, working alongside families, clinicians, and other patient groups - co-ordinating a wide range of campaigning, policy, and parliamentary activity and representing the Duchenne community at NICE committee meetings.

This year NICE began the process of appraising **vamorolone**, a treatment for the inflammation associated with Duchenne muscular dystrophy. The treatment is a potential alternative to **corticosteroids** and evidence suggests it may have **fewer** acute side-effects. In October 2022, we took part in a NICE scoping workshop for Vamorolone, and subsequently made a joint submission to this stage of the appraisal.

In May 2022, NICE selected the investigational gene therapy

fordadistrogene movaparvovec for Duchenne muscular dystrophy for appraisal and we have begun preparations to engage in this process in 2023/24.

Pompe disease

We welcomed NICE’s recommendation of **avalglucosidase alfa** as a treatment option for Pompe disease in August 2022. We engaged in the full appraisal process and our Honorary Life President Baroness Thomas of Winchester, who lives with Pompe disease, appeared before the NICE committee that appraised the treatment and made the final recommendation. In October 2022, we also submitted a joint response to the early stages of NICE’s appraisal of a second potential treatment for Pompe disease, **cipaglucosidase alfa with miglustat**.

Spinal muscular atrophy

Considerable activity took place across three spinal muscular atrophy (SMA) treatments this year. Two of the treatments - **Evrysdi** (also called **risdiplam**) and **Spinraza** (also called **nusinersen**) - are currently available through Managed Access Agreements (MAAs) and we continued in our role as a member of the Managed Access Oversight Groups (MAOG) for them. We also worked in partnership with clinicians and other patient groups to successfully engage with NHS England to overcome a potential barrier to patients receiving these treatments while

participated in clinical trials for other SMA treatments. This was a serious potential challenge for the SMA community and the viability of future clinical trials in England.

Having submitted a joint response to the scoping stage of NICE’s appraisal of **Zolgensma** (also called **onasemnogene abeparvovec**) in August 2022, we welcomed the news in March 2023 that NICE had recommended onasemnogene abeparvovec for pre-symptomatic babies.

Myasthenia gravis

In May 2022, we participated in the NICE scoping workshop for potential myasthenia gravis treatments **ravulizumab** and **efgartigimod**. We then submitted a joint response to the appraisal of ravulizumab in November, and successfully nominated an MDUK peer support volunteer to appear before the NICE committee who will be conducting the appraisal in 2023/24. In March 2023, we also made a joint submission and nominations to the appraisal of efgartigimod.

FSHD survey

In May 2022, we promoted an international survey co-ordinated by FSHD Europe about the FSHD community’s preferences around involvement in clinical trials. Thanks to our support, approximately 350 people from across the UK completed the survey – the highest volume of responses from any one country.

Connecting and upskilling health professionals

Our conferences

This year saw the return of our face-to-face national conferences for two key groups of health professionals involved in the care of people living with muscle-wasting and weakening conditions, providing crucial opportunities to upskill, share best practice and network.

The **MDUK Neuromuscular Physiotherapy Conference** took place in April 2022 with over 80 physiotherapist participants from across the UK.

Our **Care Advisor Conference** returned in September 2023 with 42 attendees, with a focus on how to support the mental health and wellbeing of our community and looking after Care Advisors' own mental health.

Virtual upskilling and networking opportunities

We continued to provide virtual upskilling and networking opportunities to health professionals; running a series of four webinars for Allied Health Professionals involved in the care of people living with muscle-wasting and weakening conditions with a combined attendance of around 470 health professionals. Across the year, 20-50 people per month enrolled on our e-learning modules.

Our regional neuromuscular networks

We continued to manage five MDUK regional neuromuscular

networks and engaged with the four NHS funded networks across the UK, collaborating on regional upskilling and patient information events. These networks are an important way in which healthcare professionals and people who use neuromuscular services can be brought together to identify and address gaps and challenges in service provision.

This year major changes in the commissioning of neuromuscular services were introduced in England through the Integrated Care System model. We supported networks in a series of engagements with Integrated Care Boards and produced two policy reports that explored and explained the new commissioning landscape. These will also assist community services (such as community physiotherapy) to support people affected by muscle-wasting conditions.

Our Centres of Excellence Awards

One of the ways we identify best practice and challenges across neuromuscular services is through a national audit, using these findings to create MDUK Neuromuscular Centres of Excellence Awards. This has traditionally been undertaken every three years but due to Covid-19 the last audit took place in 2018. This year, we began major work to update the process we use so that it is more flexible around different sizes of neuromuscular services and so that it can reflect the availability of new treatments and developments in standards of care. Thirty-three neuromuscular

centres across the UK submitted an Expression of Interest to participate in the 2023 audit.

Parliamentary Work

Support to muscular dystrophy parliamentary groups

We continue to support cross-party groups on muscular dystrophy in the Houses of Parliament, the Scottish Parliament, the Welsh Parliament, and the Northern Ireland Assembly, ensuring that issues affecting people with muscle-wasting conditions receive the political attention they deserve. We delivered a number of meetings across these groups this year, including launches of our report on the impact of the cost-of-living crisis on people affected by muscle-wasting and weakening conditions.

Joint secretariat of UK SMA Newborn Screening Alliance

We continued in our role as joint secretariat of the UK SMA Newborn Screening Alliance, which is led by Professor Laurent Servais, Professor of Paediatric Neuromuscular Diseases at the MDUK Oxford Neuromuscular Centre. We launched an All-Party Parliamentary Group on Muscular Dystrophy inquiry into newborn screening for rare conditions.



Living well

Being diagnosed with a muscle-wasting condition means adjusting to a new, unexpected, and ever-changing reality.

We believe it is vital that people have easy access to the information and support they require throughout their experience of living with a muscle-wasting or weakening condition. We provide personal, free, expert information resources and confidential support, covering every topic from the latest research to money worries, physical symptoms, and emotional well-being.

Our helpline service

Our helpline team continue to provide practical advice and support and listen to people's concerns. The five topics people contacted us most about this year were welfare information requests, care plan/alert cards, the cost of living, housing and adaptations advice, and an introduction to MDUK. We responded to these requests by phone, email or through neuromuscular clinics. People also visited our website care and support areas and used our online forum to share experiences and to support one another.

Our advocacy service

Our advocacy service supports people who may be struggling to get the care and services to which they are entitled – providing advice or acting on their behalf. This year, not only did we support people through this service, but we also provided people with the information and skills to advocate for their own needs.

Providing grants

As well as supporting people to access financial support, we also provided grants through our grant-giving arm the Joseph Patrick Trust, to help meet the costs of powered mobility equipment. We also launched a one-off cost of living grant for individuals with muscle-wasting and weakening conditions this year.

Muscle group sessions and Muscles Matter seminars

We continued to bring our community together through our Muscle Group sessions and our online Muscles Matter seminar series.

The programme of seminars covered a range of specific muscle-wasting conditions. For the first time since the Covid-19 pandemic, we also held two face-to-face information days in London and York, and our Muscle Groups held face-to-face events in the summer and online sessions during autumn and spring.

Living well resources

Working with clinicians and people living with muscle-wasting and weakening conditions, we produced two major resources this year. In July we launched a suite of videos to accompany the Consensus Guideline for the Standard of Care for Adults with Duchenne Muscular dystrophy, produced with MDUK funding and published in the Journal

of Neuromuscular disorders – having first been presented at the World Duchenne Organisation. The videos provide a summary of each section of the standards of care document with a focus on the key points a person with Duchenne should know, supporting their conversations with a range of health professionals involved in their care. During the year these were accessed 1,857 times.

We also launched a resource on managing fatigue for people with muscle-wasting conditions – a culmination of a long partnership with a range of neuromuscular health professionals. Ninety-five people attended the webinar to launch the guide and it was downloaded 758 times across the year.



Fatigue has been a significant part of living with a muscle-wasting condition for me and it has taken over my life. MDUK's new fatigue management resource is vital to increasing awareness. It covers so many aspects of fatigue and signposts for further advice, which is of enormous help to those affected."

Hilary, living with mitochondrial disease



28%

increase on the previous year in support requests

169

people supported by our advocacy service

24

people received a grant through our Joseph Patrick Trust

196

people attended our Muscles Matter online seminars: with 3,973 views on YouTube and Facebook

99,103

visits to the care and support sections of our website; a 15% increase on the previous year

15,696

unique page views to our online forum allowing people to share experiences and support each other

78

people attended our information days in London and York

The impact of rising costs on people living with a muscle-wasting condition report

A major barrier facing people affected by muscle-wasting and weakening conditions is the rising cost-of-living, which has had a particularly acute impact on disabled people. We conducted a survey on the cost of living with 170 participants and held three focus group sessions. We used the insights gained - combined with our previous research and contemporary research and policy publications by other charities and policy groups - to produce our report 'The impact of rising costs on people living with a muscle-wasting condition'. The report sets out why the muscle-wasting community is particularly impacted by the rise in the cost of living and makes key recommendations to a number of decision makers as to the support our community need. We launched the report in October at the



Having a muscle-wasting condition means there are lots of additional costs, which other households don't have. For example, my electric bill. I've got to charge my two power wheelchairs and an electric hoist. I can't use a manual wheelchair because the muscle weakness in my arms means I can't get out of it. We worry about whether we can look after ourselves."

Trevor, living with Becker muscular dystrophy

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

Our Moving Up programme

This year, our Moving Up programme supported 12 young disabled people through work experience placements, paid internships, and employability support. Participants were supported in developing plans to help aid their long-term development and achieve their goals. They were also taught how to maximise their chances at landing a suitable role, whilst maintaining their mental health. The programme also provides individuals with information on their legal rights in relation to disability employment law, so they are aware of what they are entitled to and eligible for, either at interview stage, or when they have gained employment. Of the 12 participants on the programme, nine have successfully found work or gone onto the next stage of their education. It was great to see two Moving Up alumni return to the charity in short term contracts, alongside one alum who received a promotion to a new role following their return on a permanent contract last year.

Co-chairing the Changing Places Consortium

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



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

UK Prime Minister Rishi Sunak

largely driven by our connection to government programmes for which we support delivery. We continued to administer a £2m grant programme in partnership with the Department for Transport (DfT) to ensure increased provision of Changing Places toilets in motorway services across England and began delivery of a second DfT programme to increase provision across the rail network. We also agreed a third programme with DfT to increase provision of these facilities across the A road network.

Our partnership work with the Department of Levelling Up, Housing and Communities (DLUHC) continued to provide insights to help shape a scheme for the distribution of £30m government funding to install Changing Places toilets in existing buildings in England, and to provide advice and support to local authorities in receipt of this funding. We provided support in managing a second round of funding applications to the programme.

In total, we registered 177 new Changing Places toilets in 2022/23, 124 of which were installed outside of the government funded programmes.



Moving Up is a project supporting young disabled people. It provides opportunities to participate in workplace internships to get the experience to move up and gain employment. Jack has end-to-end experience of the project and since November 2020 has been our Moving Up Project Manager.

I joined the Moving Up project as a work experience participant after struggling to find work as a disabled person following graduating from university. My first placement was in the advocacy team at Muscular Dystrophy UK. Not only did it give me experience in an area I would not otherwise have known, but it also allowed me to experience balancing work with my disability. Most importantly, it boosted my confidence, which had taken a serious hit after years of unsuccessfully looking for work.

After leaving the project, I applied for and secured a job as a HR Assistant at the charity in October 2016. I got to work right across the organisation along with getting a bit of experience in nearly every part of HR. One area that I worked on a lot was recruitment for the charity. Now I'm the Moving Up Project Manager.

My personal experience of trying to find work as a disabled person, coupled with my years of experience in HR, have given me a passion for improving employment opportunities for young disabled people."

Our work in Scotland

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

£5,600

raised by our Family Funds

£4,504

raised from our Spirit of Christmas event

£4,820

raised by two skydivers

361

support requests responded to

Over the past year, we continued to provide comprehensive and tailored information and advice and emotional and practical support to individuals and families living with muscle-wasting conditions in Scotland. Our focus has been on engagement, outreach, and connection, helping people to get the care, support, and equipment to which they are entitled.

This year we responded to 361 requests for support in Scotland, of which 53 were advocacy cases. Our close work with the Scottish Muscle Network

continued and we successfully carried out our role as the secretariat to the Cross-Party Group on Muscular Dystrophy in the Scottish Parliament. Our work in Scotland is guided by our Muscular Dystrophy UK Scottish Council, working closely with our Head of Information, Advocacy and Care and Regional Development Manager, both based in Scotland.

The Scotland Care and Support Alliance

Scotland is currently in the process of setting up a National Care Service and care packages will be moved from local authorities to this new national system. In response to this, we established a Scotland Care and Support Alliance with other leading charities in Scotland, including MS Scotland and Epilepsy Scotland, to identify overarching barriers to access and to drive forward key recommendations on how the National Care Service can better meet the needs of the people we support.

Neuromuscular wellness sessions

We worked closely with Neuromuscular Physiotherapy to develop a series of in-person holistic wellbeing sessions for adults living with muscle-wasting conditions. These sessions covered a range of topics including exercise, activity and fitness goals, fatigue management, sleep

and posture improvements, nutrition and benefits. We are hoping to run these sessions virtually over the next year so that we can reach more people across Scotland.

Free training and support sessions

In collaboration with PAMIS, we supported people to access free training and support sessions (funded by the Scottish Government) throughout 2022/2023. Helping people with muscle-wasting conditions, their carers, family or friends, to understand some simple exercises and techniques. With our support, PAMIS have facilitated three four-week online training courses. This collaboration has also supported us in producing resources on postural care and will inform future postural care seminars/workshops. **We held a face-to-face Muscle Group meeting in August alongside the virtual ones in Spring and Autumn.**

Research

We continued to support research in Scotland this year. Our grant to Professor Eric Schirmer at the University of Edinburgh ended, but we continue to support Dr Lyndsay Murray of the University of Edinburgh, and Professor Judith Sleeman at the University of St Andrews.



“I have days that I call “Only my eyelashes do not hurt”. On these days I cannot physically or mentally deal with all the calls, emails and messages. Jackie, Muscular Dystrophy UK Regional Information, Advocacy and Support Manager, is right there to help.”

Person living with muscular dystrophy

Regional development

Family Funds

We continued to grow the number of our Family Fund's this year, with Team Thomas joining in November 2022 and taking on a variety of successful fundraising activities. These included, a new year's dip and a team of runners entering into events as part of the Edinburgh Marathon Festival. Our family funds in Scotland raised a fantastic £5,600.

Supporting community fundraising activities

Aligned with our new fundraising strategy, we took the decision to cancel all future Question of Support events and invest this time in supporting those planning their own fundraising activities for the wider community. One example was the return of our Spirit of Christmas (SOX) event for the first time since Covid-19, with two events successfully organised by Stagecoach Performing Arts who raised a brilliant £4,405. Plans are already underway for the 2023 events where the hope is that fundraising will be raised to £5,000.

Outdoor events

With the growth of outdoor events, we have continued to see new and re-engaged supporters taking up challenges, these have included the Edinburgh Marathon, the Kiltwalk series, which has seen increased participation and income, in total raising £6,000 this year, with one supporter even taking on an Ultra challenge in the Isle of Wight.

Skydives

Due to pandemic restrictions we had to postpone some skydives and are still in the process of trying to reschedule some, but we have also had some success with two skydivers raising a combined total of £4,820.

Our total fundraising in Scotland

Despite the ongoing difficulties brought about by the pandemic, we have raised a fantastic £117,000 across Scotland in this financial year. Going forwards we will continue to raise the profile of muscle-weakening and wasting conditions and promote more fundraising activities that people enjoy doing, with the aim of increasing our targets year on year.



Our President's Award winners

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

Alexander and Valerie Patrick Award for Carer of the Year

Emma-Jayne Ashley

Emma-Jayne is a dedicated caregiver to her son, Dregan, aged 23, who lives with congenital myotonic dystrophy. She also works as a consultant patient representative, supporting families and helping improve the quality of life for people with muscle-wasting conditions. Alongside her husband, Peter, she represents the myotonic dystrophy community in various European research and care organisations.

Volunteer of the Year

Claire Boylan

Claire lives with miyoshi myopathy which caused her to take early retirement aged 31. Since leaving full-time work, Claire has volunteered with us as an active campaigner, Peer Support Volunteer, and organiser of the Spirit of Christmas annual fundraising concert in Belfast.

Early Career Scientist of the Year

Dr Vino Vivekanandam

Dr Vivekanandam, a Neurologist & Clinical Research Fellow at University College London (UCL), is dedicated to finding new treatments, improving patient diagnoses, and increasing our understanding of rare muscle channelopathies with far-reaching benefits for patients across the UK and internationally.

Fundraiser of the Year

The Chubb Family

Charlotte and James Chubb, who set up The Chubb's Crusade - Understanding Ullrich family fund, won this award for raising £30,000 in their first year. They threw themselves into a range of fundraising activities including marathons and cycle rides, as well as inspiring friends and family to get involved. (Picture left)

Peter and Nancy Andrews Community Achievement

Tiffany Hesson

In her first year as our Equality, Diversity, and Inclusion (EDI) Ambassador, Tiffany has been an influential spokesperson, representing the charity, and championing EDI at a national level. Attending meetings with stakeholders to give her perspective as a parent of a son living with LMNA-CMD as well as championing diversity, and encouraging the development of our EDI document.

Richard Attenborough Award for Outstanding Achievement

Chloe Ball-Hopkins

Chloe lives with Nemaline Myopathy, a Team GB Para Athlete in Archery in 2014, model and fashion designer having designed an accessible jumpsuit in association with ASOS. She has been involved with us from a young age and has often spoken at our events.



The difference your support made

Thanks to your amazing generosity, income from gifts, grants, and donations, campaigns and events totalled £4.4m this year.

Highlights of this year's fundraising

Games Nights

In July 2022, we hosted our first ever Games Night at Flight Club, Islington, an interactive darts venue where twenty teams of six joined us to take part in the tournament. We were delighted with the success of this inaugural event. Our event committee and guests had so much fun, we decided to organise a second games night at Electric Shuffle, London Bridge, an interactive shuffleboard venue. This sold out and together the games nights raised £36,700. Both events attracted a new audience of supporters, and we look forward to hosting our third Games Night very soon.

Microscope Ball

Our annual Microscope Ball returned for a record-breaking year raising a phenomenal £424,000. The theme was 'Strike A Pose' and was hosted by the drag queen Miss Demeanour with entertainment from the fabulous Globe Girls, all of which helped to create a fun and uplifting evening. Chloe Ball-Hopkins was our guest speaker, who's rousing speech about living life to the fullest captivated the audience and generated the most successful live auction and pledge in the history of the event.



Our fundraising year in numbers:

£36,000

raised at the BGC Charity Day thanks to the appearance of Gabby Logan MBE and Sam Allardyce alongside our families

£12,000

raised from the 10,000 participants from schools, workplaces and communities across the UK who took part in our Go Bright event

£2.9m

from 62 individual legacies

£31,000

won by Gabby Logan MBE by appearing on ITV's Celebrity Catchphrase and CH 4's I literally just told you hosted by Jimmy Carr

£318,000

raised by the 7,330 participants who took part in our Town & Gown running events

Our challenge events

Pedal Paddle Peak 2022

This was the seventh year of our Pedal Paddle Peak challenge event, which involves a 30-mile cycle ride, a two-mile canoe paddle across Ullswater lake, and a huge climb to the second highest peak in England, Helvellyn Mountain –all in one day. A total of 126 participants took part this year, raising a record £107,195.

London Marathon 2022

We had 124 runners in the London Marathon this year, 108 with a charity place and 16 with their own. Nine people also took part in a virtual event across the UK. This team of runners raised a fantastic £323,194, our highest yet for the London Marathon.

Our Family Funds

Our Family Funds continue to amaze us with their dedication to fundraising, having raised £70,000 this year. We held our first post covid Family Fund weekend at the Calvert Trust in Devon. The 11 families attending the weekend were given the

chance to do the unusual such as stack crates, abseil, ride horses and lots more outdoor activities. With the evening being a time to relax and build friendships, as well as take part in our Family Fund Big Quiz, with the opportunity to take the winner's trophy home!

Supporter led events

Rollits, with the support of Brian Deehan, Chair of the East Yorkshire Branch, held their 36th annual golf event for the charity this year – in total they've raised a fabulous £97k over the years. While the Source to Sea event, the brainchild of our supporter Andy Davies who has limb girdle muscular dystrophy, raised over £27,000. Around 90 walkers and 40 volunteers took part in this day event, following the Thames River from source to sea and finishing in central London. Eight members of the CMT Friends UK Support Group, set up by Peter Neville, dared to take on the world's longest zipline together to raise awareness of Charcot-Marie Tooth disease and raised an amazing £3k in the process.

Our volunteers

Our volunteers and groups have really surpassed themselves with their community fundraising post pandemic, attending events, holding collections, nominating us to benefit from local organisation donations, running, jumping, dancing, walking and even wing walking all to raise funds.

Medical Research Charity Support Fund

In the last year, we were delighted to receive £274,145 from the Medical Research Charity Support Fund, which has helped us regrow our grant portfolio since the pandemic. The Medical Research Charities Early Career Researchers Support Fund is administered by the Medical Research Council (MRC) and UK Research and Innovation (UKRI) on behalf of the Government. The donation has contributed towards six of our research grants, furthering our understanding of conditions and helping to develop interventions and therapies for muscle-wasting conditions.



Michael, who lives with Beckers muscular dystrophy, completed the marathon having trained using the couch to 5k programme, when only four years before he had been struggling to walk more than a few hundred metres, had a powered wheelchair and barely walked outside.

“ It hurt so much, and I was so tired, but I later felt amazing. I was so proud that I was able to run, after being told for years, I couldn't do this...although it was very hard and took me just over eight hours the day was amazing, and the support was fantastic even for us back of the pack runners. ”



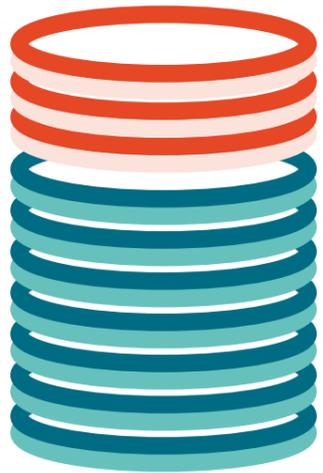
Brian, aged 72, and his family team, which included his daughter, took on Pedal, Paddle, Peak in memory of his nephew Mark who died from Duchenne muscular dystrophy at the age of 17. Since Mark was diagnosed at the age of four, Brian has been dedicated to fundraising for us to help improve the lives of people with muscle-wasting and weakening conditions. Over the course of more than 35 years, Brian has raised £680,000 for the charity. He said of the event:

“ This year will mark the 25th anniversary of Mark's death so we are taking on the Pedal Paddle Peak in his memory and honour...It will be fun - which will be a fitting tribute to Mark as he was full of fun and remained cheerful throughout his short life.”

Our finances

How we raised our funds

For every **£1** we spent we ensure:



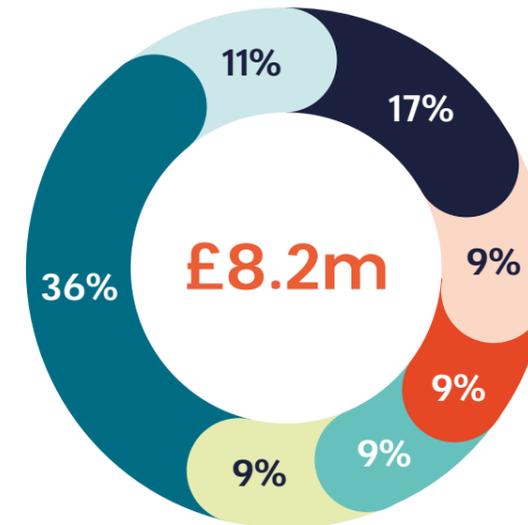
30p

Invested in fundraising to ensure we maintain a diverse income portfolio to support our community

70p

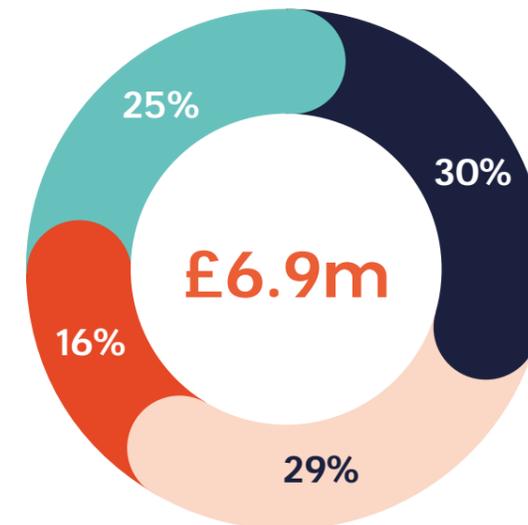
Charitable activities

For every **£1** invested in fundraising we raised **£4**



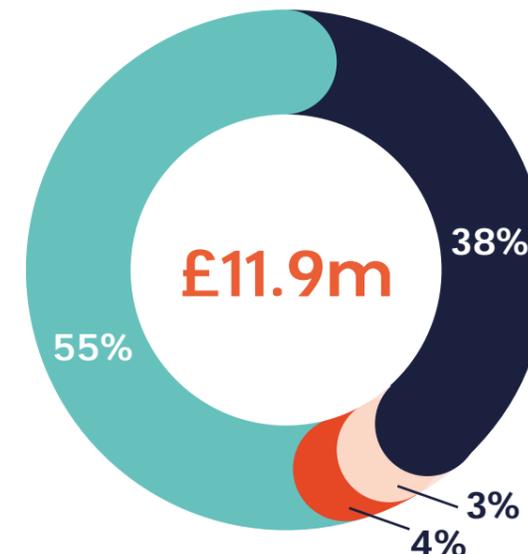
Total income

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



Total expenditure

- Fundraising (£2,030k)
- Medical research (£1,997k)
- Access to specialist care and support (£1,110k)
- Independent living (£1,719k)



Total funds

- Restricted (£4,578k)
- Endowment (£387k)
- Designated (£437k)
- General (£6,511k)

Our future plans



Going forwards, in 2023/24 we will:

- Award successful grants in our £1m joint fund with LifeArc to accelerate projects to develop new treatments for congenital muscular dystrophy.
- Launch a new £1.5m programme to pump-prime strategic research.
- Invest £500k into the 2022/23 new research grants programme.
- Launch a £90k three-year programme to drive innovative research into enhancing the quality of life for people living with muscle-wasting and weakening conditions.
- Engage in a range of partnerships to begin new projects, including Horizon Europe and UKRI funded grant "Next-generation models and genetic therapies for rare neuromuscular diseases", the nemaline myopathy natural history study at the University of Oxford and a jointly funded project with the Myotubular Trust.
- Engage with the largest number of neuromuscular centres and patient viewpoints, through our neuromuscular services audit and Centres of Excellence Awards.
- Continue to ensure that neuromuscular services and the needs of our community are represented in decisions about future provision as commissioning reforms continue; new treatments become available; and the needs of our community evolve.
- Launch two new initiatives through our Mental Health Matters work to provide psychological support to our community, with the aim of providing increased access to support from a specialist neuromuscular psychiatrist or receiving targeted counselling support.
- Contribute to virtual and physical support events for both people living with muscle-wasting and weakening conditions and professionals who support them.
- Provide support to neuromuscular services and fellow charities at their events.
- Deliver an Allied Health Professionals conference, a Care Adviser conference and two Information days in England and Northern Ireland, before the return of the Scottish Conference in March 2024.

- Continue to evolve our local muscle groups, with virtual events providing condition specific information and support.
- Continue to fight for access to treatments and for support services to be resourced for their roll-out. Engaging in the NICE and SMC appraisal processes for new treatments through to campaigning for SMA to be added to the NHS Newborn Screening Programme on the Newborn Screening list.
- Complete our role in supporting the roll-out of the Department for Levelling Up, Housing and Communities (DLUHC) £30m Changing Places fund and the Department for Transport (DfT) Motorway Service Area Changing Places programme.
- Deliver £6.6m gross budget through active fundraising (£4.2m), legacies (£1.6m) and other income (£772k), which will result in net figure of £4.4m available for our charitable activities.
- Invest in our legacy team to maximise the potential of this long-term income stream.
- Maximise the return on investment through effective deployment of resources and continued monitoring and improvement where possible of return on investment, maintaining at least 2.7 ratio or above.
- Work towards our Patient Information Forum (PIF) accreditation - a signal that we are a trusted information creator through our updated factsheets and alerts cards. A standard our community requires.
- Reduce our overhead costs to 15% of total costs as a result of moving to smaller office.
- Launch our refreshed brand, and our organisational strategy to reach more of the 110,000 people living with one of 60 muscle-wasting and weakening conditions.
- Continue working on reducing our surplus reserves through careful investment planning alongside the new strategy.
- Remain committed to responsible leadership in the sector, with a continued focus on our team's wellbeing, our impact on the environment, and equality, diversity, and inclusion for the whole community.



Thank yous

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- Gabby Logan MBE

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- Professor Martin Bobrow CBE FRS FMedSci

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- Ian Corner
- Bill Ronald
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- Kate Bushby MD
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- Dr Kate Adcock, Director of Research and Innovation
- Rob Burley, Director of Care, Communications and Support
- Emma Jones-Parry, Director of Development (from April 2023)
- Wojtek B Trzcinski, Finance and Resources Director and Company Secretary
- Leanne Thorndyke, Director of Marketing (from May 2023)

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- Frances Carey
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- Charles and Donna Scott
- Sally Whittet and Professor Michael Joy OBE
- The Q Trust
- MAP Nemaline

Corporate Support

- Bidwells
- BGC Charity Day
- BMW North Oxford
- CeX
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- GE Foundation International Grants Fund

- Mail Metro Media
- Marchmont
- Intel Group
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