



MUSCULAR DYSTROPHY UK IMPACT REPORT 21/22

**Muscular
Dystrophy UK**
Fighting muscle-wasting conditions





WELCOME TO OUR 2021/22 IMPACT REPORT

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Cover image: Mubin, who has Duchenne muscular dystrophy, enjoying Go Orange Day 2022.

Our 2021/22 Financial Statements are available upon request.

Muscular Dystrophy UK is the operating name of the Muscular Dystrophy Group of Great Britain and Northern Ireland (a company limited by guarantee: 705357 Registered Charity No 205395 and Registered Scottish Charity No SCO39445)

Welcome to our 2021/22 Impact Report, where we reflect on the highlights over the past year as the world emerged from COVID-19 restrictions. We focused on supporting our community as we adapted to the new normal and continued investing in the highest quality research into treatments and cures, bringing the day where no one is limited by muscle-wasting conditions ever closer.

After a financially turbulent couple of years, we now have more clarity on the financial affects of the pandemic. It is estimated that the charity sector has lost £12bn due to COVID-19 – and with the current cost-of-living crisis, we know our challenges are far from over.

Despite this, we have stayed responsive to our community's needs. We were there for even more people than in years gone by through our helpline and online resources, and structural changes within the charity allowed us to remain focused on our charitable objectives.

One of the most important learnings this year came from the epidemiology study we supported, which found 110,000 people in the UK currently live with muscle-wasting conditions – a huge jump from the 70,000 people identified in 2010. We know most of these people don't have access to treatments for their condition, and specialised care in the NHS can be a postcode lottery.

We have worked tirelessly to address this lack of care and treatment by training 1,600 NHS healthcare professionals and by working with patient representatives, fellow charities, NICE, the Scottish Medicines Consortium and pharmaceutical companies to secure access to new treatments for five different conditions. We are confident this will have a significant impact on the quality of life for those living with rare and very rare conditions for whom, until recently, there have been no treatments. In 2016, there was only one

treatment available to our community; as we move into 2022/23, we are now working on access to 10!

To further address the lack of treatments and cures for neuromuscular conditions, we funded nine new research grants over the past year. The scope of the research is outstanding, looking at a broad range of conditions and stages of research, from biological understanding of conditions through to clinical studies.

Increased collaboration between research centres, charities and pharmaceutical development has also played a huge part in improving access to treatment. We have continued our partnership with the University of Oxford to drive forward new treatments and increase access to clinical trials. The MDUK Oxford Neuromuscular Centre completed its fundraising drive to raise £1.2m; a huge achievement given the effects of the pandemic on fundraising, and we are already seeing the fantastic impact that the centre is making.

We are stronger together, and by sharing our expertise and time, we can help create a world where no one is limited by muscle-wasting conditions.

Finally, we'd like to thank our President, Gabby Logan MBE, along with our dedicated volunteers, fundraisers, supporters and donors who have graciously given their time and money throughout the year, and our dedicated trustees and staff team. The support from every one of you has helped to make every day count for people living with muscle-wasting and associated conditions. We couldn't be more grateful.



Catherine Woodhead
Chief Executive



Prof Mike Hanna
MDUK Chair



OUR **VISION**

A world with effective treatments and cures for all muscle-wasting conditions, and no limits in life for individuals and families affected.

OUR **VALUES**

We care

We are inclusive

We are collaborative

We are determined

We are focused on results



Tiffany Hesson and her son Roman who has LMNA-CMD.

We know we can make our vision a reality quicker if we work together. We are uniting skills, knowledge and resources in the UK and working with others around the world so we can improve the quality of life for those affected, and bring treatments and cures closer to reality.

OUR MISSION

We are the UK charity for individuals and families living with muscle-wasting conditions.

We support research to drive the development of effective treatments and cures.

We ensure access to specialist NHS care and support.

We provide services and promote opportunities to enable individuals and their families to live as independently as possible.

MDUK'S YEAR IN NUMBERS

Income generated:

£6.7m

We supported

2,078

people over the
phone or email.



We funded 31

research projects, including
nine new research grants.

We successfully concluded the

£1.2m appeal

for the MDUK Oxford Neuromuscular
Centre.



We supported the allocation of
Government funding to Local
Authorities that will see the
installation of an additional

500+

Changing Places toilets in
England over the next two
years.



We provided training to

OVER 1,600

NHS health and care professionals.



We worked on securing access to

SEVEN TREATMENTS

for four different conditions.



“MDUK has helped me do things that the average person does, I just need to do them in a different way.”

Kiera Santry, 26, has limb-girdle muscular dystrophy (LGMD). She shares how MDUK supported her from diagnosis until now with her role as Senior Challenge Events Officer.

“When I was nine years old, I started having trouble bearing weight on my arms when I was playing sports. We visited the GP who brushed it off but the weakness in my limbs progressed, so they did lots of tests which showed I had a muscle abnormality.

“I was referred to hospital and the paediatrician told me I had LGMD when I was just nine years old.

“After my diagnosis, my parents contacted the MDUK helpline and attended the Scottish conference. They met others with muscular dystrophy for the first time and saw their conditions weren’t holding them back. This was a huge turning point for them.

“But by secondary school, my condition was progressing. I decided to go to a school that caters for additional needs, and they brought in adaptations for me before I started using my wheelchair.

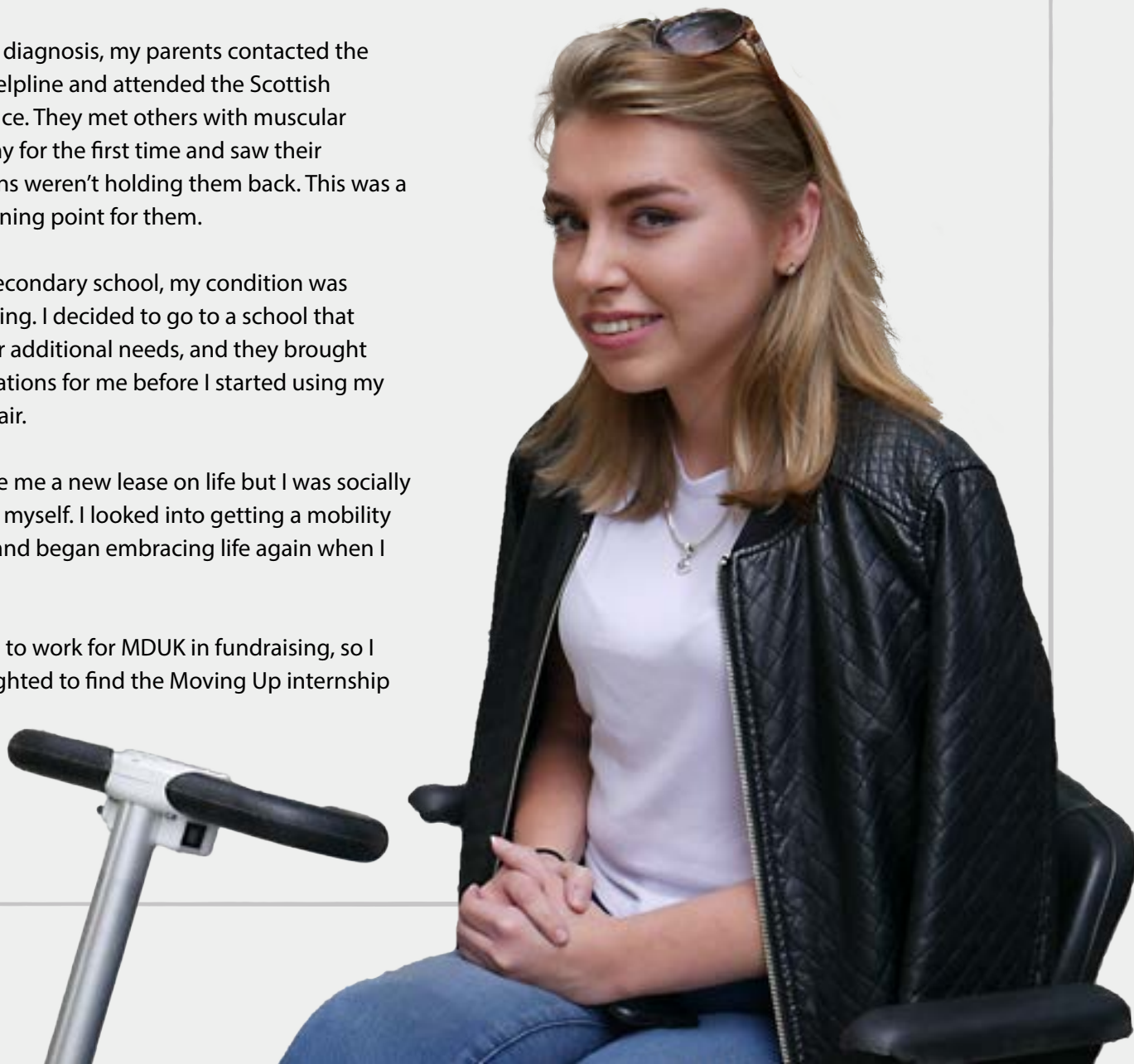
“This gave me a new lease on life but I was socially isolating myself. I looked into getting a mobility scooter and began embracing life again when I was 18.

“I wanted to work for MDUK in fundraising, so I was delighted to find the Moving Up internship

programme. I started working part-time in 2017, and I still work for the charity today as the Senior Challenge Events Officer.

“MDUK’s information, advocacy and support team supported me with getting home adaptations for my first home as well. I now have the adaptations I need so I can do simple things like open the front door, cook and clean.

“LGMD has stripped me of a lot of independence but thanks to MDUK’s support, I can do things that the average person does; I just need to do them in a different way. I’m thankful that I’ve always got someone to lean on.”





LOOKING BACK ON WHAT WE'VE ACHIEVED

GOAL:

Fund high-quality research to find effective treatments and ultimately identify cures for all muscle wasting conditions

We funded **eight innovative projects**.

We **funded a four-year PhD studentship** as part of our spinal muscular atrophy (SMA) PhD Partnership with Spinal Muscular Atrophy UK.

We launched a **full-capacity 2022 grant round**.

GOAL:

Ensure everyone has access to specialist NHS care from a multidisciplinary team

We secured NHS funding for **two new** neuromuscular specialist posts, meaning that since 2013 we have secured NHS investment of **up to £7.5m per year** in specialist services.

We supported clinical networks and **provided training to over 1,600 healthcare professionals** through online training modules, to better equip them to meet the needs of people affected by muscle-wasting conditions.



Paula and Andy Bailey, Susan and Keith Prideaux at the Leeds muscle group.

GOAL:

Provide services and promote opportunities to enable each affected individual to live as independent a life as they wish

We responded to **more than 2,078 requests** for information or support over the phone and by email, and **9,354 people used our online forum** to share experiences and support.

We saw a **3.7% increase** on the previous year in the number of visits to the care and support section of our website.

GOAL:

Generate income to continue supporting the community

Total income for the year was **£6.7m**, a **20% increase** compared to 2020/21.

More supporters took on fundraising challenges, and more corporations chose us as their charity of the year.

The MDUK Oxford Neuromuscular Centre and Trust **appeal brought in over £1.2m**.

Thanks to the generosity of our funders, our Trust team had one of their most successful fundraising years ever, **raising over £1m**.



ADVANCES IN RESEARCH

Research to beat neuromuscular conditions

We are dedicated to creating a world where no one is limited by muscle-wasting conditions. Finding treatments and cures for all associated conditions plays a huge part in this.

Our research achievements in numbers:

Invested

£1.3m



into our grant portfolio.

Our 'Live Research Portfolio' totals

£6.1m

awarded to date in 31 active research grants covering over 20 conditions at 16 different institutions across UK, Europe and the US.

£1M JOINT FUND LAUNCHED

with charity LifeArc to accelerate promising research projects to develop new treatments for congenital muscular dystrophy. We have been able to create this partnership thanks to a very generous legacy.

SUPPORTED A FOUR-YEAR PHD

through our SMA PhD Partnership with Spinal Muscular Atrophy UK.

INVESTED IN A BROAD RANGE OF PROJECTS

that cover many stages of research, from biological understanding of conditions through to clinical studies.

Breakthrough in genetic research for Ullrich congenital muscular dystrophy

MDUK funded research led by Prof Francesco Muntoni at University College London, which successfully developed molecular patches that can correct the faulty gene that causes Ullrich congenital muscular dystrophy (UCMD).

The patches restore healthy collagen-VI production by correcting the faulty gene present in animal and cell models of the condition without overriding the healthy gene. They do this using an 'exon-skipping' approach. The molecular patches showed promising effects in skin cells obtained from patients; however, their delivery into muscles of mice with UCMD requires further investigation.

Researchers hope to take these findings to the next step in developing potential treatments for people with UCMD.

Cell therapy identified as possible treatment for Duchenne muscular dystrophy

A lack of dystrophin causes muscle cells to weaken and break down over time in those with Duchenne muscular dystrophy. Thanks to funding from MDUK, Prof Jennifer Morgan and her team at University College London found the optimal conditions for packaging the full-length dystrophin in mice models of Duchenne.

The results showed a significant increase in dystrophin production compared to control mice. The restored full-length dystrophin appeared to function similarly to the healthy dystrophin.

While this study shows promising results for the future, it is still only in its pre-clinical phase. It is hard to tell when it could reach clinical application, but it will take many years.

Nevertheless, when available, this approach could potentially be used in combination with other therapies for Duchenne, thereby providing longer and more durable protection of muscles.

Advancement in understanding underlying causes of Emery-Dreifuss muscular dystrophy

Understanding the causes underlying Emery-Dreifuss muscular dystrophy (EDMD) has always been challenging, as different patients tend to have changes in different genes, making it almost impossible to develop treatments.

Funded by MDUK, Prof Eric Schirmer and his team at the University of Edinburgh looked to identify if these genes are involved in the same cellular process in patients with EDMD. In fact, they found three separate cellular processes were involved.

Understanding which processes are affected in those with EDMD will help focus on the pool of potential therapeutic targets, which was previously not possible. These results also have the potential to be used to develop new diagnostic approaches for the condition.



ACCESS TO TREATMENTS

Bringing the day no one is limited by muscular dystrophy ever closer

Increasing access to treatments is a core part of our work to fight muscle-wasting conditions. This year, we worked to secure or improve access to seven treatments that help people with Duchenne muscular dystrophy, SMA, Pompe disease and myotonia in adults with non-dystrophic myotonic disorders.

Translarna/ataluren:

A treatment for people with Duchenne muscular dystrophy with a nonsense genetic mutation currently available in England through a Managed Access Agreement (MAA) and in Scotland through the Ultra-Orphan Pathway. MDUK is a member of the Managed Access Oversight Group (MAOG) and this year we helped to secure an extension to the MAA and began preparation for the full NICE appraisal in 2022/23.

Spinraza/nusinersen:

A treatment for people with SMA currently available in England through an MAA and in Scotland through the Ultra-Orphan Pathway. As a member of the MAOG, we worked with Spinal Muscular Atrophy UK to help ensure that more people became eligible to access the treatment.

Evrysdi/risdiplam:

An oral treatment for people with SMA. This year, working with Spinal Muscular Atrophy UK, we successfully helped to secure access to the treatment in England through an MAA. We helped to secure recommendation of the treatment in Scotland by the Scottish Medicines Consortium.

Zolgensma/onasemnogene abeparvovec:

A gene therapy for SMA. It addresses the genetic cause of SMA by delivering a functional copy of the SMN1 gene into nerve cells. This gene is critical for the function of the nerves that control muscles. This year we worked with Spinal Muscular Atrophy UK to help successfully secure NICE approval of the treatment for babies under 12 months who fit the criteria. It is also available in Scotland.

Avalglucosidase alfa:

A potential treatment for Pompe disease. This year we actively engaged in the early stages of the NICE assessment process of the treatment.

Cipaglucosidase alfa (with miglustat):

Another potential treatment for Pompe disease. This year we actively engaged in the early stages of the NICE assessment process of the treatment.

Mexiletine/NaMasucula:

A treatment for myotonia in adults with non-dystrophic myotonic disorders. This year we helped to secure NICE recommendation for the treatment in England. MDUK had previously played a role in ensuring the treatment was recommended for use in Scotland by the Scottish Medicines Consortium.

“Finally able to live the life of a nine-year-old schoolboy”

Through our engagement in the appraisal processes for new drugs and treatments with NICE, we have been able to help individuals living with muscle-wasting conditions access new opportunities to live with more freedom.

Finley is nine years old and lives with SMA. His mum, Rosie, talks about the life-changing impact that receiving new treatments has had on Finley's strength, energy and freedom.

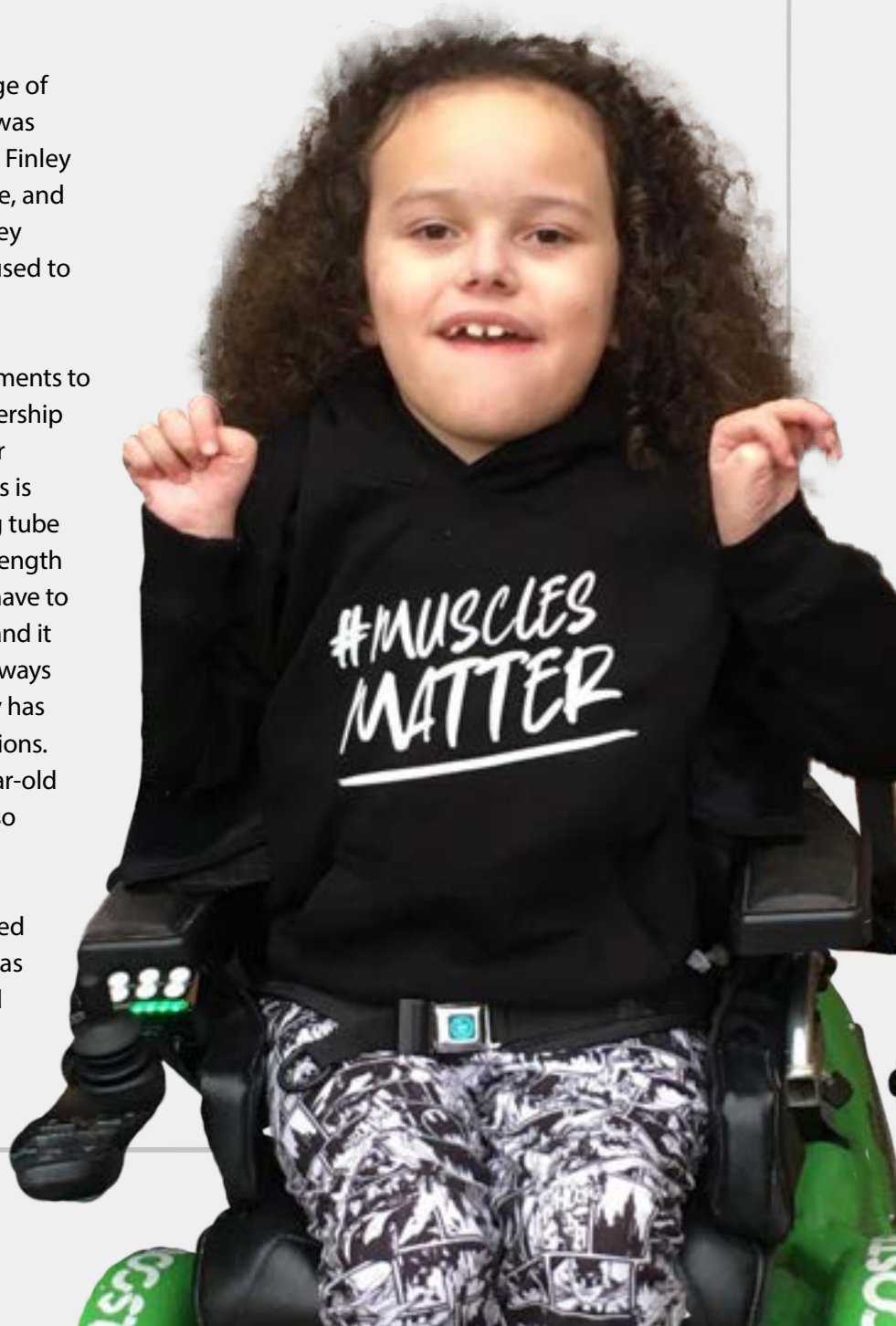
“It's incredible to think that there are a range of treatments available for SMA when there was nothing at all for years. Spinraza has given Finley so much more strength than he had before, and than what we had hopes of. However, Finley significantly struggled [with the infusion used to deliver Spinraza].

“Several months back, Finley changed treatments to risdiplam; a treatment that MDUK, in partnership with Spinal Muscular Atrophy UK fought for and secured access to through an MAA. This is administered daily through Finley's feeding tube and is massively helping to maintain his strength and energy. Finley is delighted he doesn't have to experience any more pain with treatment and it also means less time in hospital, which is always welcomed! Since starting treatments Finley has not had any emergency respiratory admissions. He is finally able to live the life of a nine-year-old schoolboy and we are able to live without so much sadness and worry.

“Recently, we've also got him a new powered wheelchair, that supersedes the chair he has had since he was three. He is really excited

about having a new, faster, more efficient chair, and this would not have been possible without his strength and energy levels that have been maintained by the treatment he has been able to access. Our excitement is at fever pitch.”

Below, Finley is wearing his Tikiboo #MusclesMatter hoodie, created in partnership with MDUK. 20% of the collection goes directly to MDUK. Shop now: www.tikiboo.co.uk/collections/mduk



ACCESS TO SUPPORT

Every day we are working towards a world where no one is limited by muscle-wasting conditions

While new treatments are a huge part of this, we are also helping people to access the care they need, live well and are working to change government policy to better support the community.

Highlights in 21/22:

8,113

views of the Muscles Matter webinars.

**HELPED TO
SECURE TWO**

further NHS specialist neuromuscular roles.

368

people attended
MDUK Muscle
Groups meetings.



SIX REGIONAL NEUROMUSCULAR NETWORKS

have been supported with
engagement and admin.

PROVIDED THE SECRETARIAT TO FOUR CROSS-PARTY AND ALL-PARTY GROUPS

in the UK Parliament, the Welsh
Parliament, the Scottish Parliament
and the Northern Ireland Assembly.

100 SPECIALIST NEUROMUSCULAR ROLES

secured by our work in this area since
2013; an annual investment of around
£7.5m by the NHS.

SUPPORTED DEVELOPMENT OF THE STANDARDS OF CARE FOR ADULTS WITH DUCHENNE

The Adult North Star Network's
Clinical Standards of Care for Adults
with Duchenne muscular dystrophy
were published by the Journal of
Neuromuscular Diseases.

“Now I don’t have to worry about things like paying for bills and affording food”

When 55-year-old Donna Ashcroft, who lives with myasthenia gravis, was faced with a huge cut to her Personal Independence Payment (PIP) award, she reached out to MDUK’s helpline, advocacy and support service.

With our help, Donna was able to successfully appeal the decision and fight for the level of PIP award she is entitled to.

“When the time came to reapply for my PIP award, I was sent lots of complex paperwork that I hadn’t filled in before. I didn’t understand a lot of it, but I did my best to complete the documents so I wouldn’t lose the financial support.

“After filing the paperwork, I was told my award would be cut drastically even though my myasthenia gravis had not improved at all. I had recovered from cancer since the last time I was awarded PIP, but my mobility issues meant I could no longer work as a chef which had been my profession since I was 16 years old.

“I heard about MDUK’s advocacy and support helpline through a Facebook group and got in touch. Romla, MDUK’s Helpline, Advocacy and Support Officer, helped write a letter that was aimed at increasing my PIP, including all the necessary information written in the correct way.

“My PIP award increased to the standard level due to the letter, but this still wasn’t enough to even cover my bills and let me live a decent quality of life. MDUK helped me continue fighting for the PIP I am entitled to, and I took the issue to court.

“Before my court date, a doctor rang me to say I didn’t need to attend the hearing as it was clear I should be awarded the enhanced PIP amount for 10 years. I was overjoyed to hear the news, and I couldn’t have done it without MDUK’s support. Now I don’t have to worry about things like paying for bills and affording food, alongside living with a chronic neuromuscular condition.”

Our helpline, advocacy and support service saw a 10% increase in the number of people it helped compared to the previous year.

If you need support with your neuromuscular condition, please contact the helpline on 0800 652 6352.



Changing Places

One of the ways we have worked to support the community over the past year has been our involvement in Changing Places as co-chair of the Changing Places Consortium.

The Changing Places Consortium is working to ensure that highly accessible toilets and changing facilities are available in public places to people who need them most, which includes many people affected by muscle-wasting conditions.

Key achievements:

SUPPORTING NEW INVESTMENT

We launched a new partnership with the Department of Levelling Up, Housing and Communities (DLUHC) to help shape and deliver a scheme for the distribution of £30m of government funding to install over 500 Changing Places toilets in parks, town centres and nature sites in England.

TOILETS IN MOTORWAY SERVICES

We continued to administer £2m of government grant funding in partnership with the Department for Transport that will see the installation of 59 new Changing Places toilets in motorway services across England by March 2023.



The Marsham Court Hotel, Bournemouth, becomes the first UK hotel to install a Changing Places Toilet.

PROVISION ACROSS OTHER TRANSPORT NETWORKS

We continued to administer £450k of government grant funding in partnership with the Department for Transport.

CHANGING PLACES IN SCOTLAND

PAMIS, the co-chair of the Changing Places consortium, registered a total of 19 Changing Places toilets in the past year, totalling 246 toilets in Scotland.

Every local authority across Scotland now has at least one Changing Places toilet.

“Going to the toilet is a basic human right”

Fraser Simmonds lives with Duchenne muscular dystrophy and has never been able to walk. He uses a powered wheelchair and needs assistance to use the toilet. His mum, Shelley, explains why Changing Places toilets are so important to families like hers.

“Regular disabled toilets are dark, dingy and smelly. They’re rarely found clean and they often are filled with dirty nappies which are left to overflow and fester. Fraser needs help removing his clothes to use the toilet and I have to kneel on the floor to support him with this. They are often far too small and I dread to think what I’ve knelt in over the years.

“We like to explore different places and have lots of adventures. Changing Places toilets allow us to do that without the stress of wondering what the loo will be like. It makes such a difference to open the door of a Changing Places toilet and find a bright and clean space waiting for us. Changing Places toilets make disabled people feel like they matter; going to the toilet is a basic human right and everyone deserves the same dignity.”

At MDUK, we’re proud to co-chair the Changing Places Consortium to help meet our vision that everyone affected by muscle-wasting conditions has access to clean, secure toilets and changing facilities, wherever they are.





DRIVING CHANGE

‘Shining a Light’ for our community

We have worked to increase access to healthcare for people living with neuromuscular conditions as the UK begins to recover from the pandemic. Through our ‘Shining a Light’ reports, we outlined key ways to overcome the challenges the community told us they face when seeking to access neuromuscular specialist care and support across England, Scotland, Wales and Northern Ireland.

Our five UK-wide action points call for the delivery of both short and long-term priorities to improve the lives of people living with muscle-wasting conditions.

UK-wide

1. Access to a specialist multidisciplinary team with input from a core team of specialist consultants, physiotherapists, mental health professionals and neuromuscular care advisors across the UK.

2. The establishment of NHS-managed regional neuromuscular clinical networks across the UK to help raise standards and benchmark services.
3. The provision of neuromuscular outreach clinics and improved connection with community services.
4. Access to a psychologist or mental health specialist with expertise in working with people with a neuromuscular condition.
5. Faster access to new treatments and therapies, from assessment to patient roll-out.

In our devolved nation reports we made recommendations specific to Scotland, Northern Ireland and Wales.

Scotland

- Increase the number of neuromuscular nurse specialist roles to ensure every neuromuscular team has at least one of these vital roles.
- Increase investment in the national neuromuscular teams with more neuromuscular consultant, physiotherapy, nurse specialist and psychology time.
- Appoint a full-time network manager with administration support for the Scottish Muscle Network.
- Reduce waiting lists and address the growing backlog of new and follow-up appointments, by implementing virtual outreach clinics in local areas.
- Strengthen the administrative support for data collection and improved clinic co-ordination.
- Consider introducing flexibility into the yearly growth of block contracts to accurately reflect the growing neuromuscular population and the resulting increase in complex care needs.

Northern Ireland

- Allocate sustainable and consistent funding for neuromuscular services to accurately reflect the care needs of the neuromuscular



The Wilson family enjoying quality time with their son, Aadi, who has SMA.

population, including more neuromuscular consultant, physiotherapist, nurse specialist, psychologist, speech therapy, occupational therapy, and care advisor posts.

- Increase the number of trained neuromuscular staff who can work with community services, and bridge the gap between specialist neuromuscular teams and their surrounding areas.
- Improve access to specialist psychology and mental health services for people with muscle-wasting conditions.
- Reduce waiting lists and address the growing backlog of new and follow-up appointments by implementing virtual outreach clinics in local areas.
- Establish a Northern Ireland NHS-managed regional neuromuscular clinical network and re-appoint neuromuscular leads to connect government and the network.
- Provide specific clinic space where people with muscle-wasting conditions can access an appointment when they need to.

Wales

- Allocate sustainable and consistent specialised funding for neuromuscular services to accurately reflect the care needs of the neuromuscular population, including more dedicated neuromuscular consultants, physiotherapists, nurse specialists, psychologists, and care advisor posts.
- Secure NHS funding to support the Wales Neuromuscular Network to appoint a network manager to help identify local service gaps and implement more timely solutions.
- Access to specialist psychology and mental health services for people with a neuromuscular condition.
- Timely and local access to new treatments and therapies for people across Wales.
- Increase the number of trained, neuromuscular staff who can work with community services and bridge the gap between specialist neuromuscular teams and their surrounding areas.

KEY IMPACTS FOR THE COMMUNITY

- The UK-wide report was launched in the UK parliament at a meeting of the All-Party Parliamentary Group on Muscular Dystrophy.
- The report was featured on major television channels and news outlets across the UK.
- The National Institute for Health Research and the Department of Health and Social Care have warmly engaged with us about the reports.
- We met with the Neurological Conditions' Clinical Priorities team within the Scottish Government to discuss the report.
- The Northern Ireland Department of Health and the Belfast Trust are keen to work collaboratively on pushing forward these recommendations.



OUR PRESIDENT'S AWARDS WINNERS 2021

This year, we were delighted to announce the winners of MDUK's President's Awards 2021 in recognition of those in our community who go above and beyond to help make muscles matter.

The six awards recognise success over the past 12 months in fundraising, caring, volunteering, community engagement and research, as well as an outstanding achievement award. We're thrilled to congratulate our winners:

Fundraiser of the Year: Sam Taylor

Sam launched the Duchenne Research Relay – a major fundraising event where 19 cyclists completed a 380-mile bike ride from London to Newcastle via Oxford and Liverpool. Their journey took them to four of the UK's neuromuscular research centres and raised a staggering £43k. Sam and his team never faltered in their determination, even when cycling conditions were gruelling and despite having had to postpone the event because of the pandemic until 2021. Sam's grit is inspired by his son, Will (aged 12), who lives with Duchenne muscular dystrophy.

Volunteer of the Year: Patricia Lock

Throughout the past year, Patricia has been a

beacon of light to those she supports in her volunteering. Her time, expertise, and valued perspective makes a huge difference to MDUK. Patricia lives with congenital myopathy and uses her experience to chair the Milton Keynes Muscle Group, chats with others as a peer support volunteer and sits on our Joseph Patrick Trust panel. She approaches everyone with warmth, friendliness and compassion, and gives her all to volunteering with MDUK.

Richard Attenborough Award for Outstanding Achievement: Carmela and Lucy Chillery-Watson

In a year that brought fear and darkness, mother and daughter duo Carmela and Lucy brought colour, courage, and ambition to make muscles matter. The pair led a number of national and local fundraising drives and have helped MDUK raise more than £125k over the years. They have also raised the profile of LMNA-CMD, the condition that Carmela lives with, during the pandemic, and even hosted a series of Joe Wicks-style workouts for children living with muscle-wasting conditions. Their commitment and dedication has made a huge difference to those in our community.

Peter and Nancy Andrews Community Achievement: Lorna Fillingham

Changing Places campaigner Lorna Fillingham

was the winner of this inaugural award, which honours lifelong MDUK supporters Peter and Nancy Andrews. Lorna has taken her tireless campaigning to Downing Street, and she regularly meets with government ministers and departments to lobby for better Changing Places provision. Most recently she has been involved in encouraging local authorities to bid for a portion of £30m funding to install more of these vital toilets across England.

Early Career Scientist of the Year: Amy Vincent

Amy Vincent is an exemplary winner in this category and is making fundamental discoveries, which will hopefully contribute towards the development of new treatments for people living with muscle-wasting conditions. Amy has an outstanding research publication record, has shown tremendous leadership qualities and has even been awarded the highly prestigious

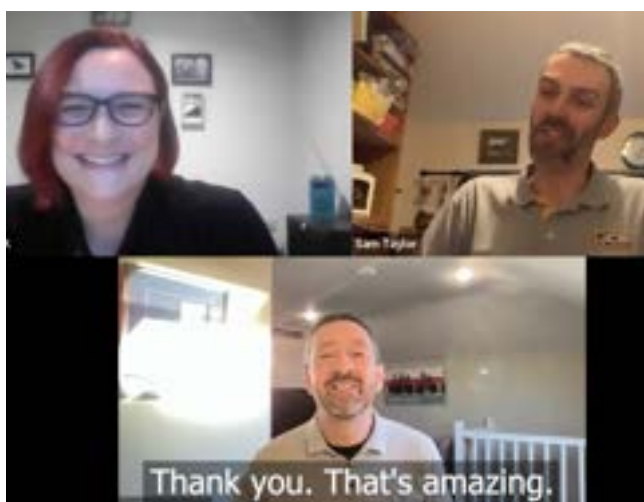
Henry Wellcome fellowship. Her outstanding commitment to public and patient engagement in leading several events for patients with muscle disease means she is undoubtedly a future research leader.

Alexander and Valerie Patrick Award for Carer of the Year: Shelley Simmonds

Alexander and Valerie Patrick were lifelong supporters of Muscular Dystrophy UK, and their eponymous award recognises outstanding and selfless commitment. Shelley Simmonds truly deserves this award, as she works full-time while also caring for her son, Fraser, who lives with Duchenne muscular dystrophy, and her daughter, April. She also speaks with newly-diagnosed families and gives a voice to the community through her popular blog Fraser & Friends, providing support to those in the Duchenne community. Her positivity and knowledge has been warmly embraced by everyone who meets her.



l-r: Catherine Woodhead, Shelley Symonds and Gabby Logan MBE.



l-r: Catherine Woodhead, Sam Taylor and Chris Boardman MBE.

THANK YOU

Thank you to our judging panel, Ian Gordon (Chair), Martin Cardoe and Scott Keown, and to Mike and Karen Attenborough for judging the Richard Attenborough Award. Thank you also to, Olympic cyclist Chris Boardman MBE, TV news anchor Julie Etchingham and our President Gabby Logan MBE for joining surprise video calls with our winners.

THE DIFFERENCE YOUR ASTOUNDING SUPPORT MADE

Thanks to your unwavering generosity, income from donations, gifts, grants and fundraising activities totalled £4.5m.

This year has seen us welcome our generous fundraisers back to in-person events for the first time since the pandemic. Their tireless commitment allows us to carry out our vital work for people living with muscular dystrophy and associated conditions. Thank you to everyone who has helped us raise funds this year – none of our work would be possible without your support and we're delighted to see the amazing impact it's having for the community.

Our fundraising year in numbers:

£31k



raised as Jon Richardson hosted a charity comedy night for MDUK.

£61k



raised through partnering with regional businesses.

£32k



won by Gabby Logan MBE on *Who Wants to be a Millionaire?*

£107k



raised at the 40th Oxford Town and Gown race, delivered in secure COVID-19 conditions.

£252.6k



raised by Family Funds, Fundraising Groups and Branches.

£91.1k



raised at our Pedal Paddle Peak event by 112 participants, a record year and our first one since COVID-19.

Let's look back on some of the events that made last year so fantastic

The Q Trust

In March 2021, we celebrated the completion of our commitment to fund a new centre of excellence in the form of the MDUK Oxford Neuromuscular Centre. We successfully fulfilled our pledge made in 2017 to raise over £1.2m to secure more neuromuscular research in Oxford and to establish a third major centre to increase the capacity of clinical trials in the UK.

This five-year appeal was led by members of one of our longest standing family funds, The Q Trust, who include MDUK Trustee Charles Scott and Charles Manby MBE who is a former Trustee, former Chair of the Appeal Board and a key supporter. The Q Trust was set up 20 years ago by Mark Reynolds in memory of his friend Quentin Crewe who was a celebrated journalist. Mark and his wife Jemima worked tirelessly to raise awareness and support for others with muscle-wasting conditions. Sadly, Mark died in 2005 as a result of his own muscle-wasting condition and Jemima passed away 10 years later.

The Q Trust is now made up of friends and family of Quentin, Mark and Jemima and, in 2022, their total fundraising hit £3.1m thanks to the incredible generosity of their supporters. The Q Trust continues to put on

a number of superb fundraising events to celebrate the lives of their dear friends and to ensure that their legacy is a lasting one.

Following another successful Q Trust Quiz event in November 2021, hosted by Evan Davis, the Oxford Appeal was closed with a celebratory dinner at Merton College in Oxford which was attended by 70 members of The Q Trust, who heard speeches from leading scientists from the centre including Professor Matthew Wood (Director of the centre), Professor Laurent Servais who was funded by The Q Trust's support of MDUK and our Chairman, Professor Mike Hanna.

Microscope Ball

In 2021, the annual Microscope Ball returned for its 37th year with a superhero theme inspired by Carmela Chillery-Watson's Wonder Woman Walking Challenge. Seven-year-old Carmela, also later commended in MDUK's 2021 President's



Sally Whittet, a Celebrity Sports Quiz committee member at the Celebrity Sports Quiz 2021.

Awards, joined the party to wow everyone with her story of raising thousands of pounds for research and living with LMNA-CMD.

Taking social distancing into consideration, this gala event welcomed fewer guests than in previous years. Nonetheless, 55 companies from the property sector attended to raise a record £129k on the night, taking the total funds raised by the event to £328k. Thank you to the Microscope Ball Committee and Chair Michelle Anthony for leading this fabulous fundraiser for MDUK.



Microscope Ball Chair, Michelle Anthony, and Carmela Chillery-Watson at the Microscope Ball 2021.



Duchenne Research Relay 2021

London Marathon

The London Marathon returned in October 2021, combining participants who had registered for the previous year and a new wave of runners. This event saw 94 people taking part in the live London event on behalf of MDUK and 26 people taking part virtually around the country. Together they raised a whopping total of over £200k for MDUK. Thank you to everyone who took part, not only for their efforts on

the day but also for the dedicated months of training in preparation.

The Duchenne Research Relay

In August 2021, 19 cyclists completed a massive 380-mile ride from London to Newcastle in just three days to raise £40k for MDUK. The amazing event was organised by Sam Taylor, winner of the Fundraiser of the Year in the 2021 President's Awards. Sam's fundraising initiatives are not for the faint-hearted, having raised over £100k for MDUK over the years.

It's Game On for MDUK's Rianna

Rianna, who worked at MDUK through a Moving Up Internship, raised £228 in her 12-hour Game On challenge for MDUK. Rianna has congenital myasthenic syndrome, a rare type of

myasthenia gravis that affects her mobility. "I wanted to take part in Game On as it seemed fitting that I could do something I love while also raising money for MDUK. It's a special charity to me as they offered me a lifeline when I needed it most," says Rianna. Thank you to Rianna for fundraising for us, and being part of the MDUK team.



MDUK Charity Golf Day 2022



Rianna, who lives with congenital myasthenic syndrome.

Thank you to everyone who has supported us this year. With your generosity, we are closer to a world where no one is limited by muscle-wasting conditions.

Our finances

Thanks to the generosity of individuals, families, corporate partners, trusts and foundations and those who chose to include us in their legacy we have raised a total income of £6.7m in 2021/22. This represents a 20% increase from the previous financial year, where our income was impacted by the pandemic.

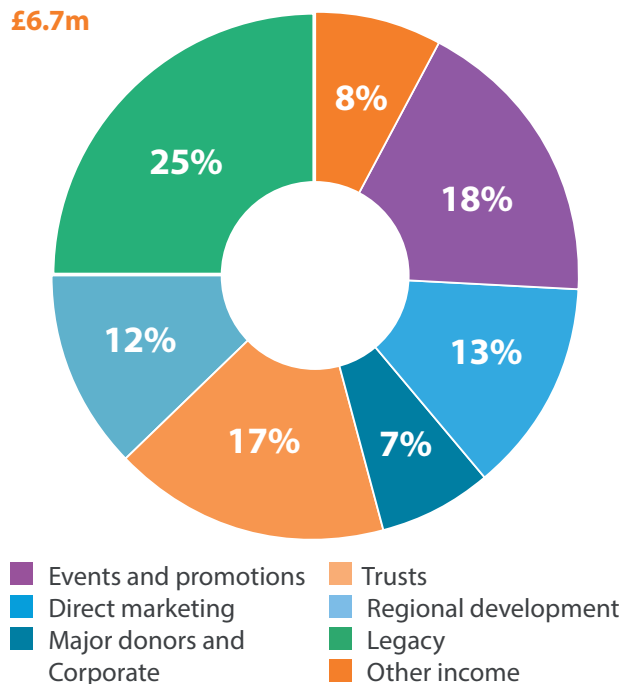
Expenditure on charitable activities was in respect of medical research, improving access to specialist NHS care, and provision of information, support, and opportunities to enable independent living. With the charity returning to pre-COVID-19 operations, the total charitable expenditure has understandably increased compared to the previous year to £3.8m (2021: £2.4m).

We ended the year with a surplus of £1.1m, which mainly represented funds received for future projects, including £300k received from the Garfield Weston Foundation for a two-year project starting April 2022 and a £450k legacy restricted to the congenital muscular dystrophy translational research call scheduled for 2022/23 in partnership with LifeArc.

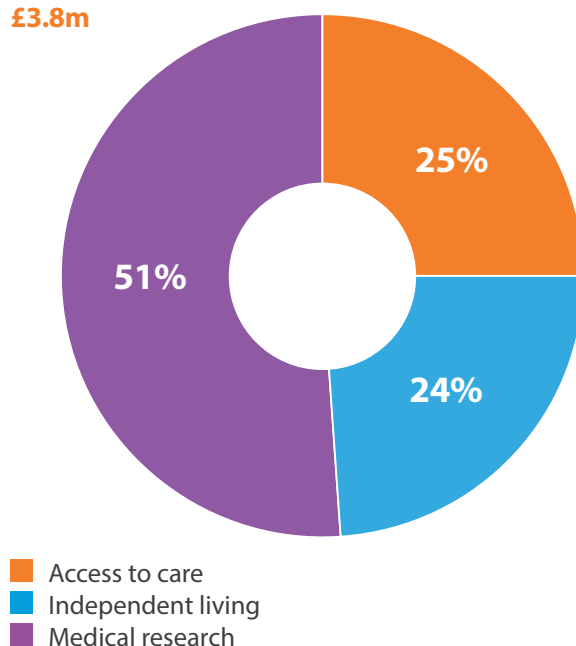
The 2021/22 financial year was a recovery year for the charity following the impact of COVID-19. The changes implemented in 2020/21, to cut costs and protect reserves, were fully embedded and through prudent financial management, MDUK remains in a strong financial position supported by the reserves and continued fundraising to face any future risks in the challenging economic environment.

MDUK closed the year with a £10.8m strong balance sheet, demonstrating the strength of having a mixed fundraising portfolio to continue raising income for the charity when the pandemic affected all areas of society. For every £1 we spent on fundraising activities we have raised £3.65.

Total Income 2022
£6.7m



Total Charitable Expenditure 2022
£3.8m



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Thank you so much to those that have supported us throughout the year

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Steve Gauder, Jack's grandad



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We have partnered with the National Free Wills Network to offer our supporters the opportunity to have a simple Will written or amended for free. There is no obligation to leave a Gift to MDUK however we hope you might consider it.

www.musculardystrophyuk.org/giftsinwills

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