TMD

Target MD August 2021

"Tough, but I'd do it again!"
OUR TOTAL WARRIOR

Muscular Dystrophy UK
Fighting muscle-wasting conditions

Contents

COVER STAR

Hello and welcome to Target MD

I'm thrilled to welcome you to our new-look lifestyle magazine. It's a joy to bring it to you after such a long break – the last time we published *Target MD*, now called TMD, was at the beginning of 2020. Little did we know what lay ahead.

The world has changed since then but our commitment to you, our community, hasn't. You'll read in the pages that follow about our wonderful care and support team who are there to help you get the care, benefits and services you're entitled to. No matter where you live in the UK, we're here for you.

And if you want to fundraise for MDUK, we have a brilliant team of regional development managers to support you. You'll also see some of the events they have coming up in their areas so you can get involved.

Many people get involved in different areas of the charity's work, as volunteers. We introduce you to Patricia, who chairs one of our Muscle Groups, and to Brian, who's supported us over the past 30 years as a fundraiser and now campaigner. Thank you, too, to Freya, Romla and Shivam who share stories of their work, studies and interests.

You'll read about our plans for research, as well as our report on the impact of COVID-19 on services for people with muscle-wasting conditions. And then Josh, our very own puzzlemaster, has devised a page of brainteasers to get you thinking.

I hope you enjoy this new edition of TMD. If you'd like to share your story, or any thoughts or ideas you have about the magazine, please do get in touch. I'd love to hear from you.

Until the next time!

Ruth

Ruth Martin
Editor

Friends of MDUK
Join our new, refreshed Friends of MDUK membership scheme for just £15 a year (when paying by Direct Debit), and get access to a host of benefits. Plus, if you join before 30 September 2021, you'll get exclusive entry into a draw to win two nights' accommodation for two in a UK/European destination, courtesy of Handiscover accessible breaks.

Find out more at
www.musculardystrophyuk.org/friends-of-mduk

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On the cover:
Susanne Driffield, MDUK Regional Development Manager, got together a team to take on the Total Warrior challenge in July 2021. Read more on p27. Photo credit: www.mybibnumber.com

FOLLOW US ONLINE

News from MDUK

Hello everyone. It's great to be able to greet you from the pages of this magazine once again. So much has changed over the past 18 months that it's good to be able to bring back something familiar, albeit with a fresh new look and feel!

When coronavirus hit last year, it brought not only an entirely new need within our community but it also affected our ability to deliver our services, meet with you and fundraise. We faced an immediate and significant funding gap and, in a world of enormous uncertainty, our community was relying on our services more than ever. We had to make key decisions and innovations, at pace.

Our priority was to keep our frontline services going and continue to be there for our community across the UK. We reduced spending to a minimum, supported our helpline team to work from home, collaborated with clinicians and other charities to keep our coronavirus guidance and information up-to-date, created new virtual fundraising opportunities and made use of the government's furlough scheme. But there were still difficult decisions we had to make: to reduce our staff team, and to transfer Trailblazers, our young campaigning network, to a new home with pan-disability charity, Whizz-Kidz.

Some positives came out of the past 18 months, too. Thanks to the campaigning efforts of the Changing Places Consortium, which we co-chair, the government announced an investment of £30m in new Changing Places toilets in 2020 and, working with MDUK, launched the programme to deliver this in 2021.

This means thousands more disabled people across England, including those with muscle-wasting conditions, will have better access to leisure and sports facilities, cinemas, and arts and tourism venues.

And thanks to the generous support of our community, we're thrilled to be able to invest in new high-quality research again in 2021, to build upon our current research portfolio. Although research has paused for a time, we remain on the cusp of change, with fantastic news on treatments, too. The first baby has been treated on the NHS in England with Zolgensma, a potentially life-changing gene therapy for spinal muscular atrophy (SMA); and more people are now eligible for access to SMA treatment, Spinraza. There's also been the disappointing news that NICE is not recommending SMA treatment, Risdiplam, for use on the NHS in England. We'll continue fighting for access to this and treatments for other muscle-wasting conditions that become available.

As a charity, and a sector, we're addressing the wider global issues of climate change and racism, diversity, equality and inclusion, by identifying what we can do to create a better, safer future for generations to come.

I want to thank all of you for your ongoing support of MDUK and for helping us to make a difference, every day, in the lives of people with muscle-wasting conditions.

Thank you

Catherine Woodhead
Chief Executive, MDUK

Our special history with HRH Prince Philip

We were deeply saddened to learn of the death of His Royal Highness, Prince Philip, our Royal Patron, in April. We were privileged to have had more than 50 years of his commitment to the fight against muscle-wasting conditions.

When Prince Philip became our Patron in 1966, very little was known or understood about muscular dystrophy. He always took a genuine interest in the work of MDUK, and was always keen to hear about the pioneering research we fund into treatments and cures.

MDUK Patron, Ian Corner, a prolific fundraiser and supporter of the charity since the mid-1990s, met Prince Philip four times. It was his wicked sense of humour that Ian remembers fondly.

"I first met Prince Philip at Lord Attenborough's birthday party at St. James's Palace. He asked me how I'd become involved in the charity and I told him about my son, who had Duchenne muscular dystrophy. He asked a few like-minded people in my group the same question, and each said they'd become involved with the charity because of me! With a twinkle in his eye, he told me he didn't need to talk to me again! He was clearly impressed I'd got so many people involved!

"I met him on three other occasions at MDUK events, and he was always friendly and well-informed about each guest. Our charity community will miss him."

Tanvi Vyas, MDUK Trustee, met Prince Philip on two separate occasions:

"I found Prince Philip to be really charismatic, charming and well-humoured. He had an incredible memory, and recalled meeting me on a previous occasion, which was really surprising considering the number of people he must meet. It's been wonderful that Prince Philip supported the charity and its aims for many years."

SHIVAM NATHWANI

"I continue to express my interests in the automotive industry through my work on YouTube."

Watch his YouTube videos here:

SCAN ME

Driving his own success

With brilliant support from a huge and loving family, Shivam Nathwani has been able to achieve many of his dreams.

Ever since this 23-year-old Leicester man was diagnosed with Duchenne muscular dystrophy at the age of five, his family has surrounded him with their positive spirit.

He comes from a big family: his father Vipin, originally from Uganda, has seven brothers and four sisters; his mum Dinakshi was born in Kenya and has three brothers and one sister.

"I have got Duchenne muscular dystrophy and a tracheostomy but this hasn't stopped me living an above average lifestyle. My childhood was filled with die-cast toy cars, episodes of *Top Gear* and *Need for Speed Underground,*" said Shivam.

"I continue to express my interests in the automotive industry through my work on YouTube. To top it off, I continue to dominate the *Need for Speed* servers on a daily basis.

"My brother, Pritesh, has helped me turn my dreams into a reality. Just like all siblings, we do fight but we put our differences aside and are now taking great leaps to raise awareness for those around me. Together we are unstoppable and we have so much more planned for everyone!"

Pritesh said being close as a family and working as a team helps their parents cope with the worry of having a son with a disability.

"Shivam, who was a late walker and has been using a wheelchair since early childhood, has had an endless cycle of operations, physiotherapy and medication but nothing has stopped him. Between trips in and out of hospital, he attended and completed college in Loughborough. He achieved a pass but was not happy with his grades and re-took his exams in media, eventually coming away with a distinction," said Pritesh.

Shivam's passion has always been cars and he has visited the Formula 1 at Silverstone many times. Taking his health and his passions into consideration, last year he decided to focus on turning his dreams into reality, and become a car reviewer.

And then Pritesh surprised him with a supercar convoy, which drove past his home.

"Now the lockdown is easing, I am focused on making plans to complete my brother's wish list. He's already visited the Porsche Centre, but these are also on his list:

- going to the F1, meeting the drivers in the pit lane, and making a recording for his YouTube channel
- visiting the Rolls Royce Factory
- becoming an ambassador for Sytner Group.

If you'd like to share your story, please get in touch with us at targetmd@musculardystrophyuk.org

Embrace, accept and be fearless

Freya Masters

When I was 10-and-a-half years old, I was diagnosed with limb girdle muscular dystrophy (LGMD) Type 2i. Now I am 22 and whilst I still have LGMD as letters attached to my name, I also have a degree in Biochemistry from the University of St Andrews!

In September 2017, I was daunted and hugely excited to leave for university. I knew how special a place St Andrews is; my older brother Luke is an alumnus and graduated with a degree in Physics in 2016. Whilst I was anxious about the unknown challenges of university with a muscle-wasting disease, I was inspired by my brother. Luke's own struggles with Type 1 diabetes didn't stop him from pursuing his academic interests, so I wasn't about to let my condition deter me.

"University has taught me that you really can do anything you put your mind to."

My MD has always challenged me – physically, mentally and emotionally. Sometimes, the simplest things in life can be a struggle. Whilst St Andrews is a small, flat town (perfect for my condition), there have been many challenging situations, from navigating lecture hall stairs to long, tiring lab days. My 18-year-old self tended to ignore my MD, refusing to acknowledge it as a part of me.

However, with struggle gradually comes acceptance. Now I'm 22, my perception has shifted, and I perceive my MD as a part of 'Freya'. University has taught me that you really can do anything you put your mind to. However, I was unfortunately let down on different occasions by a strained university disability team. I have therefore learned that it is important to be proactive in speaking up for your needs. Indeed, you cannot assume people will simply 'join the dots'.

Now, I am proactive about asking for help. I can even perceive my MD in a positive light. Quite amusingly, my friends and I decided that my 'boggart' (the shape-shifting entity from Harry Potter, which transforms into your worst fear) would be a great big staircase. I'm eternally grateful for my friends and my wonderful boyfriend Will's love and support (and for coping with my 'h-anger', or 'hungry anger' which comes with burning copious amounts of calories when walking).

I intend to pursue a career in medical writing/science communication. University has been immensely challenging but equally a very special time in my life. If I could talk to my 18-year-old self, I would tell her about the incredible experience ahead and to embrace, accept and be fearless.

Freya has recently joined our Content Advisory Group, and also shared her experience of uni in our Muscles Matter online seminar in August. Find out more at www.musculardystrophyuk.org/musclesmatter

Moving up with MDUK

Romla Kadir

"Moving Up was a useful and fun experience that has greatly inspired me as I begin my career."

During my work experience time with MDUK's Moving Up scheme, my work was to evaluate the work experience scheme by creating a survey for past participants and researching the impacts of the COVID-19 pandemic on the employment and job searches of disabled people across the country.

What I found most interesting about my work was that I was able to use my lived experiences as a young disabled person during the pandemic, while also hearing about the shared experiences of others. The pandemic has opened up a lot of discussion about flexible working arrangements. As we ease out of lockdown, there are a lot of changes to be made to ensure that disabled people are accommodated fully, both during the pandemic and after it in physical spaces too.

Before I began, I was worried it would be very easy to not feel a part of the team because of remote working. Luckily, this was not a problem and I got a good understanding of the departments within the charity and was able to speak to a few of them to understand how they work together.

From my own experience in the past couple of months on it, I have seen the value of taking part in Moving Up and how beneficial it can be for young people, their confidence, and their understanding of the workplace.

Since my placement, I have completed my degree in Politics and International relations and will be graduating soon. I am now pursuing freelance journalism. I began exploring journalism earlier this year because I am keen to write about disability and share my perspectives that are often under-represented. I have had a few articles published this year and hope to have more.

My time at MDUK made me realise that I would love to work within a charity too, and so I am looking for roles within charities to apply to. Moving Up was a useful and fun experience that has greatly inspired me as I begin my career.

If you're a young disabled person in London looking for work experience for your CV, or other support to help you into work, do get in touch with us at j.mclellan@musculardystrophyuk.org

LUCA AND HIS DAD PEDRO

"I never thought I'd see my son learn to ride a bike."

A lifeline for Luca

Luca's family has welcomed the news that a drug used to help treat symptoms of Duchenne muscular dystrophy has been extended for use on NHS England until January 2023.

The news was a huge relief for Pedro and Joanne Fernandes in Dorset. Their 11-year-old son Luca, who has Duchenne muscular dystrophy, has been on Translarna since September 2016. While most boys with the condition need to use a wheelchair by the age of 12, Luca rides a bike, is learning to skateboard and surf, and can keep up with his three-year-old brother Micah.

Despite being told he'd need mobility aids from the age of eight, Luca has recently completed his cycling proficiency test. That's something Pedro and Joanne never thought they'd see him achieve.

"The news that the Managed Access Agreement (MAA) for Translarna has been extended is an enormous relief for my family. As it is for so many other children, Translarna is a lifeline for Luca because it helps keep him active and mobile and slows down the progression of his condition.

"I never thought I'd see my son learn to ride a bike – I can't explain how powerful that moment was for my family, and we believe that's because of Translarna. We'll continue campaigning with MDUK to see Translarna approved for permanent use on the NHS," said Pedro.

Translarna can help treat a version of Duchenne muscular dystrophy caused by nonsense mutations, accounting for around 10 to 15 percent of diagnoses. Eligible boys had been receiving the drug under a MAA, an agreement between NHS England, NICE, and the drug manufacturers, allowing patients to receive treatments while long-term data is gathered.

The MAA was due to expire in July 2021, and in May we learnt it was being extended until January 2023. This means new eligible patients can get access to Translarna during this time.

"We've campaigned for Translarna since 2015. So while we welcome this update, it's vital that all parties continue working together to ensure the right decision on Translarna is made by the end of the extension period, and there's clear communication with the Duchenne community throughout," said Rob Burley, MDUK Director of Campaigns, Care and Support.

To find out more about our work to get access to treatments for muscle-wasting conditions, please visit www.musculardystrophyuk.org/fast-track

The value of volunteers

Calley Clay, Volunteer Engagement Manager

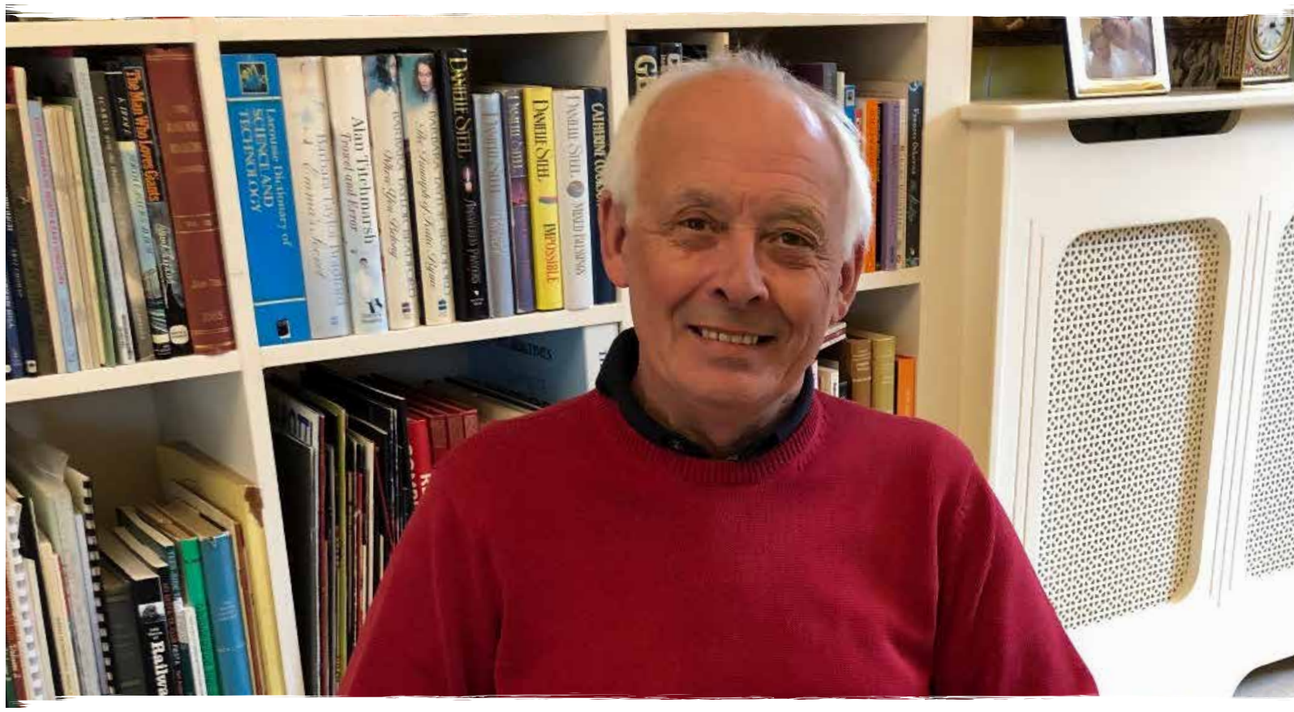
I joined MDUK as Volunteer Engagement Manager in March 2021, and I've had the pleasure of meeting an array of incredible volunteers. It's cliché to say that they are inspirational, selfless and wonderful people, but it's hard to express how I've felt when meeting MDUK volunteers without resorting to these clichés!

I want to thank the hundreds of volunteers who give their time to us, whether it's one day for an event or over many years as a Trustee. We couldn't do our work to support people living with muscle-wasting conditions without you all.

One of the first things that struck me as I started at MDUK was how many different ways volunteers support our work. From providing peer support to organising fundraising events, from making decisions on awarding grants for mobility equipment, to moderating our TalkMD forum or chairing Muscle Group meetings. You can find volunteers in every corner of MDUK's work.

Thank you to every one of you who makes a huge difference to the work of MDUK.

If you'd like to find out more about volunteering for MDUK, please get in touch at c.clay@musculardystrophyuk.org or visit www.musculardystrophuk.org/volunteering to find out more.



"Being actively involved for 30 years has allowed me to do something positive for people with muscle-wasting conditions."

A lifelong involvement

Brian Deehan (pictured) and his family, from Bainton in North Humberside, founded MDUK's East Yorkshire branch in 1992. Brian is an example of someone who's been not only an outstanding volunteer but now also an important regional ambassador for the charity.

"Being actively involved with MDUK for nearly 30 years has, I hope, allowed me to do something positive towards helping people with muscle-wasting conditions. These conditions are usually lifelong and my involvement will also be for the remainder of my life."

Brian and Avril's son, Chris, was diagnosed with Becker muscular dystrophy in 1992. They got in touch with MDUK, who supported them as they came to terms with what was initially a vague diagnosis.

When deciding what they could do to support MDUK's research into cures and treatments, they combined running their successful interior design business with gathering a network of supporters to take part in major fundraising events. Over the last 30 years, they've raised more than £150,000 for MDUK through everything from holding the first-ever mass abseil from the Humber Bridge, to signing up friends and family to run in the London and Paris marathons and the Great North Run.

Brian has also volunteered as a patient representative on a number of different groups, including the Regional Specialised Commissioning Working group, the Regional Neuromuscular Clinical Network, and on the Family Advisory Board of York University Martin House Research Centre. He also chairs our Yorkshire and Humber Muscle Group.

"I love being able to help people who are going through difficult times in their lives."

Using my experience

Patricia Lock is a volunteer three times over: she chairs MDUK's South Central Muscle Group, is a peer support volunteer, and sits on our Joseph Patrick Trust (our equipment grant-giving arm) panel too. Patricia has congenital myopathy, and appreciates the opportunity to use her own experience to support others.

"I'd been attending the Milton Keynes Muscle Group meetings for years before I began to chair it in February 2015. I was already aware of the value of being part of a group that understood exactly what I was going through, and I found being able to share information and access advice from others was extremely valuable to me. Once I started chairing the meetings, I realised the important of being able to say to others, 'In my experience…'

"Unless someone has first-hand experience of living with a muscle-wasting condition, they can never truly understand what it's like. For example, I've transitioned to using an electric wheelchair and I can help people realise that in doing so, they aren't giving up, they're just going to have to do things differently. In fact, it probably enables us to do more. Also, in being involved, I've found out information I didn't know before that I can then share with others. I love being able to help people who are going through difficult times in their lives.

"I find great value in supporting others currently going through what I've already experienced. Helping them realise that life is just different and that they can still manage to do things in their own way is a wonderful feeling.

"And it's always interesting to meet new people and hear their stories, and I certainly get that in my volunteering roles."

Meet your local MDUK support team

Every day counts when you're living with a rare, progressive muscle-wasting condition. At MDUK, our care and support team is here for you, from diagnosis and through every life stage and changing need. If you're struggling to get the care, equipment and services you're entitled to, our team can help too. And they can connect you with others who have similar experiences – people who understand what you're going through. Let them tell you more:

Neeru – Head of Information, Advocacy and Care

I'm mum to six-year-old twins and a 15-year-old. I've worked for MDUK for almost 10 years, having moved into the charity world from my previous job in finance. My brother, Mahesh, has Duchenne muscular dystrophy and, in 2009, he got lost in the system between paediatric and adult services and nearly lost his life. He was in a local hospital, where the staff knew very little about his condition. We didn't know what to do; my sister and I took on a 'care advisor' role and spoke to specialist consultants weekly.

That experience was a real catalyst for change. I left my job, worked for the NHS for a year before joining MDUK. Having started as a care advisor, I now head up the information service. My passion and connection has always been frontline support.

Our team offers a listening ear, and I can see the huge, invaluable difference they make. It can be by talking on the phone, listening to someone, sending information or signposting them to the services they need. My team is great at building long-term relationships with supporters, which is amazing, and I'm proud of what they do on a daily basis.

Jackie – Regional Information, Advocacy and Support Manager for Scotland

Hello! I live just outside Glasgow with my family and dog, and love travelling around Scotland. I like discovering new places, being in nature and taking in the scenery. I'm happiest at the seaside!

I've worked for MDUK for nearly four-and-a-half years and really love what I do. My background is in social work and this knowledge and experience contribute towards achieving positive outcomes for people living with muscle-wasting conditions. I especially enjoy meeting individuals and their families and I really value the time I get to spend with each of them.

After such a difficult year, I'm looking forward to being able meet with people again, and working collaboratively with others. I'll also be re-developing the advocacy and support service in Scotland, following the pandemic.

Sam – Regional Information, Advocacy and Support Officer for Wales

Hi everyone, I live just outside the beautiful harbour town of Aberaeron on the west coast of Wales. I enjoy going for walks and learning Italian – my dream is to retire in southern Italy!

Having worked in the charity sector for 16 years, I have particular expertise in welfare benefits; I'm passionate about supporting people in claiming the financial help they're entitled to. I've worked at MDUK for two years and no two days are ever the same. Whether it's chairing a Muscle Group meeting, taking part in a Wales Cross-Party Group meeting to campaign for better services, or meeting people attending clinic, my goal is to support those living with a muscle-wasting condition to the best of my ability. I'm really looking forward to supporting more people in person as life returns to normal.

Kyri – Advocacy, Support and Information Lead, London

Hello! I'm based in London and work as part of the head office team. I also support patients at the King's College Hospital neuromuscular clinic and I chair the London Muscle Group too. In my spare time I love to bake and cook and find it really therapeutic. I'm lucky to have some lovely open spaces and parks close by and often go for morning or evening walks, which helps me to switch off.

I've worked for MDUK for three years and before that I worked in the retail sector. I truly enjoy my job and love supporting individuals and families living with muscle-wasting conditions. I really cherish meeting people we support – whether that's at our national conference, a Muscle Group meeting, or in a hospital clinic setting. I'm really looking forward to contact returning, when it is safe to do so.

Demelza – Regional Information, Advocacy and Support Manager for Northern Ireland

Hello! I live in Belfast with my husband, two kids and pet pooch. I love days out in the countryside and around our gorgeous coastline. In my spare time, I enjoy reading and learning about personal development and keeping a positive mindset, which has helped me greatly over the past year.

I've worked for MDUK for nearly seven years and love supporting people from all over Northern Ireland. I'm a trained Occupational Therapist, and this healthcare experience has really helped me in understanding people's needs and how potential gaps in services can have a detrimental effect on quality of life. I'm looking forward to meeting people virtually through our Muscle Groups, which we'll be holding on Zoom. Hopefully, it won't be too long before I can get back out to meeting people again!

If you need information, support or guidance, our team is here for you. You can call our free helpline 0800 652 6352, Monday to Friday (10 am to 2pm), or email info@musculardystrophyuk.org

Shining a light on the impact of COVID-19

At MDUK, we know that the COVID-19 pandemic has had a significant impact on everyone's lives. And it continues to bring complex challenges for people with muscle-wasting conditions.

When you live with a muscle-wasting condition, it's essential to have access to specialist health care, regular exercise, care packages, family support systems and physiotherapy. But for many, this has not been possible.

That's why, in early 2021, we ran two national surveys: one to learn more about the impact of COVID-19 and lockdown on people living with muscle-wasting conditions,, as well as their families, and one on the impact of delivering specialist neuromuscular care in lockdown and through the pandemic.

More than 400 people took the survey and here are some of the key findings:

- **68 percent** said lockdown and shielding had had a negative impact on their physical health, and 62 percent said the same in terms of their mental health
- **45 percent** experienced reduced access to family carers or care workers because of lockdown or shielding
- **75 percent** experienced disruption or delays to accessing specialist muscle clinical appointments because of COVID-19.

We published the full results in a report, *Shining a light: the impact of COVID-19 and the future of care for people with a muscle-wasting condition*, which we presented to the All Party Parliamentary Group for Muscular Dystrophy in July. We'll use the findings to press the government and the NHS to make the health and care needs of people with muscle-wasting conditions a priority.

Equally, we'll call for specialist psychological support as part of holistic neuromuscular care, access to new treatments, and consistent care from multi-disciplinary teams in centres across the UK.

You can read more and download the report here:
www.musculardystrophyuk.org/Hardwick-story

"I feel scared that nobody's really monitoring what's going on with us. There are massive inequalities to accessing healthcare when you have a disability and COVID-19 has shone a magnifying lens on this." Charlotte and Tom Hardwick

A family that runs together

The McClean family from Ballymena in Northern Ireland love to run. Last year, they took on the Virtual London Marathon not only in support of 12-year-old Ethan (pictured right, and below with his mum and sister, Yvette and Amie) who has Duchenne muscular dystrophy, but *with* him.

Ethan's mum and dad, Yvette and Andrew, along with older sister, Amie, and Team McClean supporters, have taken on many fundraising runs since Ethan's diagnosis in 2010. Some years ago, Yvette took on her first marathon – the London Marathon, for MDUK – and two weeks later, the Belfast Marathon Festival with Amie, and Ethan walking across the finish line with them. Two marathons in two weeks! They had also fundraised for a Hoyt running chair so Ethan could join them on their runs.

But after Ethan lost his ability to walk during the first lockdown last year, the family were determined that Ethan would return to running by being in one of the biggest virtual runs held to date. In his specially designed running chair, he joined Yvette and Amie to take on the Virtual London Marathon, on a miserable rainy day in Ballymena.

"Our initial plan was to do the Marathon on Benone Beach on the north coast of Northern Ireland, our favourite place to escape after shielding

during the pandemic. But because of Storm Alex arriving on the day, we had to change our plans. We quickly found accessible routes on the Ecos Environmental Centre in Ballymena, and we were able to complete all 26.2 miles with Ethan by our side.

"We had amazing support the whole way round the route in Ballymena. Local runners came and ran part of the route with us and locals, having seen us on the BBC TV newsfeed that day, came out and found us to give donations. In the build-up to the day, a national clothing company, Cross Check Clothing, designed a 'Team McClean' T-shirt, which they sold and donated all the profits to our JustGiving page.

"A little bit of pain for the two of us is absolutely nothing compared to what Ethan has to endure daily. Slowly, Duchenne has robbed him of the ability to walk, and he's still coming to terms with this massive change. But the fighter he is battles on with courage and determination to make the most of his life," said Yvette.

A huge Belfast Giants ice hockey fan, Ethan wore Darcy Murphy's helmet on the run, to help him shelter slightly from the never-ending rain. Not only was it a great talking point in his BBC interview, but it also protected his eyes from the rain.

"Running has always been a big part of the family since early on in our Duchenne journey. It's nice to be able to run together," said Amie.

The McClean family launched their Family Fund in 2016. They fundraise mainly for research but recently have focused more on funding for mobility aids and equipment for Ethan as his condition progresses.

Just getting on with it

As Thomas Wildblood cycled 100 miles around Weymouth this May, his mind was full of happy memories of times spent with his friend Joshua.

Thomas, now 20, met Joshua when they were 11 and at secondary school. Joshua had Duchenne muscular dystrophy and, sadly, died in January this year.

"We shared a huge enthusiasm for football, and a love for film. Josh was an avid Spurs fan. We went to lots of football matches together, at different grounds across the country.

While at school, Thomas was awarded the Lions Club Award for being a supportive friend and helping Joshua.

"I know I helped him, but I hope he knew how much he also helped me. We could always turn to each other if we needed to talk about anything. Josh was very brave and had to cope with lots of surgery. He had two favourite sayings. 'Just get on with it' and 'To dare is to do', which is the Spurs slogan. I've had this second saying tattooed on my arm."

With his cycle ride, Thomas raised over £1,752 for research into Duchenne muscular dystrophy. It was a first fundraiser for Thomas, who's a chef and had to fit cycling in around studying and work. He chose to cycle around the end of Weymouth beach, as it was Joshua's favourite area.

COVID-19 and clinical trials

Dr Kate Adcock, MDUK Director of Research and Innovation

When the COVID-19 pandemic first swept across the world last year, it became clear early on that the only long-term solution for managing the spread of the virus – and indeed future variants – would be a vaccine.

And, as the UK adapted to a new way of life, so too did the protocol for vaccine development.

Clinical trials rigorously test and validate new drugs and therapies. While it usually takes years to get approval for use of such drugs or therapies, UK agencies, including the Medicines and Healthcare Products Regulatory Agency (MHRA), were swift to review and, where appropriate, approve trials, treatments and vaccines to help with the pandemic.

This, of course, has been vital for the health of the nation. The success of the UK's vaccine roll-out in particular has seen an incredible drop in both COVID-19 hospitalisations and deaths.

There is no denying, though, that the pandemic brought with it an urgent reprioritising of other health conditions. For example, many clinical trials, including those for neuromuscular conditions, were paused or delayed.

In response, the MHRA issued guidance on how clinical trials could be managed during the pandemic. This guidance is still very much live as we continue to navigate our way through this new version of normal.

Among a range of measures, the MHRA currently supports video or phone calls as a way of monitoring people taking part in trials, reducing the need for appointments at test centres. It also supports direct home deliveries of the drug (or placebo) being investigated. These measures would have been simply unimaginable in a pre-pandemic world and they highlight just some of the ways the virus has streamlined the way clinical trials are managed.

With the COVID-19 vaccine roll-out well underway, some other clinical trials have been able to resume. We were pleased to report a couple of exciting developments for the neuromuscular community earlier this year. In May, a boy living in the UK with Duchenne muscular dystrophy was enrolled on a Pfizer gene therapy trial. And in June, Fulcrum Therapeutics announced encouraging results from its Phase II clinical trial of losmapimod in patients with facioscapulohumeral muscular dystrophy (FSHD).

So while we wait with bated breath as life inches closer to a more normal future, MDUK is hopeful that agencies will maintain the flexibility and responsiveness they've shown towards clinical trials throughout the COVID-19 pandemic.

Funding new research in 2020 and 2021

Because of the COVID-19 pandemic, things have been very different for MDUK's support for new research projects. Here we look at how we normally fund research and the changes over the last 12 months.

Applying for funding

Normally, every autumn, we let researchers know they can apply to us for new research grants. Applications usually arrive in January. After a few checks, we send them to expert researchers all around the world.

We ask the experts if they think the scientific plans are achievable and if the results will help answer important questions for people living with muscle-wasting conditions. This is an essential part of our 'peer review' process.

Deciding on what to fund

Once the experts have commented, the applicants can respond with additional information or to give clarity. Then our Lay Research Panel (LRP) and our Medical Research Committee (MRC), both made up of volunteers, review the applications, usually in early summer.

The LRP considers and discusses each application carefully, not judging the science, but prioritising applications based on the benefit to people with muscle-wasting conditions. The MRC discusses the scientific merit of each proposal. Members of both panels meet to bring their feedback into the discussions. We usually announce funding decisions in the late summer.

What happened in 2020

As we began the peer review process, professionals started telling us they didn't have the capacity to review applications because of the pandemic and other demands on their time. We began to see that things would be challenging. Coupled with logistical challenges, the COVID-19 pandemic had a big impact on our financial situation so, after careful consideration and discussion with our Trustees, we made the difficult decision in early April to cancel the 2020 new grants round.

What are we doing in 2021?

After the disappointments of 2020, we're delighted to say we're holding a new grant round this year. We're working to a different timetable – the applications arrived in early June and we'll make decisions in the winter.

Unlike previous years, we've limited the scope of our grant round as we navigate the long-term financial impact of the pandemic. So, we've asked researchers for proposals of up to 12 months' duration, in Becker muscular dystrophy, collagen VI-related disorders, Duchenne muscular dystrophy, facioscapulohumeral muscular dystrophy, myotonic dystrophy and congenital myotonic dystrophy.

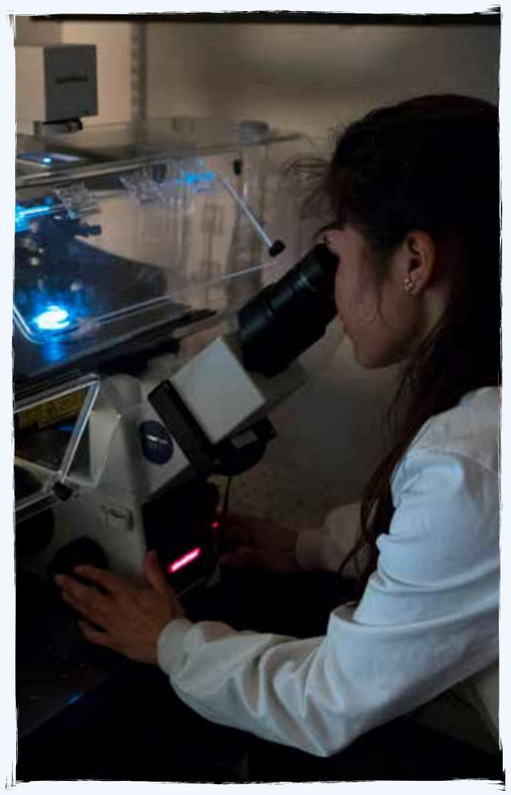
We're also delighted to continue our SMA PhD Partnership with Spinal Muscular Atrophy UK to support one four-year PhD studentship in SMA research.

We'll announce our new grants early in 2022. And we hope we can return to our normal routine soon.

Updates on research

Update on LMNA research

With funding from MDUK and Cure CMD, Dr Gisèle Bonne and her team at the Myology Institute in Paris are looking for genetic modifiers that lead to the wide range of clinical severity experienced by people with changes in the lamin gene. These changes can lead to LMNA-Congenital muscular dystrophy (LMNA-CMD). The team will be looking at muscle and/or skin biopsies from people who have the same change in their lamin gene, but who experience different symptoms. The pandemic has slowed this work down because the biopsy samples are being sent from patients from all around the world. But, once the samples have arrived, the team will use state-of-the-art research techniques to look for the modifiers.

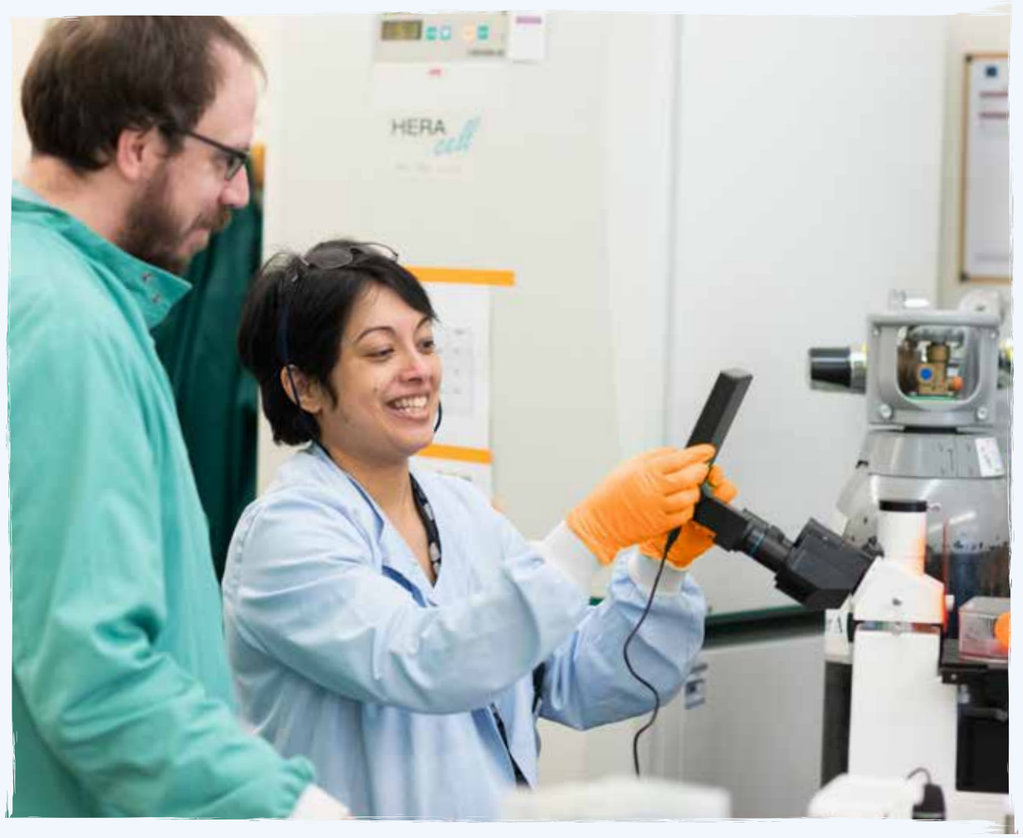


Update on congenital muscular dystrophy research

Dr Laura Swan and her team at the University of Liverpool are investigating why changes in an enzyme called INPP5K cause a form of congenital muscular dystrophy. INPP5K is involved in a process that decorates proteins with sugars (called glycosylation). Correct glycosylation of proteins is important for many of the cell's functions. In some cases, the sugar decorations help direct a protein to the correct place within a cell – a process called 'trafficking'. Over the past year, Dr Swan's team has seen that interfering with INPP5K changes the trafficking of proteins that should be at the surface of the cell. They have also found that INPP5K is involved in regulating a pathway involved in mitochondrial function (the energy-producing part of the cell). They saw that disease-causing variants of INPP5K find it difficult to travel to these structures. They now aim to look at how changes to INPP5K lead to the muscle wasting seen in muscular dystrophy.

If you have any research-related questions for us, you can email
research@musculardystrophyuk.org
Keep up-to-date at
www.musculardystrophyuk.org/research-news

Update on UNITE-DMD



UNITE-DMD is an international collaboration working on gene therapy for Duchenne muscular dystrophy. There are two arms to the research:

- continued optimisation and development of microdystrophin gene therapy products, led by Dr Linda Popplewell (formerly by Prof George Dickson) at Royal Holloway, University of London
- assessment of the safety and effectiveness of an investigational gene therapy, called GNT 0004, as part of an international multicentre clinical trial led by Prof Francesco Muntoni from the Dubowitz Neuromuscular Centre at UCL Great Ormond Street Institute of Child Health (as Global Chief Investigator for the trial), together with Prof Volker Straub at the John Walton Muscular Dystrophy Research Centre, Newcastle University.

Until recently, MDUK was funding the clinical work in the UK of the UNITE-DMD study. We're delighted that the trial sponsors Généthon – and their partners, Sarepta Therapeutics – have taken over the financial support for this work and are taking the trial forward with clinical research teams in France, the UK and other international sites.

Ashleigh Venables

Scotland and Northern Ireland

Ashleigh, who lives in Orkney and loves being outdoors, has worked for MDUK since 2018. Initially covering the south east region, she's delighted to be working with the MDUK community in Scotland and Northern Ireland.

Annual northern fundraising events like the Edinburgh marathon festivals, MDUK's Question of Support dinner and quiz, our Spirit of Christmas concerts and Kilt Walks are very familiar for this fundraiser. She is looking forward to meeting everyone and growing the network, as the nations open up once again to participation events.

She said: "I currently live in the north of Scotland in Orkney, where I grew up. I will soon be moving to Glasgow.

"I look forward to supporting you all in Scotland and Northern Ireland with your fundraising journey with MDUK."

A seasoned fundraiser herself, Ashleigh completed the 40th London Marathon virtually in 2021, braving storms along the coast in Orkney to raise £1.5k for MDUK. And she plans to start the SW Coastal path this year.

Ashleigh is getting to know some of the community in Scotland. Finlay is the wonderful brother to Georgie of Family Fund, Georgie's Genes. Georgie has LMNA-CMD and this May, Finlay followed his father's ultra-marathon example by walking the seven hills of Edinburgh, covering 14.2 miles, and climbing 2,200 feet.

And four-year-old from Glasgow, Alfie (pictured below with his Auntie Emma) ran 5k last July, with his dad, Scott Hadden. Alfie's 5k Mini Marathon raised a whopping £4,570 for MDUK, a cause close to the family's heart because Alfie's Auntie Emma has limb girdle muscular dystrophy. Well-known across social media platforms, "Simply Emma" shares accessible travel guides, tips and reviews.

Key dates:

- **The Question of Sport:** 22 October 2021, subject to government guidelines
- **Skydive for MDUK:** 11 and 12 September
- **Northern Ireland virtual Spirit of Christmas event:** 2021
- **Belfast marathon:** May 2022
- **Edinburgh Marathon festival:** 28/29 May 2022

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Charles Horton

Wales, West Midlands and South West England

Charles, who's worked at the charity for over 22 years, has seen enormous changes in the regional team and the way they support people and families in our community.

"Progress in research has played a huge part in the charity's history. In recent years, following MDUK's extensive lobbying, specific drugs have become available after passing clinical trials, bringing positive outcomes and hope to our supporters. It's a very healthy picture with great hope for future breakthroughs. There have been wonderful developments, right across the charity."

Charles, who is based in Wales, looks after the region covering Wales, West Midlands and South West of England plus Jersey and Guernsey. Previously his work centred on the North West, and he's also covered the North East and the East Midlands.

The new region has strong corporate support from the Soho Coffee Company, Great Western Railway and Qualcomm Limited. Family Funds are important to every region and the Walk with Carmela campaign is a fantastic example of supporter-led fundraising.

Last year, Bob Moulden (pictured right) looked for a challenge to take him out of his comfort zone, so he started daily swims. He hasn't missed a day since October 2020 in his 365 sea-swim challenge. After meeting Jamie and Samantha McNamee (pictured), who lost their son Alfie to muscular dystrophy at the age of four, Bob had found a fundraising cause he wanted to commit to.

The many branches in the region, most of which have existed for a number of years, have existed for many years, are a huge support for the work of the charity, with their huge reach into their local communitiess and great local knowledge. Charles looks forward to visiting these branches once all restrictions are lifted.

Key dates:

- **Skydive for MDUK:** September 2021
- **The Bournemouth running festival:** 9 and 10 October
- **The Celestial Ball:** Family Fund Hugo's Research Fund is organising this on 9 October

Get in touch with Charles on

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@VfmHorton

Louise Moffat

London, South East and East of England

Louise has worked for MDUK for three years. Her community stretches from Peterborough and Northampton across to East Anglia and the whole of the South East of England, including London, and the Isle of Wight.

"This region is incredibly good at producing runners," says Louise, who supports people to register and set up fundraising pages for events.

Louise also works with many of our supporter-led fundraising events. The fundraisers come up with outstanding, unique events, which they achieve with the support of the charity, friends and family.

Jamie Hockin, whose brother Will has Becker muscular dystrophy, and four friends banded together to take on a tough `everesting' cycling challenge. They cycled up and down Leith Hill 74 times in a 24-hour non-stop challenge, and raised £21,000.

Renowned cinematographer Chris Howard took 40 beautiful pictures and, with his good friend Andrew Robertson, produced a unique online exhibition, Reflections in Colour.

Andrew, who has limb girdle muscular dystrophy, invited people with muscle-wasting conditions each to reflect on a picture and describe the impact on them.

Visit Reflections in Colour on Chris' website, where you can also buy prints and copies of a coffee table book. A percentage of the profit from sales is going to MDUK. www. crispandsharp.co.uk/photos

Another supporter, Anne Peterson (pictured below) has raised almost £140,000, in memory of her son, Paul, who had muscular dystrophy and sadly passed away in 2014. She's taken on skydives and runs, an annual quiz night and disco. With her running club friend, she's taking on the London marathon this year and plans to do a wing-walk next year.

Key dates:

- **Royal Parks Half Marathon:** 10 October
- **Cambridge Half marathon:** 17 October
- **The Great South Run:** 17 October
- **The Hackney Half:** 26 September
- **The Brighton Marathon:** 12 September

Get in touch with Louise on
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@LouiseMDUK

Susanne Driffield

North England and East Midlands

Susanne has worked for MDUK for two years. She supports the community, including Family Funds and branches, in a region which stretches from the Scottish borders to Leicester.

"My passion is to make a difference to the hundreds of people in my region who live with muscle-wasting conditions. I'm determined to find cures and treatments for people like my 11-year-old son Joe, who has Duchenne muscular dystrophy."

Susanne first met many of the families in her region, pre-pandemic, during a weekend at The Calvert Trust, Keswick in the Lake District.

"I met George's Journey, I'm in For Will, The Jetpack, Love for Louis and Walk with Carmela. Alexandra Gardyne and Muscle in For Somhairle travelled from Scotland to attend the event too. It was a brilliant two days, and I was truly blown away with their positivity, inspiring fundraising stories and sense of fun!

Amazing fundraisers in her region include Ben Ridsdale, whose sight is impaired and who used his free bus pass to travel from Crewe to London. He raised £500 for MDUK, in memory of his two best friends, who both had muscular dystrophy. Kerry Bentley, a childminder whose son has Becker muscular dystrophy, signed up to do a virtual climb up the Shard and has since decided to set up an MDUK Family Fund.

Sam Taylor (pictured below with Sue and their son, Will) fundraises for MDUK Family Fund, Where There's a Will There's a Way, because his 11-year-old son was diagnosed with Duchenne muscular dystrophy when he was four. So far, they have donated over £100,000 to MDUK, and in August, they're taking on their amazing Duchenne Research Relay.

Susanne, who features on our cover, joined #TeamOrange, along with friends and family, to take on a Total Warrior Challenge in July. Together, they raised just under £12,000 for MDUK.

Key dates:

- **Grab the Baton, and cycle for Duchenne research:** 4 July to 7 September 2021 www.musculardystrophyuk.org/events/duchenne-research-relay-380-grab-the-baton

Get in touch with Susanne on
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Martin Hywood

Regional Corporate New Business Officer

We're pleased to announce that Martin has recently joined the regional team at MDUK. We're thrilled to have his enthusiasm and commitment to the work of the charity, as he builds relationships with corporate companies across the UK.

Martin (pictured on one of his fundraising challenges, with family and friends) has been a valued MDUK ambassador for over 20 years. Armed with an infectious positivity, he played a key role in launching the charity's Move a Mile for Muscles fundraising campaign, and he and his family have been outstanding fundraisers with their Family Fund, Hywood's Heroes.

Martin's new status is a popular move with colleagues, as well as external contacts.

Since joining MDUK, he's been going through a 'networking mapping exercise' to work out where and how his contacts can help him to connect with corporate organisations.

With thousands of friends and contacts, his reach is already extensive. With considerable corporate knowledge of the national car, energy, pharmaceutical and IT sectors, he's started his search for corporate partners in these areas.

"I've found that the corporate companies I've visited since joining the charity have been more compassionate and more giving. I expected them to be spending-averse, but some top national companies have welcomed my contact. It's been a surprising, positive post-pandemic response," said Martin.

"I feel this process will be evolutionary. I believe it will only get better for both MDUK and for all those potential corporate partners out there."

Get in touch with Martin on

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@HywoodMartin

Join our community
Get involved

Cambridge Festival of Running
Saturday 16 and Sunday 17 October 2021

In celebration of both events' 10th anniversaries, our Cambridge Town and Gown 10k and the TTP Cambridge Half Marathon are joining forces to create the first Cambridge Festival of Running. We're also thrilled to be a national charity partner with the TTP Cambridge Half Marathon for the first time, and we have places available to join #TeamOrange.

The Cambridge Festival of Running weekend kicks off with the MDUK Town and Gown 10k, which is wheelchair accessible, and our Junior 3k (for those aged 9-15) on the Saturday. The TTP Cambridge Half Marathon takes place on the Sunday.

Both the 10k and Half Marathon routes take runners through the beautiful city of Cambridge and countless historic landmarks, with TTP Cambridge Half Marathon's route passing through two iconic colleges of The University of Cambridge.

Join #TeamOrange for the 10k, Junior 3k, or TTP Cambridge Half Marathon and run the race to beat muscle-wasting conditions. Visit
www.townandgown10k.com/cambridge

Celebrity Sports Quiz – our 10th anniversary
Thursday 4 November 2021, The Nursery Pavilion, Lord's Cricket Ground, London

Do come and join us at one of the world's most prestigious sporting venues to celebrate the 10th anniversary of our Celebrity Sports Quiz. Our President, Gabby Logan, will host the event and comedian and test match statistician, Andy Zaltzman, will be our quizmaster.

You and your team will have the opportunity to pit your skills against other teams to win the coveted Celebrity Sports Quiz title. We're delighted that some of Britain's most famous sports stars will be there too, so the competition will be fierce! You'll enjoy a great night out in the much-loved home of international cricket, and help beat muscle-wasting conditions at the same time.

To book a table, get in touch with us at
events@musculardystrophyuk.org

A virtual marathon for their dad

Last October, siblings Scott and Beth Calver (pictured) took on the Virtual London Marathon in honour of their dad, Martin, who died last year after getting COVID-19.

Having trained and fundraised through lockdown, the two planned their 26.2-mile route to cover significant landmarks to honour their dad. They ran from Epping, where Scott lives, past the Peckham house where their dad grew up, through Dulwich where their parents met. They raised an extraordinary £17,800 for MDUK.

"My dad was diagnosed with myotonic dystrophy when he retired at 60. It's a debilitating disease and we saw over time how it affected him physically, losing the ability to walk long distances or take part in the sports he loved. He never let it change his quality of life and continued to do everything he wanted to do with a smile on his face, even if it was painful for him. He also began to raise money for MDUK and, as a family, we were all involved in helping raise awareness and funds for research," said Scott.

"I wanted to do something positive during this terrible year for me personally and also for people all over the world.

"I know my dad would have been proud."

Super support from our President

We're extremely grateful to our President, Gabby Logan, who has again offered outstanding support by going many extra miles for MDUK during the past year. In her already busy life, she supported us by:

- hosting both of our Celebrity Sports Quizzes online
- taking on an online Cookalong for MDUK
- doing a Supermarket Sweep for MDUK
- supporting our Walk with Carmela campaign
- joining in our virtual BGC Charity Day in 2020, and confirming her involvement in the 2021 event too
- launching our Euro2020 #MusclesMatchdaySelfie.

Thank you, Gabby, for all you do for everyone in the UK who's living with a muscle-wasting condition.

A story of Jon, #MyMateMartin and BBC Radio 4

Thank you to everyone who listened in and donated to our BBC Radio 4 Appeal, which aired on Sunday 25 April 2021. The Appeal has brought in £22,000 to date.

We were privileged to have been awarded the Appeal, and were over the moon when comedian Jon Richardson agreed to present it on our behalf.

The Appeal focused on the extraordinary friendship between Jon, stand-up comic and star of *8 out of 10 Cats*, and Martin Hywood, a fellow Leeds United fan.

Theirs is a friendship of lively banter, a love of football, and helping each other through the tough times

"Martin and I first met at the football, like proper lads. I remember the game specifically; we lost 1-0 to a team that went on to be relegated. But things are better now and we can appreciate the good times for having been through the bad. That's a good metaphor for Martin's approach to life," said Jon.

"It's great to have a mate like Jon… he's a fantastic friend who endorses all the good things I'm trying to achieve, especially when I'm trying to raise awareness and funds for MDUK on social media," said Martin.

After the Appeal aired, a corporate donor generously offered us some valuable advertising space at various sites across the UK. Between May and August, you will have seen Jon and #MyMateMartin on digital billboards on the side of the road, in shopping malls and on bus stops. We are hugely grateful for this generous boost to our awareness-raising.

If you haven't heard Jon and Martin's amusing and heartfelt appeal, you can still listen at:
www.musculardystrophyuk.org/bbc-radio-4-appeal

BILLBOARD STARS

Last year, we were able to use Europe's largest digital billboard, the Piccadilly Lights, to invite people to Walk with Carmela. This was thanks to the hugely generous pro bono support of companies such as Landsec (one of our corporate sponsors), who donated the space, creative agency Atomic London, who transformed Carmela into an 8-bit digital character, and 8-bit artists Eboy, who created the film.

Seven-year-old Carmela Chillery-Watson, who has LMNA-CMD, walked a distance of 300km on specially-designed crutches, with mum, Lucy, by her side. This amazing Wiltshire family has raised more than £50,000 for MDUK, and in the past year have been on *BBC Breakfast*, *ITV News*, *Good Morning Britain*, and *The One Show*. Carmela also won a Points of Lights award from Downing Street and, at the end of June, she got an extra special surprise. Prince Harry presented her with an Inspirational Child Award for her age category at the WellChild Awards, which celebrate the inspirational qualities of the UK's seriously ill children and young people. No wonder Gal Gadot, star of *Wonder Woman 1984*, called her "my real Wonder Girl".

Puzzles page

Joshua Azizollah, our puzzlemaster

WORDSEARCH

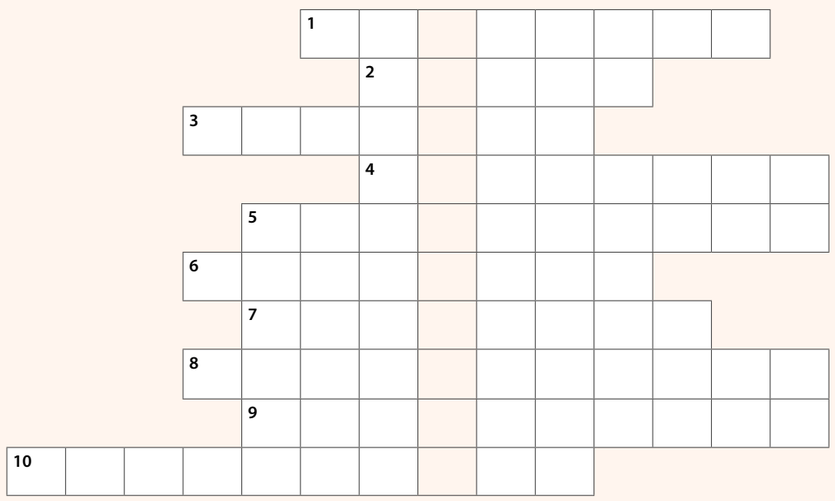
Find and circle the words that are hidden in the grid.

CAMBRIDGE
CHARITY
COMMUNITY
DOCTOR
FRIENDS
FUNDRAISE
HELPLINE
LONDON
NURSE
OXFORD
RESEARCH
THERAPY
TRIALS
VIAL

H	C	R	A	E	S	E	R	D	T
M	E	F	C	R	B	S	V	R	H
N	A	L	T	H	O	I	I	O	E
U	R	O	P	C	A	A	O	F	R
R	O	N	N	L	L	R	L	X	A
S	T	D	A	S	I	D	I	O	P
E	C	O	M	M	U	N	I	T	Y
E	O	N	C	A	Q	U	E	A	Y
S	D	N	E	I	R	F	C	I	R
M	C	A	M	B	R	I	D	G	E

WORD PUZZLE

You'll find some answers in this edition of TMD. Fill in all the words across to find the mystery word in the shaded column!



Clues

1. Muscular Dystrophy UK's employment skills project (6,2)
2. Gabby _____, Muscular Dystrophy UK's President since 2018
3. _____ Matter, our popular series of online seminars
4. _____ muscular dystrophy; most common condition, named after a French neurologist
5. Treatment for 4 in certain young patients
6. 26.2-mile run, a popular way to fundraise
7. Scientific study, to find new information or greater understanding
8. _____ in Colour, virtual photography exhibition, raising money for Muscular Dystrophy UK
9. _____ Ball, property sector's annual fundraising event for Muscular Dystrophy UK
10. Jon _____ , comedian who featured in our BBC Radio 4 appeal

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