TMD

Target MD January 2022

Muscular Dystrophy UK
Fighting muscle-wasting conditions

"I'm doing this for Roman."

TIFFANY HESSON, EDI AMBASSADOR FOR MDUK

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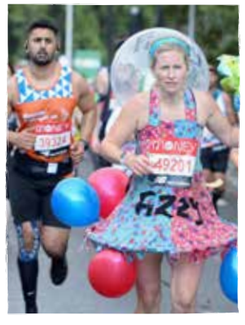

Hello and welcome to Target MD

I'm thrilled to bring you another edition of TMD, and to wish you a happy, fulfilling, and bright 2022.

This edition is again bursting with stories from our amazing community. You'll read about the different ways people express their creativity and, in so doing, nurture their wellbeing. Whether it's music, exercise, volunteering, writing, connecting with others - there are so many ways to take care of our mental and physical wellbeing.

You'll read about the amazing challenge that Catherine, our CEO, and our senior leadership team completed at the end of 2021. And you'll meet some lovely supporters across the UK who jumped out of planes to support our work, including the new research grant round for 2022.

We also bring you a photospread from a very full summer and autumn season of brilliant events. Thank you to everyone who took part and made a huge difference in helping to beat muscle-wasting conditions.

Again, you'll read some exciting research updates, as well as news of our new research grant round for 2022, and the chance to enjoy Josh's fun puzzles again.

So, grab a cup of coffee, and I hope you enjoy reading about more of our outstanding supporters in the MDUK community. If you have a story you'd like to share, or any thoughts or ideas you have about the magazine, please do get in touch with me at targetmd@musculardystrophyuk.org. 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.

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

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On the cover:
Tiffany Hesson with her son, Roman (read more on p10).
Photo credit: Chris O'Donovan

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News from MDUK

Hello everyone.

On behalf of all at MDUK, I'd like to wish you a happy, and fulfilling 2022. Thank you, sincerely, for your continued and ongoing support. We really do appreciate our wonderful community. And when you read the magazine, you'll see why!

I hope you'll feel encouraged by the stories you'll read, especially when considering our physical and mental wellbeing. In these strange and uncertain times, we know how important it is to look after our wellbeing, whether that's through talking, writing, music, exercise or connecting with others. Our helpline is always here for you, should you need to talk to someone or find out where to go for more specialised support. And you can always email the helpline if that's easier for you.

I'm pleased to introduce you to our cover stars, Tiffany and Roman Hesson. Tiffany's our new Equality, Diversity, and Inclusion (EDI) ambassador, and she's going to help us in our work to create a better future for Roman's generation and beyond.

We're committed to actively tackling and countering all forms of racism, discrimination, and inequality in our workplace, and in the services we provide. Please let me know if you'd like to join us in this work too.

The poignant stories that motivate people to take on challenges make for rewarding reading – and if you feel motivated to join them, there's always room in #TeamOrange for one more!

Last January, I took on my toughest-ever challenge to fundraise for research and services for our extraordinary community, who'd been there for us through the uncertainty of 2020. A severe injury stopped me, 225 miles into the 874-mile Land's End to John O'Groats (LeJog) challenge. So my brilliant senior leadership team (pictured below) grabbed the baton and completed it for me. We walked the final mile together in November.

Thank you again for all that you do to make every day count for people living with muscle-wasting conditions.

Catherine Woodhead
Chief Executive, MDUK

(l to r) Jacqueline Gaffin, Rob Burley, Wojtek Trzcinski, Catherine Woodhead, Emma Jones-Parry, Kate Adcock

Mother Bee

Thank you for visiting her
You never failed to enthral
She is resting now
She was ninety-five, after all

She made us better than we were
Left memories to treasure
Yet still here, somehow
Her presence the sweetest pleasure

Manifest, pure mother bee
Her warmth and loving smile
Her gentle, healing hands
My yearning, reconcile

Love and joyous repartee
Fills my heart with gratitude
As life's hourglass sands
Mark temporal time, mere interlude

PHILIP ANDERSON

"I thank the bumblebee for reminding me my life is for living."

How a bumblebee helped my wellbeing

Philip Anderson shares ten life-sustaining truths

I am a chronic optimist. I have always looked for a silver lining in every cloud, and looked forward to better times. But my optimism has been severely tested as I become increasingly disabled with a progressively debilitating muscle-wasting condition, with all the restrictions and loss of independence. It became more challenging when COVID-19 lockdown isolated me, like many others.

Pondering how I may come to terms with my new reality, one summer's day a bumblebee came knocking on my window, as if to say, 'Look up, life is for living'. It reminded me of my 10 life-sustaining truths, which my disability, and lockdown isolation, cannot take from me. Perhaps readers will find something in these truths to help nurture their own wellbeing.

1. Be thankful for each day, we do not know whether there will be a tomorrow. Make the most of today. Even when it is difficult, there is always something that can bring joy.
2. We are human beings, not human doings. When you stop rushing around, filling your leisure time with little that matters, you have time for reflection and appreciation of the joys in living.
3. The natural world is an endless resource of fascination and sustenance. Notice changes through the seasons, be thankful for birdsong, look closely at plants, observe insects, smell flowers.
4. The most important therapy is to give and have love in your life. When feeling roughest, empathetic love is the most powerful balm. If you have faith, you know you are loved.
5. Treasure your family and friends. Appreciate those who support us in our moments of need. Reach out to others who will be encouraged by your thoughtfulness. The more supported we feel, the more resilient we feel. The more we give support to others, the more resilient we are.
6. Appreciate what you have. Stop acquiring consumer goods. Don't confuse what you want with what you need. You'll never get what you want until you value what you have.
7. Get to know yourself. Look after your health and fitness as best you can. Look after and feed your mind. Be curious and keep learning.
8. Writing, reading, audiobooks, radio plays, art, music can calm you and lift your spirits.
9. Release your feel-good endorphins, learn to laugh at yourself. You will feel happier, more positive, and calm when you laugh with others.
10. It is normal to feel sad, to grieve for who and what is lost, and cry when you feel overwhelmed. Hang on in there. Never give up. There are better days to come.

story continues on p28

You don't just listen to music, you experience it

People who produce and play music often derive huge benefits from it. Here, three people describe how tune-induced wellbeing runs through their lives.

Journalist **Sanjeev Mann** (pictured below), who has Duchenne muscular dystrophy, is a music producer who launched his second EP in November 2021. The 24-year-old has always loved music and he finally started creating his own during the first lockdown.

What started as a determined effort to 'stay sane' through five months of shielding and isolation resulted in the freelance journalist creating a new music career.

He released his second EP under the stage name 'Superman on da Beat', with Finnish rapper F.I.N., and played live for the first time last October. He describes the music as a mix of hip-hop and pop, with a rock twist.

"I'm really delighted with the success my sounds are having. I'm going to keep on and see where it takes me. Music is my form of expression. My firm belief is that good health and happiness come through keeping the mind busy. Music is my way of keeping my mind busy and creative. If I'm having a bad day, I'll put on some heavy metal or rap, and it completely lifts my mood."

Sanjeev, who has a master's degree in media comms and freelances as a journalist, also writes, and makes video content or podcasts about disability awareness and hip-hop. He also works as a development worker for Pathfinders Neuromuscular Alliance and is involved with Drake Music Scotland as a consultant.

"My firm belief is that good health and happiness come through keeping the mind busy."

Bex Eden created Decibels for Dystrophy in 2018, with some guidance from a friend who had previously hosted his own events.

"I started the event after losing my boyfriend, Christian Deehan, who had Duchenne muscular dystrophy. I didn't want to sit around and be negative, I wanted to do something to help others living with muscle-wasting conditions, or at least aid them in their daily life. I believe MDUK greatly helps many people, so I wanted to add to its funding by raising as much money as I could via music."

After the first Decibels for Dystrophy gig in 2018, it's taken place every year since (except 2020, because of the pandemic). Their next two gigs take place on 10 September 2022 and 9 September 2023, at O'Rileys in Beverly Road in Hull.

"It means a lot to me, as it's something personal. A lot of close friends and family have helped me to make this event a reality. The rock music theme is also personal, as it's an interest Christian and I shared. I really hope my efforts help a lot of people."

You can hear Sanjeev's music on all platforms and here: https://linktr.ee/supermannon_dabeat

"I can assist people to put their thoughts and emotions into a song – it can be hugely beneficial to mental health and wellbeing."

Other bands to have played at Decibels for Dystrophy are Wildthorn, Damaged Inc, Irontooth, LuKu, Megadeth UK, Maiden UK, and Natalia.

Simon Wright (pictured above, second from right) who has facioscapulohumeral muscular dystrophy (FSHD), describes himself as a natural drummer for whom music has literally been his 'life'.

"When certain music comes on, you can just stop and listen, not just to the words but to the music or the sound of the voice. With music, you don't just listen, you experience it."

When he was growing up, there was always music in the house and Simon started drumming with his mum's knitting needles! As a rock drummer, he was finding it extremely strenuous and increasingly difficult with his condition, so he stopped. But at the age of 20, he began to teach himself to play the guitar and other instruments.

Around 10 years ago, having not played in a band for more than 25 years, he started jamming with a band called Pound Cake. A change in line-up six years ago led to the forming of his current band, Broken Scarecrow. They have recently played at the Decibels for Dystrophy gig in Hull.

Simon is the group's songwriter, and the group name came from a line in his song, *Tears*. (You can find it on Soundcloud.)

"I feel I'm chasing rainbows,
halfway across the sky
Passing broken scarecrows,
everlasting hope never dies."

Not content with being one of the very few guitarists on stage to play from a wheelchair, Simon has also used his passion and belief in the incredible benefits of music for his work as a therapeutic counsellor.

"I can assist people to put their thoughts and emotions into a song and have found it can be hugely beneficial to their mental health and wellbeing."

ROMAN HESSON-ANIM

"Roman is such a funny, bubbly little boy. His cousins all love spending time with him."

I want to make change so that Roman doesn't have to

Tiffany Hesson has given up her job in banking to devote more time to her three-year-old son, Roman, who was diagnosed with a rare muscle-wasting condition at the age of just a year. And she wants to focus on her new role as MDUK's first Equality, Diversity, and Inclusion (EDI) ambassador too. She feels passionately about making sure Roman feels part of a wider community of black people, who live with a rare condition.

"I'm thrilled to have this opportunity to help MDUK reach a more diverse community and get the message across that they're here for everyone living with a muscle-wasting condition; no-one is excluded. I want Roman to see that he's not the only black child with a rare muscle-wasting condition, and to be able to identify with the charity and other little children with conditions like his.

"He's such a funny, bubbly little boy. His cousins all love spending time with him, and understand what he needs, without anyone having to tell them."

After Tiffany first noticed Roman wasn't hitting certain milestones, it took about six months until he was diagnosed with a rare form of congenital muscular dystrophy (CMD), called LMNA-CMD.

"At first, I was devastated for him. Of course, we all want our children to lead a full life, and I didn't want the condition to stop him from doing the things he wanted to do. It was tough having to face his diagnosis in the early days of the pandemic. It helped me to get my head around it for myself, but I did feel lonely. It took a while for me to tell people – I felt that telling other people would make it real."

Tiffany had never heard of the condition, so searched on the internet for information.

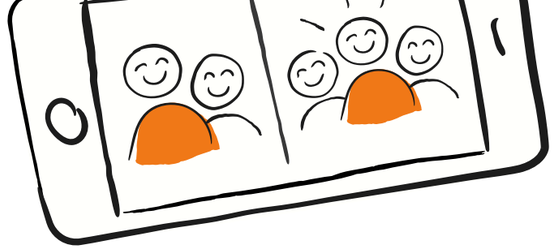
"I found MDUK, which came up as the number one charity for people with muscle-wasting conditions. The more I learnt and understood about Roman's condition, the more I realised he would still be able to do things. Just differently. And after he missed a year of development and specialists' attention, I've now been able to advocate for him and make sure he's getting the occupational therapy (OT) and physio he needs.

"Roman is very accepting and adaptable and adjusts so well, like he has a real understanding of what's going on. But he's also really determined – managing to do things doctors told us he wouldn't be able to do. He breaks through every barrier.

"That's why I also want to help other mums and dads going through what I've been going through. I can identify with what they might be feeling, and I want to be here to support them."

To find out more about MDUK's active approach to EDI, please visit www.musculardystrophyuk.org/EDI and email us at EDI@musculardystrophyuk.org if you'd like to get involved.

Muscles Matter seminars



One of the most important things we do at MDUK is share expertise and resources with our community, in an accessible way.

That's why we relaunched our Muscles Matter online seminars in 2021, following positive feedback from our 2020 series.

People told us they found the webinars, which had been moved online amid the pandemic, accessible, helpful and informative.

In future, we'll run Muscles Matter seminars alongside live events when we can host them in person again, to make sure we are reaching as many people with muscle-wasting conditions as possible.

The sessions are always free, and cover a range of topics including specific conditions and condition management, awareness days, and practical support, such as psychological and financial help.

Panellists for the sessions include clinicians and those living with a condition, and after the events, we upload videos of the sessions on our website and YouTube channel.

Last summer, we hosted a seminar on myasthenia gravis, a condition that causes muscle weakness and excessive muscle fatigue.

Consultant Neurologist Dr Fiona Norwood joined us to discuss how researchers have worked to identify biomarkers for the condition, and the importance of creating tailored treatments.

After that, Clinical Research Fellow Jennifer Spillane's video presentation expanded on the latest research into treatments for the condition.

Specialist nurse Séana Hughes, speech and language therapist Jodi Allen, and Amanda Hayes, also joined the session.

Amanda (pictured below right) was diagnosed with myasthenia gravis in 1992, at the age of 26, and over the years her condition has brought her highs and lows.

"I wanted to help show that a person can live well with myasthenia gravis and that the condition does not define me. I hope that others saw me as a positive person leading a productive life. It was great to get involved, and I felt that I was able to show everyone that there are many different people available to help. As the clinicians said on the day, there are always new medications, procedures, and ideas around how to best treat myasthenia gravis. It gave me such satisfaction to have spoken alongside them by sharing my own personal experiences, too."

Séana (pictured below left) felt it was a great opportunity to speak with other healthcare professionals about myasthenia gravis and to hear from patients outside of those she looks after at King's College Hospital.

"The most beneficial thing for me was hearing the advice Amanda was able to offer, as we often forget the value of information those living with the condition can pass on. I learn new things about myasthenia gravis from my patients every day! It was important that I took part, as it gave those without the support of a specialist nurse a chance to ask me any questions. I'm really grateful for being asked to join in – thank you!"

Visit our website to learn more about upcoming seminars and to catch up on previous sessions: www.musculardystrophyuk.org/get-support/mduk-muscles-matter

The power of Powerchair football

Like most boys his own age, Jack Gauder (pictured) loves socialising with his friends, playing with his brother, and taking part in sports.

But until recently, Jack had been growing increasingly frustrated that he couldn't play sports with his friends and family.

That's because Jack, who's 11, has Duchenne muscular dystrophy and uses a wheelchair.

In April 2021, though, Jack started playing Powerchair football for the West Bromwich Albion Baggies – and he's not looked back since.

Powerchair football is unique in that it allows people of all ages, disabilities, and genders to play together. It's the only active team participation sport for people who use electric wheelchairs and is a four-a-side version of football, played indoors on a basketball court. MDUK is a big supporter of the sport, and this season is sponsoring the National League Premiership and Championship in England, and the National Premiership and Championship competitions in Scotland.

Jack's parents, Emma and Matt, said the change in their son's mood since he started playing the game has been remarkable.

"We couldn't believe how happy Jack was after he played his first game of Powerchair football. He realised that he could play football just like other boys his own age by being part of a team and having fun."

There are about 100 affiliated Powerchair football teams within 40 clubs across England, and around 400 players train regularly.

Jack said: "All you ever really see is normal football, so once I started using an electric wheelchair, I thought I'd give Powerchair football a go because I wanted to do things that everyone else my age was doing. I've only been playing for a little while and still have lots to learn, but the main thing is that I'm having so much fun. You never really see Powerchair football showcased anywhere, and I think it should be promoted more to allow people to see what an amazing sport it is. Just because a person has a disability doesn't mean they shouldn't be able to play sports, too."

"Just because a person has a disability doesn't mean they shouldn't be able to play sports, too."

Emma said that the family's proudest moment came when Jack scored in his debut Powerchair football match on Father's Day weekend. His dad, Matt, was able to watch in person, which made it even more special.

Rob Burley, MDUK Director of Care, Communications and Support, said: "We're really proud to sponsor Powerchair football competitions in England and Scotland. It's a brilliant sport and makes such a difference to people's lives. We feel passionately that all disabled people should be able to play and enjoy sport in an accessible way. We know that inclusivity goes a long way, and stories like Jack's show just how beneficial Powerchair football can be."

If you'd like to find out more about Powerchair football or find out where your nearest club is in England, you can visit www.thewfa.org and in Scotland www.thespfa.org

Encouraging each other and making connections

When Kerry Spink's twin sons, Oscar and Seb, were first diagnosed with facioscapulohumeral muscular dystrophy (FSHD), she was desperate to talk to other parents about their experiences. She wanted to learn from other families what to expect as the condition progressed, and to get ideas of what had worked for other families that might help her sons.

"Getting peer support from other parents has been invaluable and helps us feel we're not alone in facing this diagnosis. It's hard to explain just how reassuring it is to chat to other parents who have an understanding of what your family is going through, because they're facing the same thing.

"We've found real strength, support, and made some life-long friends through the connections we've made and I'm excited to know that MDUK is encouraging other parents to come together to establish some formal parent support networks," said Kerry.

Along with other parents who've been to our virtual Muscle Group meetings, Kerry has told us how challenging it can be to meet other parents locally.

So, towards the end of last year, we brought together a group of parents of children of different ages and with a variety of conditions, to talk about how best to bring parents together. One of the ideas that came out of that was to have a Facebook group just for parents of children living with muscle-wasting conditions. A supportive space where they could ask questions at any time and receive advice and guidance from others who have had similar experiences, and instantly connect with other parents from across the UK.

This group is now live and ready for parents to join. It's open to anyone with a child living with a muscle-wasting condition, no matter the age of your child or how recent the diagnosis. While personal circumstances and experiences may vary, the challenges are often similar.

We have four fantastic volunteer moderators, without whose support we wouldn't be able to create this community. The moderators all have children living with muscle-wasting conditions, and are there to make sure our group is a supportive, friendly and safe space for all parents. You can follow this link to join the group. www.facebook.com/groups/mdukparentsupportgroup

Along with the Facebook group, we also hope to host Zoom meetings for parents, which will be an opportunity both to chat informally with other parents and to hear from speakers on key topics of interest. Again, it's our group of fantastic parent volunteers working closely with us who are making this happen.

Someone who totally gets it

Charlotte Chubb connected with Justine McAlister at a Collagen VI support group. They've met once in person and spoken on the phone.

"I've also spoken with a few other mums of children with the same condition as as my daughter, Josie's. It helps to connect with people going through the same thing, as they totally understand what you are going through. Whether this is asking practical questions and sharing knowledge, or just simply sharing experiences and talking to someone that just totally gets it."

The power of friendship

Hannah Wilson, from Ormskirk, is mum to Charlie, who is 14 and has Duchenne muscular dystrophy.

She met Dawn Pammenter in March 2020, just before the first COVID lockdown, when she spent a long weekend in Wales with other Duchenne mums (pictured opp). It followed a trip to Amsterdam with the same group.

"There were about 12 of us in Amsterdam, and it was so successful that I agreed to go to Wales. When I got there, I met about 20 mums from all over the UK, all of whom have children with Duchenne

"We've found real strength, support, and made some life-long friends through the connections we've made and I'm excited to know that MDUK is encouraging other parents to come together to establish some formal parent support networks."

but Dawn persuaded me to register for my first-ever road run with her at the MDUK Cambridge Town and Gown 10k in October. It was a pleasure to run with Dawn's group in memory of her son Jamie, who died in 2018. I am glad I did the run because it was another great weekend."

muscular dystrophy. It was very supportive to be able to exchange all our experiences and just chat to families in the same situation.

"That was when I met Dawn. I am a trail runner,

If you have any questions about our new parent support group, please get in touch with our Volunteer Engagement Manager, Calley Clay on c.clay@musculardystrophyuk.org.

Shining a light on the impact of COVID-19 – an update

In July 2021, we presented findings from our *Shining a Light on the Impact of COVID-19* report to an All Party Parliamentary Group.

During the meeting, we discussed the impact COVID-19 and lockdown had had on people living with muscle-wasting conditions, and on specialist neuromuscular care.

We presented a list of short- and long-term recommendations that we'd like to see implemented in the future.

Since the meeting, we've been engaging with NHS England and the Department of Health and Social Care to influence the ways they provide and fund neuromuscular services.

We've also met with Integrated Care Systems leads to discuss the upcoming NHS reform and future changes to commissioning of neuromuscular services.

And we've helped with the development of the Rare Disease Framework action plan, which aims to help improve the lives of people living with rare conditions.

Because healthcare delivery differs across the UK, we've created three micro-reports that reflect the situation in Wales, Scotland, and Northern Ireland.

We presented the Wales report before a Cross-Party Group in November last year and will do the same for Scotland and Northern Ireland in early 2022.

We tailored our recommendations in each report to reflect what we heard from people in each nation.

Thank you to everyone who's contributed to this report. Please keep an eye on our website and social media channels for updates.

Wellbeing and the benefits of exercise

Earlier this year, we updated our *Exercise advice for adults with muscle-wasting conditions* factsheet. We worked with some of the UK's expert neuromuscular physiotherapists to update the advice, originally produced in 2014, on the importance of exercise and how to do it safely.

The guidance, which we launched in the middle of a COVID-19 lockdown, is designed to help those who aren't able to see their specialist neuromuscular clinicians or get to sports and exercise facilities, such as hydrotherapy pools, swimming pools and gyms.

The new advice highlights the benefits to people with muscle-wasting conditions of the correct type and level of physical activity, and includes:

- examples of the benefits of exercise and activity
- tips on how to get and stay active
- how to exercise safely and correctly
- top tips
- links to other resources and FAQs about exercise and living well with a muscle-wasting condition.

Exercising doesn't mean you have to join a gym or go to a formal exercise class; it's just as important to move around more or be more physically active during the day. You can focus your exercise on a specific problem, or on keeping fit and healthy.

For Louise Halling (pictured), who lives in Poole and has limb girdle muscular dystrophy, regular exercise makes all the difference.

"I swim three times a week and, while I'm in the water, I stretch and do some of the physio exercises too. Exercise helps my pain, my energy, my mental health. It's amazing to feel the freedom of being able to do things in the water I can't do on land. When I go without exercise, I really feel so much worse. And I'm pretty sure I would crash and burn without it."

As a busy, self-employed counsellor, Louise makes regular exercise a priority.

"Exercise helps my pain, my energy, my mental health. When I go without exercise, I really feel so much worse."

"I find it easier to go out to exercise, but some people might find it easier to exercise at home. But you have to find what works for you and try to make it the priority in your weekly programme if you can."

Find out more about MDUK's exercise guidance for adults with muscle-wasting conditions
www.musculardystrophyuk.org/exercise-advice

MDUK runners and what inspires them

Many of our supporters run to raise money because they live with a muscle-wasting condition and many more run for a family member, friend, or colleague. A huge number run because they love the way we encourage and support their training and fundraising and, for a large chunk of runners, MDUK is just a great cause.

Kiera Santry, MDUK Senior Challenge Events Officer, says supporters running for MDUK are at the heart of our fundraising.

"Each year about 8,400 people take on a range of brilliant running events from our own Town and Gown 10k series to the Great North Run or the London Marathon, and many other runs elsewhere.

"The pandemic made virtual events far more popular than ever before, and many of our supporters have taken on virtual runs locally to continue supporting the charity."

Our popular Town and Gown 10k series, with runs in Oxford and Cambridge, attracts a lot of runners. Last year, Dawn Pammenter took on the Cambridge event for the eighth year running, with a team of 17. They run in memory of her son, Jamie, who had Duchenne muscular dystrophy and died in 2018.

"A fantastic event from start to finish, the route is great and very scenic. Team Jamie will be back next year!"

In the same race, Julie Norris ran with her daughter, Joely, for two-year-old Charlie (her grandson and Joely's nephew), who was diagnosed at eight months with Becker muscular dystrophy.

"Running the London Marathon is a monumental life achievement and a truly courageous thing to do. Before even reaching the start-line, runners must find the determination to dedicate months to demanding training plans and to work hard to reach and exceed their fundraising target," said Kiera.

> "Running the London Marathon is a monumental life achievement and a truly courageous thing to do."

Usman Hussain, 27, ran his first London Marathon last year in memory of his grandmother, Kaneez Begum, who had limb girdle muscular dystrophy and died in 2020 at the age of 71.

"My grandma was an inspiration to my family and community, and she absolutely refused to let the limitations caused by her debilitating condition affect her."

Judith Montgomery ran to support Elliot, who lives with a muscle-wasting condition, because she and his parents were teenage friends. Judith, a senior NHS paediatric physiotherapist at Edinburgh's General Hospital, said she was nervous to start with.

"Getting to the start-line and following all the plans for how and when to get there, having COVID tests,

> "I'd watched the London Marathon on the television for years, and always thought how amazing it would be to achieve something as big and iconic as this.

not being able to drop a bag on the day and so on, took a bit of planning. But it all seemed to go smoothly."

Karen Barlow marked the 10th year anniversary of her diagnosis with facioscapulohumeral muscular dystrophy (FSHD) by running a virtual London Marathon.

"I'd watched the London Marathon on the television for years, and always thought how amazing it would be to achieve something as big and iconic as this.

"I always knew how tough it was to enter the actual run, so when I read about the virtual event, it was a no-brainer. I don't think I'd finished reading the article before I'd entered!

"The virtual London Marathon is more accessible for people like me who will take that bit longer to cover the distance. This was my way of giving something back to those that live with this debilitating and life-changing condition, while I still have my mobility.

"My goal is to contribute as much as I can to help the organisation search for a cure. I would thoroughly recommend this kind of challenge to anyone; if I can do it then anyone can. If the prestige of owning that medal isn't enough, then raising money for this amazing charity will be."

A senior care worker from Cardiff lost nearly six stone in weight to get fit enough to take on a half-marathon to support MDUK.

Kieron Broad is training to run the Cardiff Half Marathon this March in memory of his friend's brother who had Duchenne muscular dystrophy and died in 2008.

"The run will be an incredible challenge to me, but I'm determined to raise awareness about the condition."

Every year, huge numbers of people take on runs to fundraise for MDUK:

- 5,000 – MDUK Oxford Town and Gown 10k
- 3,000 – MDUK Cambridge Town and Gown 10k
- 140 – Great North Run
- 110 – London Marathon
- 20 – Cambridge Half
- 10 – Royal Parks Half
- 10 – Big Half
- 5 – Hackney Half
- 3 – Brighton Marathon

If you'd like to join #TeamOrange and take on any of these or other runs for MDUK, you can find out more at www.musculardystrophyuk.org/get-involved/events/runs

MDUK's 2022 research grants round is open

Dr Kate Adcock, MDUK Director of Research and Innovation

We're thrilled to announce that we were able to open our grants round for research applications. Because of the impact of the COVID-19 pandemic, we had fewer funds available to disperse so we had to restrict the 2021 grant round in both number and range of neuromuscular conditions.

So we're pleased to say that our 2022 grants round sees a return of funding for project grants of up to three years' duration, in addition to four-year PhD studentships, and shorter, proof-of-principle projects. The new grant round will also accept applications to investigate a broader range of muscle-wasting conditions. Applications closed on 25 January 2022 and, as this is a return to our usual pattern, we'll announce the decisions on funding in late summer 2022.

Alongside this new grant round, our Lay Research Panel and Medical Research Committee met in November last year to assess the 2021 grant round applications. We look forward to sharing the outcome of these applications in early 2022.

Adult Duchenne Standards of Care

Robert Burley, MDUK Director of Care, Communications and Support

We were delighted with the publication of the world's first ever standards of care for adults living with Duchenne muscular dystrophy, in autumn last year.

Why is this so important?

The standards offer guidance to health professionals to make sure adults living with the condition get consistent best-practice care and access to specialist support, while promoting patient safety.

Daniel Baker (pictured below right), who is 47 and lives with Duchenne muscular dystrophy, is hopeful these standards of care will lead to better and more joined-up care.

"Nearly every time I deal with a local medical professional, I feel they don't really understand my condition or know what to do. The care isn't consistent and doesn't feel well planned. If I'm admitted to A&E, I have to tell everyone that oxygen can be dangerous for me. Hopefully, with adult standards of care in place, they will know that already. I hope the standards will create more consistent care across different NHS trusts and that it'll lead to a better quality of life for adults living with Duchenne."

Clinicians from the adult NorthStar network developed these adult standards of care. Since 2016, MDUK has funded and co-ordinated the adult network, which is an extension of the paediatric NorthStar programme that we set up and have funded since 2003. Standards of care for children living with Duchenne were first published in 2010 and revised in 2018.

How does the NorthStar network work?

Clinicians from NorthStar network centres collect data during a patient's medical appointments. They make the data anonymous before uploading it to the NorthStar national database, where it's monitored to track long-term changes.

This helps inform recommendations in both adult and children standards of care.

For example, one of the paediatric NorthStar programme's most significant successes so far is the ambulatory assessment, which is a benchmark tool to monitor condition progression and the effects of treatment in children.

We are hopeful that the adult NorthStar network will, in time, produce equally useful outcome measures.

The NorthStar data is also helpful in clinical trials to monitor whether a treatment is proving effective, and researchers will often share the results in research papers.

What do we think?

Catherine Woodhead, CEO of MDUK, said: "I'm extremely pleased that we've funded and supported the development of the first published best practice standards of care for adults living with Duchenne muscular dystrophy. We hope this will help improve the consistency of high-quality care for adults with Duchenne in the UK, but also across the world as these recommendations are adopted in other countries."

Gene therapy as a treatment for Duchenne and Becker muscular dystrophy

Elena Marrosu (pictured below), a PhD student, has recently finished her MDUK-funded project which may have implications for how to design gene therapy for the treatment of people with Duchenne and Becker muscular dystrophy.

Gene therapy aims to replace the dystrophin protein that people with Duchenne and Becker muscular dystrophy don't produce. The gene therapy treatment uses part of a virus, which is used to carry the dystrophin gene into muscle cells. However, the dystrophin gene is large, and the virus used to deliver the gene into muscles can only accommodate a limited amount of genetic material. For that reason, shorter versions of the dystrophin gene are used that can be effectively packaged into the virus.

Using this shorter version of the dystrophin gene, known as microdystrophin, gene therapy works well in the skeletal muscles (those that connect to your bones and help you move) of people with Duchenne and Becker muscular dystrophy. However, researchers in Dr Montanaro's group had shown that microdystrophin was unable to interact with another protein called cavin-1 in heart muscles, leading to the idea that microdystrophins don't function properly in the heart. This would be of particular concern, as heart failure is a major health issue in people with Duchenne and Becker muscular dystrophies.

Elena has been working with supervisors, Dr Federica Montanaro and Prof Jenny Morgan at the UCL Great Ormond Street Institute of Child Health in London. Her four-year MDUK-funded studentship focused on "Characterisation of a novel interaction of dystrophin with caveolae in the heart."

Elena faced many of the difficulties experienced by other colleagues in research on account of the COVID-19 pandemic and was unable to complete some key work without access to core facilities. But with some changes of focus, her project demonstrated some exciting outcomes.

Elena showed that loss of dystrophin affected how the proteins cavin-1 and cavin-4 were distributed inside the heart muscle cells of mice. The correct distribution of cavins is critical to maintain the function of cells. The incorrect distribution of cavins, that was seen in the absence of dystrophin, was not corrected by microdystrophin. This was also confirmed in a dog model of Duchenne muscular dystrophy where dystrophin was missing, and the distributions of cavins -1 and -4 were disrupted.

Elena's work contributed to a recent paper, *Proteomic analysis identifies key differences in the cardiac interactomes of dystrophin and micro-dystrophin*. In this paper, Dr Montanaro's group demonstrated that cavin-4 was critical for the

Elena Marrosu (top), Prof Jenny Morgan (below left), Dr Federica Montanaro (below right)

function of another protein, called ERK, which is important for the protection of heart muscles against cardiac stress.

They showed that microdystrophins couldn't rescue the function of cavins and ERK. This implies that the standard gene therapy in Duchenne and Becker muscular dystrophy would lack some of these functions associated with heart muscle.

It's clear that dystrophin is crucial for the function of cavins. The researchers had the idea that the bits of the dystrophin protein missing in microdystrophin must be important for this function. To investigate this, Elena worked with tissue from a range of mice, provided by Dr Dongsheng Duan at the University of Missouri, in which the dystrophin gene had been altered and various bits of dystrophin removed.

While these experiments couldn't demonstrate which bit of dystrophin was important for the correct distribution of cavins, they eliminated some possible areas of the protein. The findings will inform future work in this area, which will enable improved design of microdystrophins, especially when considering the specific effects in the heart muscle.

"I was awarded an MDUK-funded studentship four years ago, and I felt incredibly lucky. The funding has enabled me not only to do my thesis but also to learn a lot. I previously worked as a research assistant on collagenopathies, and MDUK had funded that work, so the charity has been there for all my research life. I'm very grateful."

Elena plans to submit her thesis in early 2022, and expects to sit her PhD viva soon thereafter.

Ashleigh Venables

Scotland and Northern Ireland

When Joseph and Nuala Robinson's eldest son, Jack, was diagnosed with Duchenne muscular dystrophy in November 2019, the family decided they wanted to fundraise for research into cures and treatments.

Joseph (pictured below, with Jack) has been blind from birth, but this didn't stop him planning a skydive at the St Andrews Skydive Centre, in Glenrothes. After several COVID postponements, he finally jumped in September 2021, raising over £1,000. He said doing the skydive was a real adrenaline rush.

"I can't wait to take to the skies again sometime. We as a family have adapted to Jack's needs and capabilities, but life in general cannot adapt to Jack, so we will do all we can to help him through life's stages."

"For Joe to do a skydive is so brave and impressive. Thanks to friends and family support, he has smashed his £399 target. I hope others will want to support him," said Ashleigh.

If Joe has inspired you to take on a skydive, you can sign up at www.musculardystrophyuk.org/get-involved/events/skydive-for-mduk

Key dates for 2022:

- **Kiltwalks:** Glasgow – 24 April Aberdeen – 29 May Dundee - 21 August Edinburgh – 18 September
- **Scotland's Virtual Kiltwalk:** 7-9 October
- **Edinburgh Marathon Festival:** 28 and 29 May
- **Question of Support Dinner and Quiz - a virtual event:** date tbc

Get in touch with Ashleigh on
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@AshleighMDUK

Charles Horton

Wales, West Midlands and South West England

Trainee Vicar Lisa Mitchell (pictured below) was 30 when she was diagnosed with facioscapulohumeral muscular dystrophy (FSHD.) She was told to expect to be in a wheelchair by her 50th birthday and she remembers feeling literally 'written off'.

But, contrary to the prediction, the West Bromwich wife and mother is still walking well and feeling great, and she marked her half-century birthday with a skydive.

"To be honest, I feel the best I ever have, both physically and mentally," said Lisa, adding that finding faith helped her turn a corner.

"I'm so pleased that Lisa has chosen to mark her 50th birthday in such a spectacular way, especially as she has lived with a muscle-wasting condition herself for 20 years.

"Lisa is well on her way to reaching her fundraising target of £1,000 and her experience certainly brings a whole new meaning to the phrase 'being closer to heaven' and will be a great story to tell her parishioners for many years to come!" said Charles.

If you'd like to take on a challenge of a lifetime, why not try one of our treks? Find out more at www.musculardystrophyuk.org/get-involved/events/challenges

Key dates for 2022:

- **Weston Super Half Marathon:** 27 March
- **BRF Supernova 5K Race:** 8 October
- **BRF Junior Race:** 8 October
- **BRF Half Marathon:** 9 October
- **Shrewsbury Half Marathon:** 9 October

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Louise Moffat

London, South East and East of England

Peter Mullins' wife and their two daughters all live with facio-scapulohumeral muscular dystrophy (FSHD) and, 12 years ago, Peter (pictured below, left) became their full-time carer.

Last year, he took on a skydive, his latest fundraiser for MDUK. He also volunteers every year at the MDUK Cambridge Town and Gown 10k.

"I was absolutely petrified of leaving the plane but the feeling of achievement and experiencing the incredible views made it all worthwhile – I'm considering doing it all again!"

"It was fab working with Peter for his skydive, and he raised such a fantastic amount to help people living with muscle-wasting conditions. If he's up for another one, we'll definitely have him back!" said Louise.

Not content with facilitating absolutely everything her colleagues needed to return to the office, MDUK Facilities and Office Administrator, Gosia Gil (pictured right) also signed up to skydive for MDUK. She did it to overcome her fear of heights and to fundraise for the charity,

"When we jumped, I felt very weird because I could not breathe for a moment or two. But then I saw how beautiful it was. I couldn't believe I had done it and now I'm very happy and very proud of myself. Everyone at work thinks I'm just a bit crazy. Admittedly, I don't think I'm exactly proving them wrong so far!"

Louise also commented on Gosia's skydive. "I was thrilled when Gosia told me she was going to do a skydive. It's always lovely when other staff members fundraise for the charity. She was a superstar at fundraising too, and smashed her target in no time."

If you'd like to take on a challenge in 2022, we have loads of runs for you to choose from across the UK. Find out more at www.musculardystrophyuk.org/get-involved/events/runs

Key dates for 2022:

- **Cambridge Half Marathon:** 6 March
- **London Landmarks Half Marathon:** 2 April
- **Ultra Challenge Windsor:** 4 September
- **Easter 50 Challenge: 50km Ultra or historic 25km:** 9 April
- **Royal Parks Half:** 9 October

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Susanne Driffield

North England and East Midlands

Lis Watson conquered her fear of heights and skydived last September to fundraise for MDUK and to support her friend, Simon Wright (pictured below, right, with Lis), who has facio-scapulohumeral muscular dystrophy (FSHD).

"It is the brilliant friendship between Simon and me that inspired me to face my fear of heights for the charity skydive.

"When we met, I was a chartered accountant, wife and mum, whose self-confidence had been knocked by events and circumstances.

"I left work and took on roles in the voluntary sector. But through our friendship, I have gained confidence to become a better version of myself. Simon has been my mentor and counsellor."

From the weigh-in to the bumpy take-off, amazing views and frightening landing, Lis described her skydive experience.

"On the day, the weigh-in was followed with a video briefing, which made it all look so easy. Once we landed, I have never felt so pleased to feel the sensation of sitting on wet, muddy ground! It was not until the instructor suggested I get up, that I realised how weak my legs felt.

For a moment, when all my limbs felt too heavy to move and I could not imagine how I could possibly stand, I got a small sense of what it must feel like for Simon."

"When Lis got in touch to tell me about her skydive, I immediately knew this was something special, I found the story of her friendship with Simon such a positive one. We are so grateful for her fundraising," said Susanne.

Looking for a new challenge in 2022? Join #TeamOrange and cycle for MDUK. Find out more at www.musculardystrophyuk.org/get-involved/events/challenges

Key dates for 2022:

- **Total Warrior:** 2/6 June
- **Hadrian's Wall Trek:** 10 June
- **Lake District Ultra Challenge:** 11 and 12 June
- **The Yorkshire Ultra Challenge:** 23 and 24 July

Get in touch with Susanne on

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Martin Hywood

Regional Corporate New Business Officer

Martin Hywood, MDUK's Regional Corporate New Business Officer, is calling on the MDUK community to join him in helping others. Could MDUK be your company's charity of the year, would you like to form a wonderful partnership with a charity that makes a huge and positive difference? Does your company have a corporate social responsibility manager and/or a human resources manager that Martin could meet and have a coffee with? Or are you indeed that person reading this right now?

"Please join me and everyone else in making a world of difference to many people like myself, who live with muscle-wasting conditions. Do get in touch, and we can discuss everything from walking miles to moving mountains, but importantly we can talk about giving people hope," says Martin.

Get in touch with Martin on

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How a bumblebee helped my wellbeing (continued from p7)

I thank the bumblebee for reminding me my life is for living, and new life to be enjoyed, even though I am increasingly constrained by my condition. It reminded of Pico Iyer's wise words, 'Sitting still is a way of falling in love with the world and everything in it.'

About Philip

Philip is a member of the MDUK Services Development Committee, and an MDUK working group developing a succinct neuromuscular hospital admissions care plan. An advocate for barrier-free accessibility, equality, and inclusiveness for persons with disabilities, he's also involved in several NHS initiatives, and with various disability and accessibility advisory groups. He's also a regular contributor to Independent Living.

About Independent Living

The Independent Living web platform and weekly newsletter are rich resources of impartial information about products and services to help with daily living, mobility, and independence.

"The information includes valuable insight and expertise from guest columnists, including our most popular contributor, Philip Anderson, whose regular articles reflecting on themes suggested by life with a progressive muscle-wasting condition always stimulate a powerful and moving response from readers."

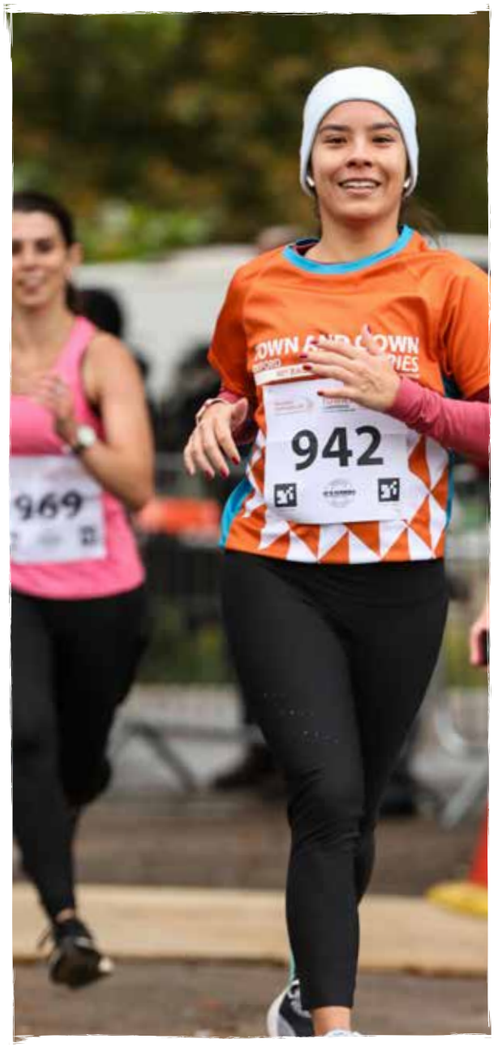
Frances Leckie, Editor of Independent Living
www.independentliving.co.uk

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

A fantastic season of events

Cambridge Town and Gown

On 16 October 2021, 955 adults and 35 juniors took on our Cambridge Town and Gown. It was a unique year, with a tweaked route, and one in which we joined forces with the TTP Cambridge Half in the Cambridge Festival of Running. Thank you to all of you who ran the race to beat muscular dystrophy, and raised a fantastic £43k.



Five-a-side football

In October last year, 178 keen footballers took part in the third annual Marchmont Challenge in Shoreditch in London. Special thanks to Tim Lumsdon and the team at Marchmont Investment Management Ltd who hosted the five-a-side tournament, which raised £10k.

London Marathon
Congrats and thank you to our 95 #TeamOrange runners, who not only ran a marathon for us in October but also raised an enormous £240k for MDUK. Thanks to our stalwart, Bernie Henderson, for his valued and ongoing support to our runners too.

If you'd like to join us in 2022 and 2023, please get in touch with us at
events@musculardystrophyuk.org

Great North Run
In September, 92 runners took on the world's most prestigious half marathon for MDUK. Thank you to all of you for your support and the £69,500 you raised.

Registrations are open for GNR22, and you can sign up here:
musculardystrophyuk.org/get-involved/events/great-north-run-2022

Our fourth MDUK Clay Pigeon Charity Shoot
Thank you to our committee, Jon Eaglesham, Nick Moldon and Simon Tann, for making the day a success and helping to raise £48k. And to Martin Hywood our speaker, and sponsors, Barr Gazetas, PIP Electrics, Alinea Consulting and Arke Creative.

MDUK's 37th Microscope Ball
In September, we welcomed 602 people to this glittering event in London, a key event in the property industry's calendar. The theme for the evening was #NotAllHeroesWearCapes, to celebrate those who supported us through the pandemic. Thank you to everyone for raising an awesome £327k, including a record £125k on the night. Special thanks to our Microscope Ball Committee, the Chair, Michelle Anthony, host Jonny Gould, our speakers Carmela Chillery-Watson and her mum, Lucy Watson, the Ambassador Band and our sponsors, Siren, Property Week, BearJam, Faithdean, Ashill Regen, Fabrix, Fairview New Homes, Hadley DM Services, Investec Bank, Roots in the Sky, Student Roost, The DSGN Studio.

Q Trust Quiz
Huge thanks to the Q Trust committee, Alex Wellesley Wesley, Candida Crewe, Charity Crewe, Emily Reynolds, Nicky Manby, Sophia Bergqvist and Victoria Elliston, who brought 370 people together for a fantastic quiz night! Thanks also to host Evan Davies and auctioneer Guy Jennings, and to everyone for raising an awesome £57k.

Celebrity Sports Quiz
On Thursday 4 November, 174 people joined us at Lord's Cricket Ground for our 10th star-studded quiz evening. Thanks to all the sports stars who joined us, and to our committee members, quizmaster Gabby Logan, host Andy Zaltzman and auctioneer Jeffrey Archer. Amazing support, and a fantastic £81k raised.

Autumn Ball
MDUK Vice President, Frances Carey, hosted 199 guests at her inaugural event for MDUK in November 2021, having had to postpone it twice because of the pandemic. It was a wonderful success, raising just under £50k.

MDUK Charity Golf Day
Fifty-two golfers joined us in September for our inaugural golf day, and raised £41k. Thanks to Stephen Rigby who got the teams together, our brilliant host Kyran Bracken, Martin Hywood our powerful pledge speaker, and sponsors, Johnson Associates, MTRE and Generation Estates.

Where have you been all my life?

When Kim Kemp, from Blairdardie in Glasgow, heard about the WelcoMe app by Neatebox at MDUK's Scottish Conference, her jaw hit the floor.

"When I heard Gavin Neate talking about the app, what it could do and how it could help people with disabilities, I was absolutely fascinated. What a simple but brilliant idea! I went to speak to him after his presentation and when I put my hand out to shake his hand, I asked him where he'd been all my life!"

"Meeting Kim at the MDUK Conference in Scotland in 2018 was an amazing moment for me too. I knew nothing about muscular dystrophy, and then to have one person say that to me – it's true, where has this solution been all our lives?" said Gavin, CEO and Founder of Neatebox.

"I'm not a technology expert, but I started thinking about assistive technology in the early 2000s, when I'd first qualified as a mobility instructor and was working at Guide Dogs for the Blind. My initial idea was to develop a solution to help visually impaired people at a pedestrian crossing using their smartphones, and this began to evolve into thinking about pan-disability solutions and, ultimately, to WelcoMe, an app that helps disabled people communicate their needs to service teams before they arrive.

"No-one had ever done this before. It took me a long time and a lot of investing to get the beta version of the app into testing in 2018, and now more than 150 venues across the UK are using it."

Kim tried out the app as soon as she got it.

"I went to VisitScotland in Buchanan Street, and, when I got there, the door opened automatically, and someone greeted me by name at the door. They showed me to a space to sit and a place where they could answer my questions. Oh, this was different!" said Kim.

"Previously, I'd visited places that had told me they didn't have staff to deal with the disabled. Well, we don't go out in packs. And I've often felt as if I'm the first person in a wheelchair ever to have the audacity to go out in public.

(I to r) Bernadette Shannon, Kim Kemp, Mandy Wolfenden, Gavin Neate

"But now, with this app, I don't need to sit in the back of the taxi with my head between my knees, stressing out about going somewhere. The fact that you can go out and they've got all those details is just fantastic.

"This app is the real deal. It does what Gavin said it was going to do. And if it makes more people feel welcome, even like a celebrity, then bring it on."

"I'm hoping the app will help end loneliness, by encouraging more people out of their homes and into a world where they feel more comfortable, more confident," said Gavin.

Kim, who works for Scottish Huntington's Association, enjoys art, music, cooking, and spending time with friends. When she was 15, one of her two older brothers was diagnosed with muscular dystrophy, so she was tested too and diagnosed with Titin-related myopathy.

"But now, with this app, I don't need to sit in the back of the taxi with my head between my knees, stressing out about going somewhere. The fact that you can go out and they've got all those details is just fantastic."

"When I was first diagnosed, I thought 'muscular what?' and was only worried about whether I could go to a concert or not. Now, the condition is affecting every aspect of my life. I'm still working three days a week, but finding things are getting harder and I get more tired.

"I first connected with MDUK in the '80s. And now Jackie Munro (MDUK's Regional Information, Advocacy and Support Manager in Scotland) is a great support to me. She's helped me campaign to get a Changing Place toilet up in Tyndrum, and she's put me in touch with the support services I need, which has been helpful."

The WelcoMe app aims to make sure every disabled person in the UK and Ireland can get the service they need when they shop or visit a venue. With the app, a user can let a venue know they're planning a visit, and the venue – if they're registered with the app – will get an overview and expert tips and advice about that person's specific access and assistance needs. Find out more at www.neatebox.com or search for *Welcome by Neatebox* in your app store.

Puzzles page

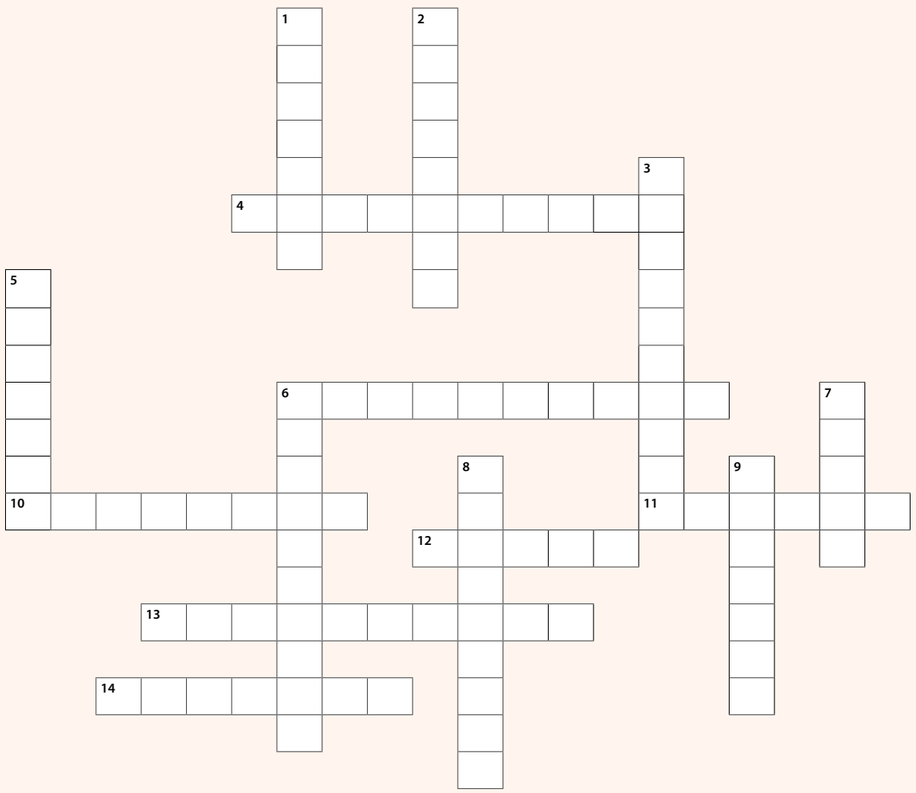
Joshua Azizollah, our puzzlemaster

Oh no, these fundraising events have got all mixed up! Can you work out what they are?

Cake, beef, a friend	**B _ _ _ _ _ _ F _ _ _ _ _ _ _**
A blunt maul	**A _ _ _ _ _ _ A _ _**
Papped lad leaked	**_ E _ _ _ _ _ _ _ _ E _ E _ _ _**
A chimp's first riots	**_ _ _ _ _ T _ _ _ _ _ _ _ _ T _ _ _**
Don't gnaw now	**_ O _ _ _ _ _ _ _ _ _ _**

WORD PUZZLE

You'll find some answers in this edition of TMD.



ACROSS

4 _____ Football, popular disability sport

6 Flying discs used for target shooting (4,6)

10 Physical activity, good for wellbeing

11 Sanjeev's music style is a mix of this and pop

12 MDUK might award you one to carry out relevant research

13 Protein found in muscles which is absent in people wih Duchenne and Becker muscular dystrophy

14 Amanda and Séana talked at a virtual one for Muscles Matter 2021

DOWN

1 Kim lives in this city in Scotland

2 _____ for Dystrophy, fundraising concert in Hull

3 _____ _____ Run, the world's most prestigious half marathon (5,5)

5 All of our sparkling fundraisers did a ____ for MDUK

6 Dr Fiona Norwood is a _____ neurologist

7 Our senior leadership team took this on, together

8 World's largest natural history study of Duchenne muscular dystrophy

9 SMA, or _____ muscular atrophy

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