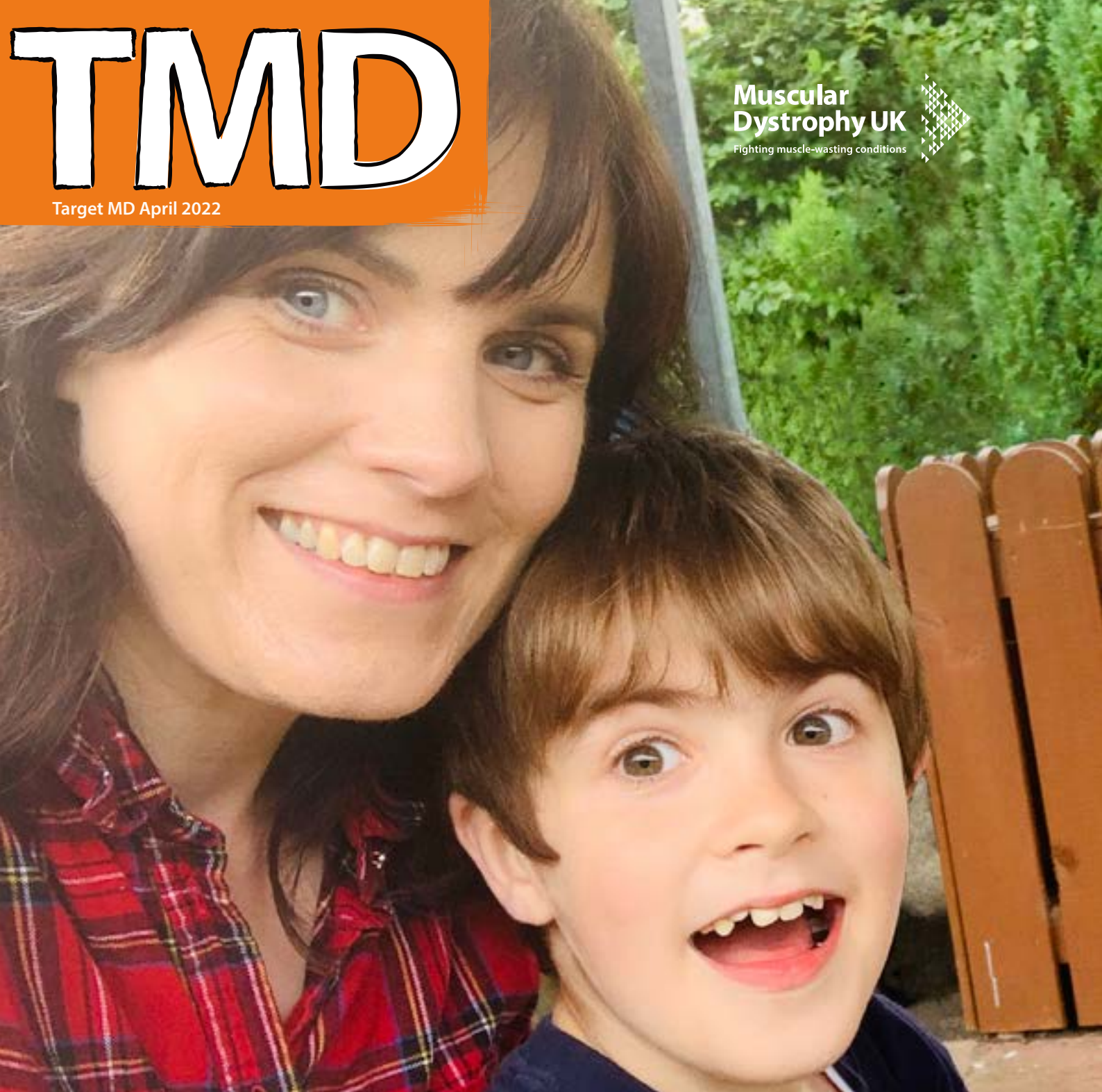


# TMD

Target MD April 2022

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



## “The Council play an essential role.”

**CLAIRE O'HANLON, CHAIR OF MDUK'S NORTHERN IRELAND COUNCIL**

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# Hello and welcome to Target MD



It's April, and your spring edition of TMD brings you another collection of incredible stories from our community of outstanding supporters. There's an exciting update on one of our Changing Places toilets projects and lots of information on the different ways MDUK is here for and can support you.

We bring you the amazing 2021 President's Award winners, and tell you a bit about the fun we had planning those surprise award presentations. You'll hear about the great work our councils in Scotland and Northern Ireland do, and the role they play in guiding our work in the respective countries.

You'll read about our awesome fundraisers – all of whom go that extra mile (or hundred miles) to raise awareness and funds for the work of MDUK, including the groundbreaking research we fund. You can read about all of those new

grants too, on p20.

If you have a story you'd like to share, or any thoughts or ideas you have about the magazine, please email [targetmd@musculardystrophyuk.org](mailto:targetmd@musculardystrophyuk.org).

My best wishes

*Ruth*

Ruth Martin  
Editor

PS And bye from me, after 11 years of sharing your amazing stories I will have moved on by the time this lands on your doorstep. I wish you and MDUK all the best.

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On the cover:  
Claire O'Hanlon and her son Luke (read more on p10).

### FOLLOW US ONLINE





## News from MDUK

Hello everyone. At the start of a new financial year, it's always motivating and gratifying to see all that we've achieved, together, over the past 12 months. It's been great to note the huge growth in volunteer activities, to see a return to a more regional fundraising approach, and to be able to hold critical meetings with our valued communities in England, Scotland, Wales, and Northern Ireland.

As a national charity we're here for you, no matter where you live. Our communities, both online and offline, have been actively working together to support each other. Our Facebook groups for volunteers, and for parents, are busy and growing at pace. We've been training some new peer support volunteers to be there for others who may be struggling to gain access to the benefits they are entitled to, or need someone to talk to, who understands what they are going through. Our new support group for young adults in Scotland has had their first meeting, and our myasthenia gravis support group has just held their second meeting.

It's fantastic when volunteers lead these much-needed initiatives and offer valuable support to one another. We hope to see you at some of our Muscle Group meetings either on Zoom or, if you live in Yorkshire and Humber, for our first event returning to a face-to-face format in Sheffield in early May. Do get in touch with us or keep an eye

on our website and social media channels for the summer programme of face-to-face meetings.

And thank you to our community in Scotland, Northern Ireland and Wales, who we are working closely with to push forward the recommendations from our report, *Shining a light on the impact of COVID-19 on people with muscle-wasting conditions*.

You'll read another collection of amazing stories in this edition of TMD, and you'll see why we say our MDUK community is the best in the UK. Please get in touch if you'd like to get involved. There's always room for one more in #TeamOrange!

Thank you for all that you do to make everyday count for people living with muscle-wasting conditions; we do appreciate you all very much.

Best wishes



Catherine Woodhead  
Chief Executive, MDUK



## MDUK support groups

We know how valuable it is to connect with other people living with muscle-wasting conditions, and our range of support groups allow you to do just that. Most of these groups are led by volunteers, who have lived experience of muscle-wasting conditions.

Our groups include regional Muscle Groups, which meet three times a year. They're open to anyone, whether you have a muscle-wasting condition yourself or a close loved one does. We've been holding these meetings on Zoom, but we'll resume face-to-face meetings in the summer of 2022 for the first time since 2019.

We also have other groups tailored to specific parts of our community, such as our Facebook

group for parents of children with muscle-wasting conditions. Our support groups for people living with oculopharyngeal muscular dystrophy (OPMD), and myasthenia gravis, meet on Zoom a few times per year.

Whichever group you join, you'll meet like-minded people and be able to share experiences and get advice and support from your peers. We'll be happy to signpost you to the most appropriate group for you and, if you're interested in volunteering to start up a new group for others living with the same condition as you, do let us know.

Get in touch with us at

[volunteering@musculardystrophyuk.org](mailto:volunteering@musculardystrophyuk.org)





# £23.5m of Changing Places toilets funding

We're delighted that the results of applications for a share of the Department of Levelling Up, Housing and Communities (DLUHC) funding for the installation of Changing Places toilets in existing buildings in England have been announced.

£23.5m worth of the funding has been allocated across 191 councils and will see 513 new Changing Places toilets (CPT) installed in public places and tourist attractions across England, meaning toilet accessibility for those who need Changing Places toilets will be vastly improved in these areas.

Mduk is the co-chair of the Changing Places Consortium. Many people in our community require access to these toilets and we have worked in partnership with consortium members and with passionate loyal campaigners to make this happen.

Mduk has provided specialist advice to the DLUHC throughout the process of launching the prospectus, assessing applications, and building a support package for Local Authorities (LAs) to access. For those LAs that have been awarded funding, they will access support and expertise that includes:

- A team of Mduk Support Officers that provide dedicated advice and information
- A recently revised 'Changing Places Practical Guide' that provides the technical know how for installation of a Changing Places toilet
- Informative specialist operational and technical training sessions for LAs to access
- Facilitating the connection of LAs with a collaborative network of support
- Signposting to a network of known suppliers and installation companies
- Support with the review of draft plans that ensures the British Standards are adhered to and the new Changing Places toilets are fit for purpose
- Registering and promoting new facilities on the national map and across social media

Changing Places toilets are well supported by Ministerial Disability Champion Eddie Hughes MP who said: "People with severe disabilities and their families or carers should not have to think about whether there are suitable toilet facilities when they go out shopping, plan a day out or travel."

"That is why it is great to hear that our funding will help provide over 500 new Changing Places Toilets in England enabling them to go about day-to-day activities like the rest of the population with more dignity and freedom"

This funding will ensure increased provision of Changing Places toilets will now be built in a real mix of venues:

- Public parks, open spaces and seaside resorts
- Tourist attractions including historic properties,
- Cathedrals and church's
- Museums, theatres, and galleries
- Shopping malls
- Libraries and public buildings

**For the full list of Local Authorities that have been awarded funding in this round, along with the number of CPTs funded please visit the DLUHC website: [www.gov.uk/government/publications/changing-places-fund-allocation-of-funding-following-round-1-assessment](https://www.gov.uk/government/publications/changing-places-fund-allocation-of-funding-following-round-1-assessment)**

But our work doesn't end here.... We are now working towards a second round of funding to allocate a further £6.5m. We will work with the DLUHC to target areas where there is little or no Changing Places toilet provision. We will also look to our supporters and active campaigners to contact their LAs to ensure they fully engage with the next and final stage of this important program when the future prospectus is launched to further increase the provision of Changing Places toilets across England. We'll keep you posted with details and timing of the launch.



Zack, a Changing Places toilet campaigner being interviewed by BBC Lancashire upon the government announcement.



Campaigners at a Round Table Event in Parliament, three years ago this month, with Rishi Sunak – when the conversations first started for the funding.

**For more information and to discuss how you can encourage your Local Authority to engage in the programme, contact the Changing Places team at [changingplaces@muscular dystrophyuk.org](mailto:changingplaces@muscular dystrophyuk.org)**



# Muscles Matter 2022

Following the success of our 2020 and 2021 Muscles Matter seminars, they've now become a popular, regular feature in MDUK's calendar. As we resume holding live events, we will continue to run a programme of virtual ones to ensure that our whole community has access to information and support

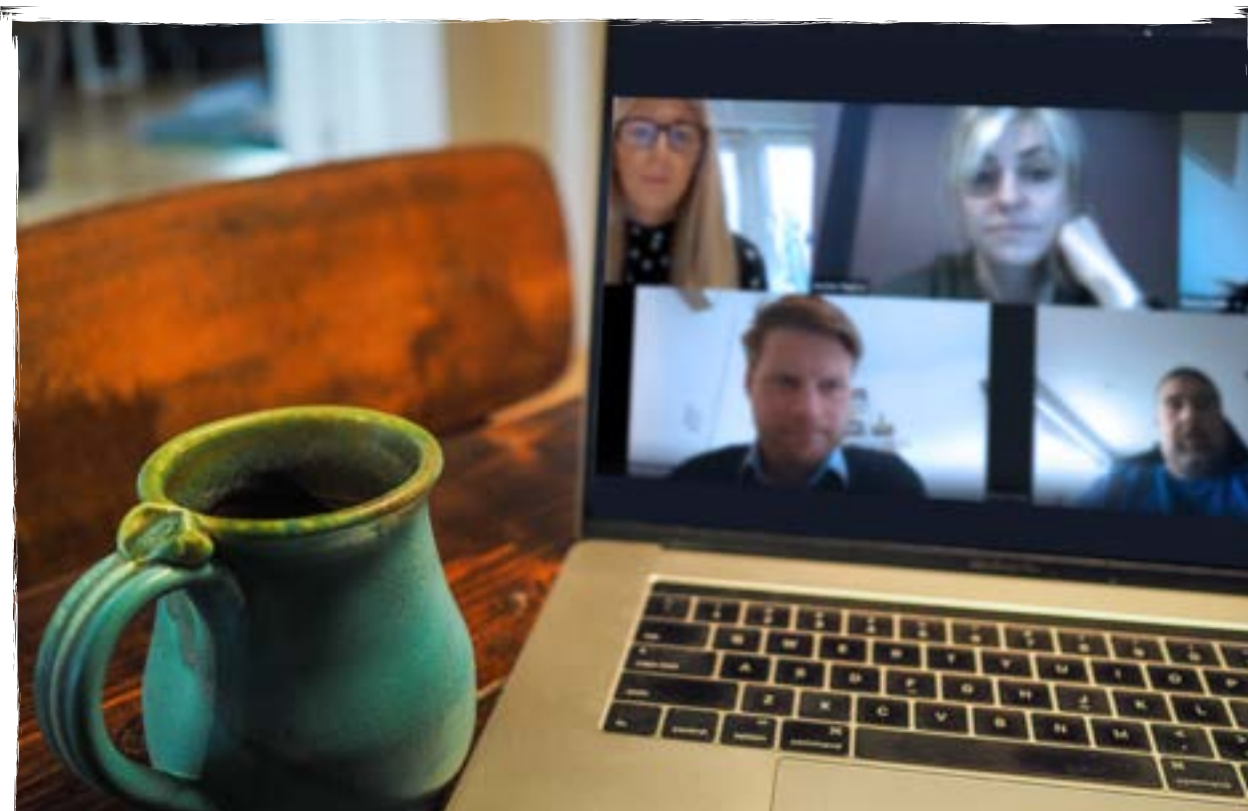
So, throughout 2022, we'll continue to bring you new seminars each month, focusing on both general and condition-specific information. We understand how overwhelming the information can sometimes feel, and so our seminars aim to present that information in a way that is clear and easy to understand.

Across our sessions, we have a range of health-care professionals including care advisors, special educational needs co-ordinators, researchers and people with firsthand experience of living with muscle-wasting conditions joining us on the

panels. The idea is to bring people together from across the UK to hold open discussions. You can submit questions for each seminar's panel ahead of, and during, the session, as an opportunity to have them answered.

Our previous seminars gave updates on the latest research, advice about managing your condition, and diet and nutrition information, to name just a few topics. You can still watch our past seminars on our YouTube channel, with all the sessions collated together on our 'Muscles Matter' playlists. You can find them at [www.youtube.com/c/MuscularDystrophyUK/playlists](https://www.youtube.com/c/MuscularDystrophyUK/playlists)

**Please join our future seminars and do get involved. We'll keep posting updates on our upcoming Muscles Matter seminars on our website and social media. You can find out more at [www.musculardystrophyuk.org/get-support/mduk-muscles-matter](https://www.musculardystrophyuk.org/get-support/mduk-muscles-matter).**



# Moving Up in my career with MDUK



My name is Imogen and I work as an Editorial Assistant in MDUK's Marketing and Communications team as part of a Moving Up placement. I studied English Literature at university, regardless of my dyslexia. I struggle with processing information and have a slower reading and handwriting speed than the suggested academic requirement, but I love the craft of language and words so I pushed through. Especially pursuing a career in writing, I worry that I am not good enough, that my work isn't valuable enough to be paid for, and I worry about whether to declare my disability when applying for jobs.

I graduated during the first lockdown and, like so many others experienced, I found the search for employment during the pandemic especially hard. As I was applying for jobs, hundreds of people were applying too, and on paper I lacked

**Moving Up provides work experience placements and ongoing employability support for young disabled people living in London.**



the experience that other candidates had. Most entry level jobs seemingly ask for multiple years' worth of experience that employers often expect you to obtain through unpaid work experience, which is difficult to afford when you live in and around London. I persisted with applications, but constantly getting rejections took its toll on my confidence, and I felt like I was failing.

But MDUK has given me an opportunity; for the first time in a long time, I haven't felt like a number, I have felt supported and invested in.

MDUK employees have made me feel incredibly welcome, given me invaluable industry-specific advice, and the skills and confidence to jumpstart my career. This placement has given me insight into a role in the third sector, challenged me with a mixture of tasks, given me support from people with true experience and has empowered me to realise my value. I've learnt how the Marketing and Communications team collaborates with teams across the organisation, challenging me to learn and write about topics such as fundraising, policy and advocacy.

Jack, MDUK's Work Experience Development Officer, takes time to help me improve my CV, explore new job opportunities, and guides me in finding my next steps. I have been given support that has significantly improved my future, and I know that this will continue even after my contract at MDUK ends.

**There are still plenty more opportunities to get involved in the Moving Up scheme, and I couldn't recommend the opportunity enough. If you're aged 16 to 30, have a disability, live in London, and are interested, contact [movingup@musculardystrophyuk.org](mailto:movingup@musculardystrophyuk.org) to enquire.**



**CLAIRE O'HANLON**

"I liaise with MDUK's advocacy, and care and support teams, who help shape the charity's activities in Northern Ireland."

## Playing an essential role in Scotland and Northern Ireland

At MDUK, we're here for everyone – no matter where in the UK you live. That's why we wanted to tell you a little bit more about our Scottish and Northern Ireland councils, what they do, and how you can get involved.

Both the Scottish and Northern Ireland councils were created to better represent the views of people living with muscle-wasting conditions in each respective country.

The councils help MDUK identify the most pressing issues for our community and play a vital part in making sure every voice is heard.

Some of the wider issues the councils have discussed over the past year include a lack of psychological support for families, care staff retention and recruitment difficulties, the importance of multi-disciplinary health and social care, and access to COVID vaccines.

The groups, which are separate from each other, meet around four times a year, and report in to the MDUK Board of Trustees. MDUK representatives attend each meeting, and work with Council members to bring the action points to life.

Claire O'Hanlon is Chair of our Northern Ireland Council, and Sheonad Macfarlane (pictured right) Chair of our Scotland Council. Each of them has a child living with a muscle-wasting condition.

"The Northern Ireland Council meetings are usually held in advance of regular All Party

Group meetings in Stormont, which helps us feel prepared to approach our politicians with a united front and clear asks. As Chair, I set the agenda for meetings and bring together key discussion points, ensuring that they are advocated for in Stormont. I liaise with MDUK's advocacy, and care and support teams, who help shape the charity's activities in Northern Ireland. The Council really does play an essential role over here," said Claire.

Sheonad sees her role as making sure everyone is heard – from those on the Council, those she's in contact with on social media, and those she meets in person.

"I also link into MDUK directors and staff, and hope I support and challenge them in equal measure! We help represent people who share their own experiences in the hope of making a real difference to others. Council members shine a light on the positives and negatives of living with neuromuscular conditions, helping to inform MDUK on moving forward with their strategies. Without the Scotland Council, I worry that as a devolved nation we'd be forgotten... and that cannot happen," said Sheonad.



If you're interested in joining either Council, please get in touch with Jacqueline Munro, our Regional Information, Advocacy and Support Manager, at [j.munro@muscular dystrophyuk.org](mailto:j.munro@muscular dystrophyuk.org)



# MDUK's 2021 President's Awards

We're thrilled to present to you the six winners of our 2021 MDUK President's Awards. 2021 was a very different year, so we wanted to do something unique to recognise the outstanding achievements within our community. Huge thanks to our CEO Catherine Woodhead for inviting the winners to Zoom calls, and to our host of amazing celebrities: MDUK President Gabby Logan, ITV presenter and reporter Julie Etchingham, and British former racing cyclist Chris Boardman, who popped up on to those calls to surprise the winners.

## Fundraiser of the Year Award

**Winner: Sam Taylor** – Sam conceived of, co-ordinated and cycled in his 19-person 380-mile DuchenneResearchRelay, from London to Newcastle via Oxford and Liverpool, and raised a phenomenal £43k. With inspiration from Sam's 12-year-old son, Will, who has Duchenne muscular dystrophy, the team never faltered in their determination. **Highly commended: the Spink family**

## Early Career Scientist of the Year Award

**Winner: Amy Vincent** – Amy, a Henry Wellcome post-doctoral fellow with an outstanding research publication record, has been researching mitochondrial DNA mutations and making fundamental discoveries. She's also hugely committed to public and patient engagement. **Highly commended: Dr Thomas Roberts, Dr Sara Aguti, Dr Katherine Schon**

## Volunteer of the Year Award

**Winner: Patricia Lock** – Throughout 2021, Patricia was a beacon of light to others, giving of her time, expertise, and valued perspective with warmth, friendliness, and compassion. Patricia, who has congenital myopathy, chairs the Milton Keynes Muscle Group, is a peer support volunteer, and sits on our Joseph Patrick Trust lay panel. **Highly commended: Alison Kay**



## Alexander and Valerie Patrick Carer of the Year Award

**Winner: Shelley Simmonds** – This award recognises the outstanding and selfless commitment that Alexander and Valerie Patrick, lifelong supporters of MDUK, embodied. Shelley, whose son, Fraser, has Duchenne muscular dystrophy, works full-time, campaigns on a huge range of issues, encourages newly-diagnosed families, and gives a voice to the community. **Highly commended: Emma-Jayne Ashley, Phil Grant**

## Richard Attenborough Award for Outstanding Achievement

**Winner: Carmela Chillery-Watson and her mum, Lucy** – Carmela and Lucy have done fantastic work fundraising and raising awareness about muscle-wasting conditions, particularly Carmela's rare condition, LMNA-CMD. They've led several national and local fundraising drives and helped MDUK raise more than £125k over the past few years. Their commitment and dedication make a huge difference to those in our community. Carmela was delighted to receive a personal message from David Beckham during her call with Cat. **Highly commended: Brian Deehan, Zac Kerr, Microscope Ball committee**

## Peter and Nancy Andrews Community Achievement Award

**Winner: Lorna Fillingham** – Active supporter, ambassador and Changing Places toilets campaigner, Lorna Fillingham, is a worthy winner of this inaugural award, named in honour of lifelong MDUK supporters, Peter and Nancy Andrews. Lorna has taken her campaigning to Downing Street, regularly meets with government ministers and departments to lobby for better Changing Places toilet provision and has encouraged local authorities to bid for part of the £30m funding to install more of these vital toilets across England. **Highly commended: Nicki Bevan, Team McLean**

After you've read this piece, please grab a coffee, sit back, and enjoy the delightful video compilation that brings all the award presentations to life. [www.musculardystrophyuk.org/Presidents-Awards-2021](http://www.musculardystrophyuk.org/Presidents-Awards-2021)



# Advocating for inclusive education

Muscle-wasting and associated neuromuscular conditions are rare, so many schools have no experience supporting students with these conditions and little understanding of their individual needs. MDUK recognises how important inclusion is for students with muscle-wasting conditions as it enables them to enjoy their time in school. We are here to support schools and families with practical advice and information relevant to children of all ages.

Here are some frequently asked questions and advice from our Information, Advocacy and Care team:

## How can I get support for my child in school?

There is support available for students with additional needs, however, the process for applying is different across the UK. The first steps are to find out what the application process is in your local area and what support your child might be entitled to. You can find out more by contacting your local authority or MDUK's helpline team who can help point you in the right direction.

## What if I have been told that my child isn't eligible?

We know that it can be difficult to hear that your child isn't eligible for support in school. But after receiving such a decision, you can still:

- contact MDUK's helpline and advocacy team who will tell you more about challenging a decision, how to find out more about yours and your child's rights, and how MDUK can support further

- speak to your child's neuromuscular team or care advisor if you need supporting evidence
- contact someone from your local government to make them aware of the situation
- talk to the SENCO (Special Educational Needs Coordinator) at your child's school for advice
- reach out to voluntary organisations that specialise in inclusive education, such as IP-SEA or Enquire.

## Are there other parents I can talk to?

We know that talking with another parent who has similar experience can be a huge help. If you want to talk to someone, MDUK can support you through our Peer Support network and through our Parent Support Group on Facebook. MDUK also has regular Muscle Groups in which you can share information and ask others about their experiences.

## Do you have any resources with more information about access to education?

Yes! We provide an eLearning module to inform education professionals on these rare conditions and our Education Manual gives information to parents and schools on inclusive education. You can also look at MDUK's YouTube channel to find our online seminars on Education.

If you have any questions, or we can support you in any way, please do get in touch with us at [info@musculardystrophyuk.org](mailto:info@musculardystrophyuk.org) or on 0800 652 6352.

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

Last year we launched our *Shining a Light on the Impact of COVID-19* report, which highlighted how the pandemic had affected those living with muscle-wasting conditions, and gave recommendations for how care can be improved in the future.

We launched the UK-wide report in July 2021 at the All-Party Parliamentary Group on Muscular Dystrophy, and the three micro-reports, reflecting the situation in each of the devolved nations, followed suit in Wales, Scotland and Northern Ireland in November 2021, January 2022 and February 2022 respectively.

These micro-reports included tailored recommendations based on what we'd heard from people in each country.

Since then, we've been engaging with health services across the four nations, as well as the Department of Health and Social Care, to influence the ways they provide neuromuscular services.

Within England, we've engaged with NHS England to highlight the role of neuromuscular

networks to support the forthcoming Integrated Care Systems. And in the other countries, we've been focusing on improving mental health service provision.

In Wales, for example, we've responded to a Health and Social Committee inquiry in the Senedd on mental health inequalities. In Scotland, we've responded to an inquiry from the Scottish Cross-Party Group on Mental Health, examining the psychological impact the pandemic has had on those with underlying health conditions. We also met with the Scottish Government to discuss the provision of psychological support for people with muscle-wasting conditions. And in Northern Ireland, we plan to establish a forum for clinicians, service users, and Belfast Trust and Northern Ireland government leads. The forum will discuss gaps in services and push for improved access to and provision of neuromuscular care.

If you'd like to attend future All Party and Cross Party group meetings, contact [campaigns@musculardystrophyuk.org](mailto:campaigns@musculardystrophyuk.org)





# Running for mum

A university student is taking on a monumental 12-month running challenge across the country in support of her mum, who lives with a type of limb-girdle muscular dystrophy.

Alex Hughes, aged 20 and from Mickley in Northumberland, is completing a '12 in 12' racing challenge this year, where she will complete one race a month to raise funds for the charity.

Most of these races are either a half marathon or 10k, but in October things will step up a gear when she takes on the London Marathon.

Alex has already completed three of her runs so far and training is well underway for the 26.2 miles later this year.

She was inspired to fundraise for us after her mum, Bex, received her diagnosis of limb-girdle muscular dystrophy last year. Bex now has to use crutches or a wheelchair to move around.

Alex and her father Chris, sister Charlotte, and twin brothers Tom and Matthew, are now Bex's main carers. This is especially tricky for Alex, who is in her final year of PE teacher training at Leeds Beckett University.

"I wanted to do something that would really challenge me, so this 12 in 12 challenge is the perfect opportunity. My family has benefited hugely from the important work of MDUK, and I'm determined to help give back to the charity. I am passionate about inspiring other people to take on challenges because, while life may throw curveballs at you, we can always work together to make things seem better," said Alex.

Alex is no stranger to fitness, having previously completed a triathlon. She hopes her runs throughout 2022 will help her persevere through the dreaded running 'wall' when she takes on the London Marathon later this year.

"Alex's running challenge will be a monumental life achievement and this is a courageous thing to take on. We're incredibly grateful that Alex has chosen to raise funds and awareness of muscular dystrophy at a time when people in our community need MDUK more than ever," said Kiera Santry, Senior Challenge Events Officer at MDUK.



"I am passionate about inspiring other people to take on challenges because, while life may throw curveballs at you, we can always work together to make things seem better"

**Alex's impressive race calendar for 2022 looks like this:**

- January: Brass Monkey Half Marathon in York – 13.1 miles
- February: Duergar Nightcrawler at Northumberland National Park – 10 miles
- March: Saturn Running Half Marathon in Durham – 13.1 miles
- April: Run Media City in Salford – 10K
- May: Leeds Half Marathon – 13.1 miles
- June: Race to be confirmed
- July: Durham City Run Festival – 10K
- August: Try on the Tyne in Newcastle - 10K
- September: Great North Run in Newcastle – 13.1 miles
- October: London Marathon – 26.2 miles
- November: Remembrance Day Run in Durham – 13.1 miles
- December: Chopwell Woods in Gateshead – 10K





## Celeb round-up

Debbie Hoods, our Head of Donor Relations, rounds up the charity's celeb action over the past few months



We were thrilled to have **Mr Motivator** kick off our Go Bright events with an energetic and vibrant online workout on Wednesday 9 February. More than 200 people joined in for the online stream, part of Mr Motivator's regular free Wednesday "Fizzical" sessions. He led the workout in his brightest fitness clothes to raise awareness of MDUK.

Mr Motivator began supporting the charity a few years ago, after meeting 14-year-old Harry Barnley, who has Duchenne muscular dystrophy, and his family. Mr Motivator was keen to continue to spread awareness of muscular dystrophy, and the Go Bright event was a perfect fit.

**Jon Richardson**, stand-up comic, and star of 8 out of 10 Cats, hosted a comedy night at The Waterside Theatre in Aylesbury in aid of MDUK. Jon put on the event in support of his friend Martin Hywood, who has limb-girdle muscular dystrophy. Jon continues to be inspired by Martin's cheerful outlook and outstanding fundraising, which Jon says, is in "complete contrast to his own slightly pessimistic attitude towards life!" **Suzi Ruffell**, **Harry Hill** and **Marlon Davis**, joined **Jon** (pictured above) for the Jon Richardson and Friends event on Sunday 27 March and raised over £32,000 for the charity. **Russell Kane** was due to join us too but his train had other ideas! He has promised to make it up to us.



At the end of last year, we received a wonderful surprise when our President **Gabby Logan** appeared on ITV's *Who Wants to be a Millionaire?* and took to the scary chair opposite host **Jeremy Clarkson**. Gabby did an incredible job as she worked her way through the questions, tackling subjects such as art, fashion, travel, and entertainment. She came away with £64,000, which she kindly split between MDUK and the My Name's Dottie Foundation.

Our CEO, Catherine Woodhead said: "We were so excited to watch Gabby on primetime TV and couldn't believe she donated £32,000 to further our work. Gabby has been an amazing supporter since she joined us, and she's really shown us the benefit of having an engaged and active President."

In January this year, MDUK Ambassador **Monty Panesar** was invited to take part in a vegan masterclass at Hoggy's Grill, which is run by his old teammate and fellow cricketer, **Matthew Hoggard**. Monty and Matthew chatted about cricket, life, and vegan cooking with guests, who got to sample a variety of food. The evening event took place in Rutland and raised £350 for the charity.



LEAVE A GIFT  
IN YOUR WILL  
TO CREATE A  
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from the limitations  
OF MUSCULAR  
DYSTROPHY.

WITH YOUR HELP  
the next generation of  
RESEARCH  
scientists will  
FINISH WHAT WE'VE  
STARTED.

"We were devastated when we found out our beautiful grandson, Jack, had Duchenne. All we wanted to do was take this horrible condition away. We can't do that, we know. But your gift in your Will could make that happen one day." **Steve Gauder**, Jack's granddad

**Muscular  
Dystrophy UK**

Fighting muscle-wasting conditions



For more information about gifts in Wills, call Grace Moran on 0300 012 0172 or email [legacy@muscular dystrophyuk.org](mailto:legacy@muscular dystrophyuk.org)

[www.muscular dystrophyuk.org/giftsinwills](http://www.muscular dystrophyuk.org/giftsinwills)



# Outcomes of our 2021 grant round

Dr Kate Adcock, MDUK Director of Research and Innovation



We're delighted to announce the outcomes of our grant round from 2021. We've been working to a different timetable from previous years – the applications arrived in early June, and we made decisions in the winter.

To help manage the long-term financial impact of the pandemic, we limited the scope of the call for our grant round. So, we asked researchers for proposals of up to 12 months' duration, in Becker muscular dystrophy, collagen VI-related disorders, Duchenne muscular dystrophy, facioscapulo-humeral muscular dystrophy (FSHD), myotonic dystrophy and congenital myotonic dystrophy. We were also delighted to continue our SMA PhD Partnership with Spinal Muscular Atrophy UK to support one four-year PhD studentship in spinal muscle atrophy (SMA) research.

Following a rigorous selection process, we awarded grants to nine applicants, with a total award value of £639,185.

The funded projects cover a broad range of conditions and stages of research, from biological understanding of conditions through to clinical studies. We're supporting researchers from across the UK, some of whom are relatively new to the field of muscle-wasting conditions. These are the grants we awarded in the 2021 round:

- £74,144 to **Dr Lyndsay Murray** of the University of Edinburgh, for a four-year PhD studentship to study a biological process called motor unit enlargement, a process that occurs in the muscles of people with spinal muscular atrophy (SMA). Half the funding for this project will be provided by Spinal Muscular Atrophy UK, and half by MDUK. The project is entitled "Understanding and supporting motor neurons following compensatory sprouting using mouse models".
- £75,000 to **Prof Jatin Burniston** of Liverpool

John Moores University, who is investigating whether proteins are processed differently in people with FSHD. His team has developed a technique that we hope will provide novel insight into how proteins might be produced and broken down differently in people with FSHD. His project is entitled "Aberrant protein degradation is a central mechanism of Facioscapulohumeral Muscular Dystrophy". (See p22.)

- £75,000 to **Dr Alberto Malerba** of Royal Holloway University of London, to investigate a novel method of increasing dystrophin production. Dr Malerba's work aims to boost the production of dystrophin, with the aim of improving its production in people with Duchenne muscular dystrophy treated with gene therapy. His project is entitled "Enhanced Steady-State Levels of Exon Skipped and gene therapy expressed "BMD-LIKE" Dystrophins Through Unfolded Protein Response (UPR) inhibition".
- £74,144 to **Prof Jennifer Morgan** at University College London, to investigate whether collagen VI genes are important for the proper function of muscle stem cells, which are called satellite cells. Her project is entitled "The role of collagen VI in satellite cell function".
- £74,564 to **Dr Chris Turner** of University College London, to carry out a natural history study of people with congenital myotonic dystrophy (CDM). Dr Turner's team will collect data from people with congenital myotonic dystrophy, with the aim of understanding which traits are clinically useful for assessment of the condition. His project is entitled "CARE CDM: Cardio-REspiratory function in adult patients with congenital myotonic dystrophy".



- £43,145 to **Dr Umesh Vivekananda** of University College London, to use brain imaging to study myotonic dystrophy. His team aims to investigate functional brain activity in people with type-1 myotonic dystrophy, because they can experience problems of their central nervous system, for example fatigue and depression. His project is entitled "Using magnetoencephalography to understand the cognitive burden associated with myotonic dystrophy".
- £40,000 to **Dr Diego Kaski** of University College London, to study balance in people with type-1 myotonic dystrophy. His team's aim is to develop measurable characteristics that will help us better predict how the condition will develop for individuals. These biomarkers could also be useful in clinical trials. The project is entitled "Understanding the cause of falls and imbalance in myotonic dystrophy type 1".
- £70,688 to **Dr Vanja Pekovic-Vaughan** of the University of Liverpool, to investigate the internal body clocks in the pathology of congenital muscular dystrophy. Her team will be studying the natural cyclic changes in cells taken from people with collagen VI congenital muscular dystrophy. Her project is entitled "Investigating the mechanisms and therapeutic potential of targeting circadian clocks in collagen VI myopathies".
- £74,622 to **Prof Peter Zammit** of King's College London, who will be studying the importance of metabolic stress in FSHD. His team will look at the relationship between metabolic stress and pathology in FSHD, an area that has been under-researched. The project is entitled "Investigation of metabolic adaptation in FSHD to identify novel pathomechanisms and therapeutics".

This is only possible due to the incredible fundraisers and donors who support our work and enable the research to continue.

You can find details of these studies, and others we fund, on our website.  
[www.musculardystrophyuk.org/research](http://www.musculardystrophyuk.org/research)



## Are proteins managed differently in people with FSHD?

We're very pleased to announce that, among our recent research grant awards, was our first-ever grant awarded to a researcher at Liverpool John Moores University.

Jatin Burniston is the Professor of Muscle Proteomics at Liverpool John Moores University. His expertise is in the field of muscle physiology, with a focus on how muscles adapt to exercise. In their work, Prof Burniston's team uses techniques to study the proteins in muscles – a field known as proteomics. Although Prof Burniston doesn't typically do research into muscle-wasting conditions, his proposal provided a novel insight into how proteins might be produced and broken down differently in people with facioscapulohumeral muscular dystrophy (FSHD).

In every cell of our body, our genes are used as a template to make proteins. Scientists refer to this activity as "expression". Generally, we would expect that the more gene expression there is, the more protein there will be. However, in people with FSHD, the expression of many genes in muscle does not match the production of protein.

A possible reason for this could be that, while proteins are produced normally, they are broken down (degraded) more rapidly in the muscles of people with FSHD.

This project, entitled "Aberrant protein degradation is a central mechanism of Facioscapulohumeral Muscular Dystrophy", will look at transcriptomics (the expression of genes) and proteomics of muscle cells taken from people with FSHD, and from their siblings who are not affected by the condition. Prof Burniston's team aims to investigate whether the degradation of proteins works differently in the muscles of people with FSHD compared to people without FSHD, and to determine the reasons why that happens. The project also seeks to test if a therapy designed to change gene expression can restore normal protein turnover in these muscles.

To our knowledge, this approach has never been taken in the investigation of FSHD. It is hoped that, while this is still very early in development, findings from the research may help scientists to develop new treatments for the condition.





## Julia Smith

Scotland and Northern Ireland

Barbara Morrow, a mum of two and keen triathlete from County Down, is taking on the Outlaw Half Nottingham in support of her swim coach, Jim, who has muscular dystrophy.

The triathlon on 15 May will involve a 1.2-mile swim, a 56-mile bike ride and a half marathon-length run.

"I've chosen to fundraise for MDUK to give back to a man who's supported me so willingly and kindly on my triathlon journey. I didn't really know much about muscle-wasting conditions before meeting Jim, who often coaches me despite really acute discomfort and pain. He never complains, and was delighted when I told him what I wanted to do!"

Barbara lives with an autoimmune disease, which means she has to be particular about how she trains, something Jim understands well.

"Jim was coaching the entry level swimmers and I'm sure his first impressions of my swimming weren't favourable. But he told me to keep coming along and trying my best, which I did. It was around that time that I found out Jim had muscular dystrophy and realised just how much effort he put in to come and coach twice a week."

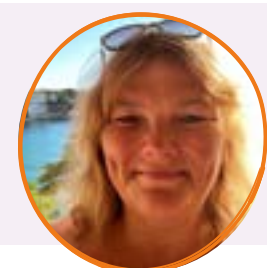
"I picked Outlaw as it's a family-oriented race and supportive of those at the back of the pack."

"Barbara's taking on an enormous challenge, and we wish her the best of luck with it. It's so great that she's fundraising for our cause," said Julia.

**You can donate to Barbara's fundraising page here:**  
[www.justgiving.com/fundraising/barbara-morrow70](https://www.justgiving.com/fundraising/barbara-morrow70)

### Key dates for 2022:

- **Kiltwalks:**  
Glasgow – 24 April  
Aberdeen – 29 May
- **Edinburgh Marathon Festival:**  
28 and 29 May
- **Scottish Coast to Coast Canoe (Loch Ness Canoe Trail):** 4-9 August



Get in touch with Julia on

✉ [j.smith@muscular dystrophyuk.org](mailto:j.smith@muscular dystrophyuk.org)

☎ 07341 560 324

## Charles Horton

Wales, West Midlands and South West England

For her 50th birthday 'treat', Melissa Domaille has set herself the challenge of running an ultra-marathon. She, and her husband Colin, who is a veteran ultra-marathon runner, have entered the Race to the King Ultra-marathon on June 11.

The event will take the two specialist physiotherapists on a 100k route along the South Downs, with a target of raising £2,000 for MDUK.

"The lovely Annie is the reason we've chosen this charity. Annie has the progressive neuromuscular condition, limb-girdle muscular dystrophy, and I've been working with Annie as one of her physios since July 2019. I'm totally in awe of her determination to be in control of her life and be an amazing mum to her 12-year-old son, Ruben."

Annie and Ruben, who also has muscular dystrophy, plan to join Melissa on a training run in April. They'll complete several laps of a local reservoir between them, with Annie in her powered wheelchair and Ruben on his bike.

"I have to admire the way Melissa's marking her 50th birthday, by doing something really positive and energetic. Running a 100km ultramarathon is not for the faint-hearted;

with Colin at her side to help her get over the line, I'm sure Melissa will accomplish what she set out to achieve. Good luck and thank you both – you'll definitely be making a real difference by raising so much in sponsorship," said Charles.

**You can support Melissa's fundraising here:** [www.justgiving.com/fundraising/melissa-domaille1](https://www.justgiving.com/fundraising/melissa-domaille1)

### Key dates for 2022:

- **River Wye Canoe Weekend:**  
27–29 May
- **Jurassic Coast Trek:**  
October TBC
- **Bournemouth Running Festival:** 8/9 October
- **18th Bolton Fundraising Concert:**  
19 November



Get in touch with Charles on

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☎ 01244 536551

🐦 @VfmHorton



## Julia Smith

London, South East and East of England

As someone who loves to play video games, Luke Hussey (pictured below left), a student from the University of Kent, has organised a fitting fundraiser: an in-person charity Fifa tournament specifically for people with muscle-wasting conditions.

"I like to play video games and I know a number of disabled people also play video games. When I watch esports tournaments for games such as Fifa, there are few players with muscle-wasting conditions taking part, so I wanted to create a tournament where those people could play against each other," said Luke.

The tournament is happening at 11am on Saturday 30 April at the Chipperfield Building at the University of Kent, Canterbury campus. Money raised from the event will be donated to our charity.

Luke, who comes from Gillingham in Kent and has Duchenne muscular dystrophy, says he likes to remain positive and tries to not let his condition limit him from achieving his ambitions and goals. He's co-hosting the event with his coursemate, Felix Rich (pictured right) – they're both studying sports and organising this event as part of their final-year assignment. They've arranged raffle

prizes and even got a sponsor on board: the Canterbury branch of Nicholas Humphreys Estate Agents.

Luke's parents used to run a local MDUK branch (the Medway branch), when he was younger.

"This is a brilliant, inclusive fundraising idea. We appreciate the time and effort Luke and Felix are putting into organising the event, and are thankful to them both for championing our cause," said Julia.

**Register for the event at:**  
<https://83987.aidaform.com/fifa-tournament> or scan the QR code

### Key dates for 2022:

- **Thames Source to Sea Community Challenge:**  
17/18 September
- **Royal Parks Half:**  
9 October
- **Great South Run:**  
16 October



## Susanne Driffield

North England and East Midlands

Triathlete Djalil Bailou, whose wife and son both have myotonic dystrophy, is preparing to represent Team GB in the gruelling Ironman World Championships, in support of MDUK.

The doctor from Nottingham hopes to get a podium place when he jets to Hawaii with his family in October for the "experience of a lifetime". When he came 10th in his first-ever Ironman in Barcelona in 2021, finishing in a speedy eight hours and four minutes, he earned a coveted place in the World Championships. Only the best athletes from around the world are invited to the challenge, which includes a 2.4-mile swim, a 112-mile cycle, and a marathon – within a maximum of 17 hours.

Djalil's wife, Emily, was diagnosed with myotonic dystrophy type 1 in 2009, and their son Isaac was born with the same condition. They also have an 11-year-old daughter, Zahra. Djalil hopes to raise awareness of MDUK and wants the donations to fund valuable research.

"Our lives will forever be affected by this degenerative condition, but we don't allow it to define us. We've adapted to the challenges that muscular dystrophy brings and try to

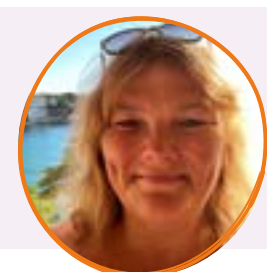
enjoy life to the fullest. This fundraiser is a way of giving back to a cause that helps people like my wife and son."

"This is a phenomenal, super-human achievement for Djalil, and we're so excited to see where the World Championships take him. We're so grateful he's chosen to fundraise for MDUK," said Susanne.

**You can donate to Djalil's fundraising page here:** [www.justgiving.com/fundraising/Djaz-Baiou](http://www.justgiving.com/fundraising/Djaz-Baiou)

### Key dates for 2022:

- **Hadrian's Wall Trek:**  
10/11 June
- **Lake District Ultra Challenge:**  
11 and 12 June
- **Total Warrior:**  
24–26 June



Get in touch with Julia on

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☎ 07341 560 324



Get in touch with Susanne on

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☎ 07825 845895

🐦 @s\_driffield



## Tikiboo partnership

The fashion fitness brand, Tikiboo, has launched two bright and bold muscle-themed activewear collections for a new charity partnership with MDUK.

And as part of our partnership, Tikiboo will donate 20 percent of all sales from their #MusclesMatter activewear to MDUK.

Four different designs – each themed around raising awareness of muscle-wasting conditions – will roll out during 2022.

The bright Chain Reaction collection is inspired by DNA sequencing, and the #MusclesMatter design features a unique muscular print. Sizes range from XXS-XXXL, and prices for the adult products start from £24.99. Children's products are available, with prices starting from £14.99. The final two collections will launch later this year.

Faye Jobbins co-founded Tikiboo with her husband Daniel.

"We're delighted to have created these new collections in support of Muscular Dystrophy UK. Our partnership is all the more special, given that Daniel has a friend who lives with muscular dystrophy, so having Muscular Dystrophy UK as our official 2022 charity partner was a no-brainer. We hope our bright and fun muscle-themed collections help raise vital money that will help the charity continue supporting individuals and families affected by these conditions," said Faye.

Martin Hywood, MDUK's Regional Corporate New Business Officer, was our internal lead for co-ordinating the charity partnership.

Over many months, Martin worked closely with Tikiboo and MDUK staff to collaborate on the activewear designs, which reflect perfectly the bold and bright nature of both our community and the fashion brand itself.

We are hopeful that our wonderful community of fitness enthusiasts and fundraisers will support MDUK and Tikiboo by purchasing the activewear, which you can also wear as comfortable

loungewear both in and out of the house.

"The synergy between Tikiboo and MDUK is fantastic. These designs are creative, bold and proud-to-be-seen, and the colourful patterns also reflect our diverse community and the bright minds of scientists conducting research into treatments and cures. Personally, I am over the moon with this partnership. I live with a muscle-wasting condition myself and feel proud to be seen in Tikiboo's bright colours, in my wheelchair. We are very grateful to the Tikiboo team for supporting MDUK, and we encourage everyone to help show that muscles matter by purchasing and wearing this fantastic range of activewear," said Martin.

**Find out more about this brilliant partnership.**

[www.musculardystrophyuk.org/corporate-partnerships/tikiboo](http://www.musculardystrophyuk.org/corporate-partnerships/tikiboo)



Freya Levy (pictured), an elite athlete and former Paralympian

## A day in the life of an event manager



*Jessie Keighley, MDUK's Event Project Manager for the Town and Gown 10k series, takes us behind the scenes on event day in Cambridge.*

My alarm goes off at 3.45am. I've roped Ed, my husband, into helping again, and along with Krishan Solanki, who heads our events team, we drive to the race site. It's pitch-black outside and absolutely freezing (it's October), so we put on our gloves, fix our head torches, and get to work.

First up we unravel the marquees, and drive around the course to put up tables and unload bottled water, before teaming up to erect the massive race arch. Meanwhile, a logistics team is busy marking the running route.

I brief the 40 event volunteers when they arrive at 6.30am, and then race around greeting and positioning suppliers, including first aiders and caterers.

There's a real buzz when the runners begin to arrive at 8am, and it's great to put faces to the names I've been chatting to on email.

My favourite part of the day is seeing the first runner cross the finish line. There's nothing better than the sense of achievement on their face while we check if they've broken a new course record. The fastest runners finish within half an hour; others take up to an hour and 45 minutes. I always take time out to cheer them on, while our volunteers do a brilliant job of handing out medals to the runners.

Once the last runner finishes, it's time to start packing down before driving back to MDUK in London ready to unpack in the morning. It's very labour-intensive, but it's worth every moment to raise money for such a great cause.

I then email the runners to congratulate them and encourage them to sign up for next year's event, and respond to lots of enquiries too. I usually come up for air about five days later, and then it's almost time to start on the next event.

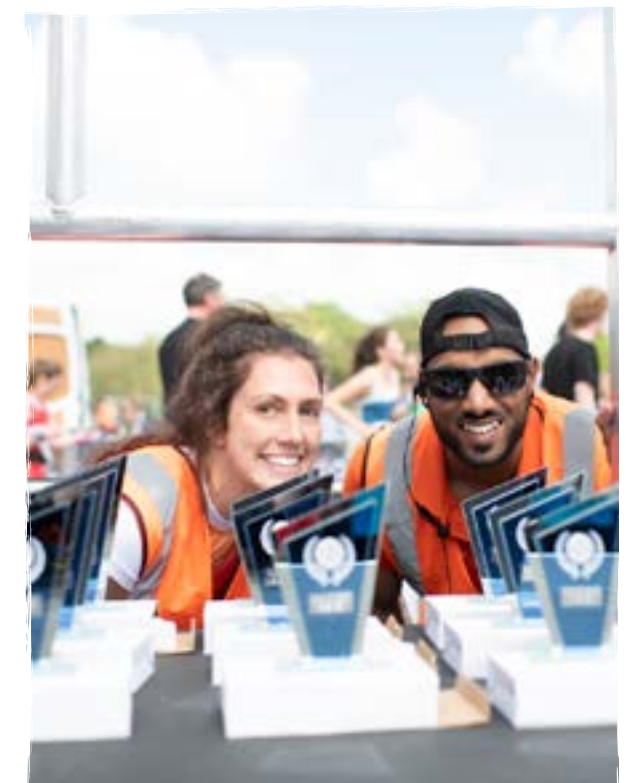
The most rewarding part is seeing everything

come together. It's 11 months from launch to event day, with site visits, meetings with key stakeholders, and more in between. Knowing how many people we've got over the line, and how much they've raised for MDUK makes it all worthwhile.

**Volunteer at the Town and Gown 10k:**

[www.townandgown10k.com/volunteer](http://www.townandgown10k.com/volunteer)

*"The most rewarding part is seeing everything come together."*





# Oxford

## Town and Gown 10k

Our Oxford Town and Gown 10k race, one of our community's favourite fundraising events of the year, will celebrate its ruby anniversary on Sunday 8 May this year.

The 40-year anniversary promises to be an event like no other, especially given that more than 5,000 runners will be back and pounding the streets of Oxford.

Local resident, Mike Cleaver, launched the Oxford run in 1982 as a way of giving back to MDUK. Michael's son Daniel had a muscle-wasting condition, and Michael wanted to help raise funds for the charity because of the amount of invaluable support MDUK had given his family.

The first race attracted 857 runners, who raised £8,300. And the 10k race has grown ever since. MDUK took over managing the event in 1995 to help with its growing popularity.

The race, with its glorious stretch along the River Cherwell and its University Parks finish, is a calendar favourite among both Oxford residents and the wider running community. This year's ruby anniversary will be more special than ever because it marks the first return to Oxford's streets since the pandemic.

In 2020, the race was cancelled altogether, and in 2021 it transformed into a virtual run, with runners competing from wherever they were in the country.

This year, we hope to raise £180,000, which will help MDUK to continue supporting people living with muscle-wasting conditions. A huge number of fundraisers are taking part, and we'd encourage you to sponsor anyone you know is taking part.

You can find out more about the route and event details at [www.townandgown10k.com/oxford](http://www.townandgown10k.com/oxford)



"This year's Oxford Town and Gown 10k will be better than ever, especially because we're celebrating its ruby anniversary! It's become a key date in the locals' calendars, and we have a lot of loyal runners. We attract a real range of people because we are the only closed-road 10k race in Oxford and it's a fast, flat course. It's also a perfect event for fun runners and it's appealing to the 'newer' runner too – it has a great atmosphere and I think the beautiful, historic route is a real pull too. There are a lot of dull courses out there, but Oxford Town and Gown 10k is definitely not one of them!" said Jessie Keighley, MDUK Event Project Manager – Town and Gown 10k series.



Get onboard with us for this celebratory year at the Oxford Town and Gown 10k:  
[www.townandgown10k.com/oxford](http://www.townandgown10k.com/oxford)



# Doing something special for MDUK

Frances Carey

I am honoured to be a relatively new Vice President at MDUK as a result of my support over the years and my personal connection to the charity via my sons who have Becker muscular dystrophy which inspired me to organise a fundraiser for MDUK.

I can't sew, bake, cycle or run, but I wanted to do something special. As I love dressing up, going out and having fun, I came up with the idea of a ball. I wanted it to be something I could enjoy with all my friends and family.

Whilst it was hard work getting people to buy tickets and organising prizes for the raffle and auctions, I had lots of help and support from Debbie, Head of Donor Relations, and her team, and between us we organised a fantastic evening.

The ball was cancelled three times due to COVID, so when it finally went ahead everyone was hell bent on having a good time, which I can assure you they did! The feedback was very positive, and we raised an amazing £29,000!

When I say people enjoyed themselves, I really mean it: a Scottish friend was doing cartwheels on the dance floor in his kilt, everyone was up dancing and having fun. It was fun to organise with Debbie and her team, and many of my friends and acquaintances supported me by attending, donating prizes and by buying raffle tickets and auction items.

In my slightly younger days, I ran the London Marathon for MDUK, and I can honestly say organising the ball was much more fun!

If you'd like to arrange an MDUK fundraiser like Frances did, we'll support you by managing the whole event, leaving you to host and have fun with your friends, family, and colleagues. Find out more by getting in touch with Debbie Hoods, Head of Donor Relations, at [d.hoods@musculardystrophyuk.org](mailto:d.hoods@musculardystrophyuk.org)





# Puzzles

## page

Joshua Azizollah, our puzzlemaster



Just a big wordsearch this time – be careful, there may be some false trails!

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

Advocacy  
Certificates  
Challenge  
Chris Boardman  
Climate change  
Comedy  
Donation  
Electric cars  
Go Bright  
Jon Richardson  
Local  
Mr Motivator  
Nominees  
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