TARGET MD

Edition 1 of 2, 2019

The emotional impact of living with muscular dystrophy

Working together - the huge difference your support makes

Transforming lives through research: news and updates

Muscular Dystrophy UK
Fighting muscle-wasting conditions

Muscular Dystrophy UK's lifestyle magazine
Helping you to live well with muscular dystrophy

Contents

On the cover

Hayley Lloyd, who shares her story on p4 about the emotional impact of living with muscular dystrophy © Roger Moody/MDUK

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Hello

Welcome to the new-look *Target MD* magazine! Taking your valuable feedback into account, we've brought you more lifestyle stories and glimpses into people's lives, as well as a range of stories that reflect the huge difference your support makes. And this first new edition comes with a special treat for you: Catherine Woodhead, our new CEO, is our guest editor!

Enjoy the read, and thank you for all that you do to help MDUK make every day count for people living with muscle-wasting conditions. Do let us know what you think of the new look and feel – we'd love to hear from you.

Ruth

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GUEST EDITOR

I'm delighted to welcome you to this spring edition of *Target MD*. It is wonderful to see Hayley on the front cover; I am truly grateful to her, Louise and Joe, for sharing the effect that living with a muscle-wasting condition has had on their mental health. I'm sure this will resonate with many of you, some of whom are campaigning with us to raise this on the national agenda to get better support.

We are always pleased to hear about the support, information and resources individuals are receiving to live well with their condition, and I'm committed to working in partnership with other organisations to improve the lives of people living with muscle-wasting conditions. I do hope you enjoy reading features about this in the magazine.

Last year we welcomed our new President, Gabby Logan. Many of you will have seen Gabby at our National Conference in London or seen her video message at the Scottish Conference in Glasgow. She is already assisting us to develop new partnerships and we look forward to working more with her throughout the year.

As we mark 60 years since MDUK was established, this year, we're asking you to tell us who deserves recognition with a President's Award for making a difference. If you received your magazine in the post, you'll find a nomination form enclosed. If not, you'll find all you need to know on our website at www.musculardystrophyuk.org/Presidents-Awards-2019

Nominations close on 1 July and Gabby is looking forward to presenting the Awards at our National Conference in London on Saturday 12 October. Please do join us and book your place today!

We simply couldn't do what we do without you. So let's celebrate your amazing achievements with our annual President's Awards, let's continue to share your amazing stories in these magazines, and let's continue to work together, to make every day count. Thank you.

Catherine

Catherine Woodhead
CEO, Muscular Dystrophy UK

I TRY TO KEEP POSITIVE AND LIVE FOR THE PRESENT

Tommy and Hayley Lloyd © Roger Moody/MDUK

Hayley Lloyd is a single mum living in Warwickshire with her 13-year-old son, Tommy, who has limb girdle muscular dystrophy, LGMD2E. Working in fundraising at an international development charity, Hayley found it difficult to juggle a stressful job and Tommy's condition. Two years ago, Hayley took a huge jump and resigned.

Over the years, Hayley and Tommy have done extraordinary, fun, innovative and effective fundraising for MDUK. Now self-employed, Hayley also volunteers for MDUK on our Content Advisory Group, and represents the charity by sharing her story at a number of events. It's hard to imagine she has time for anything else, but Hayley also enjoys keeping fit, dog-walking and writing. Tommy loves gaming and cooking.

Here, Hayley tells us what it means to live with a muscle-wasting condition, and what the emotional impact is on her too:

In 2012, Tommy was diagnosed with LGMD2E after two years of investigation into his toe walking. After trying leg plasters and special boots to get his toes down, Tommy was given a blood test, which showed an elevated level of CK*. This indicated muscular dystrophy.

Tommy was six when he got this diagnosis, and I think at 13 he's doing brilliantly. His consultant told me Tommy would be in a wheelchair full-time by his mid-teens. Although he does need a wheelchair for long distances, he can still walk short distances. He isn't able to climb stairs, get off the ground (by himself) and he falls regularly. I've lost count of the number of times we've been at A&E.

MDUK has been a support and help to me and all my family, since Tommy's diagnosis. They have helped me with fundraising, with supporting communications for Tommy's Education Health and Care Plan (EHCP) application, with event days to meet other families with muscular dystrophy, and with help answering research questions.

"I can do things, Mum, I'm fine

Although Tommy now struggles getting up from a chair and dressing himself, he's very determined and will always say, "I can do things, Mum, I'm fine,"

***creatine kinase – a type of protein found in muscle, which leaks into the bloodstream when muscles are damaged because of disease or injury**

but that isn't the reality. He can't keep up with his friends; he can't play sports or do PE at school. He is fighting against his condition.

As a teenager, Tommy wants to be like everyone else his age. He hasn't really accepted having to use his wheelchair. He doesn't want people to see him in it – he says he's embarrassed. It becomes very difficult, when all I want to do is make things easier for him and he'd rather struggle and be in pain.

I try to keep positive and live for the present

Living with a child with muscular dystrophy has affected me significantly. It's all-consuming. I found juggling a stressful job and Tommy's condition difficult, so two years ago I made the huge jump to resign. Since then I've been self-employed and have done some contract work.

Tommy has time off school for falls, for physio appointments, consultant appointments and for school review meetings too.

It would be impossible for me to be employed with the amount of time I'd need off, and unfortunately, I don't have a partner to support me with this.

I try to keep positive and live for the present. We also try to laugh a lot. But I have been seeing a counsellor since Tommy was diagnosed. I still see her monthly, and it's a godsend for me.

It's a time when I can cry, get angry or just talk about how I feel. I have also started to suffer with anxiety too, which has completely floored me for weeks at a time. I have received help from the GP with this.

Diagnosis is scary

If you're facing a new diagnosis of muscular dystrophy, I'd say to you that diagnosis is scary. I felt helpless; guilty that I couldn't do anything to change the situation. It's important to be gentle with yourself. Every emotion is temporary and there are more good days than bad as time goes on.
Life is about adapting, doing things differently. And we try to do this as best we can.

Counselling really helps me, although I have to pay for it myself. I asked for help for Tommy through the GP, but Child and Adolescent Mental Health Services (CAMHS) has told me they only deal with children with mental health problems. They referred me to MDUK or to his school for support.

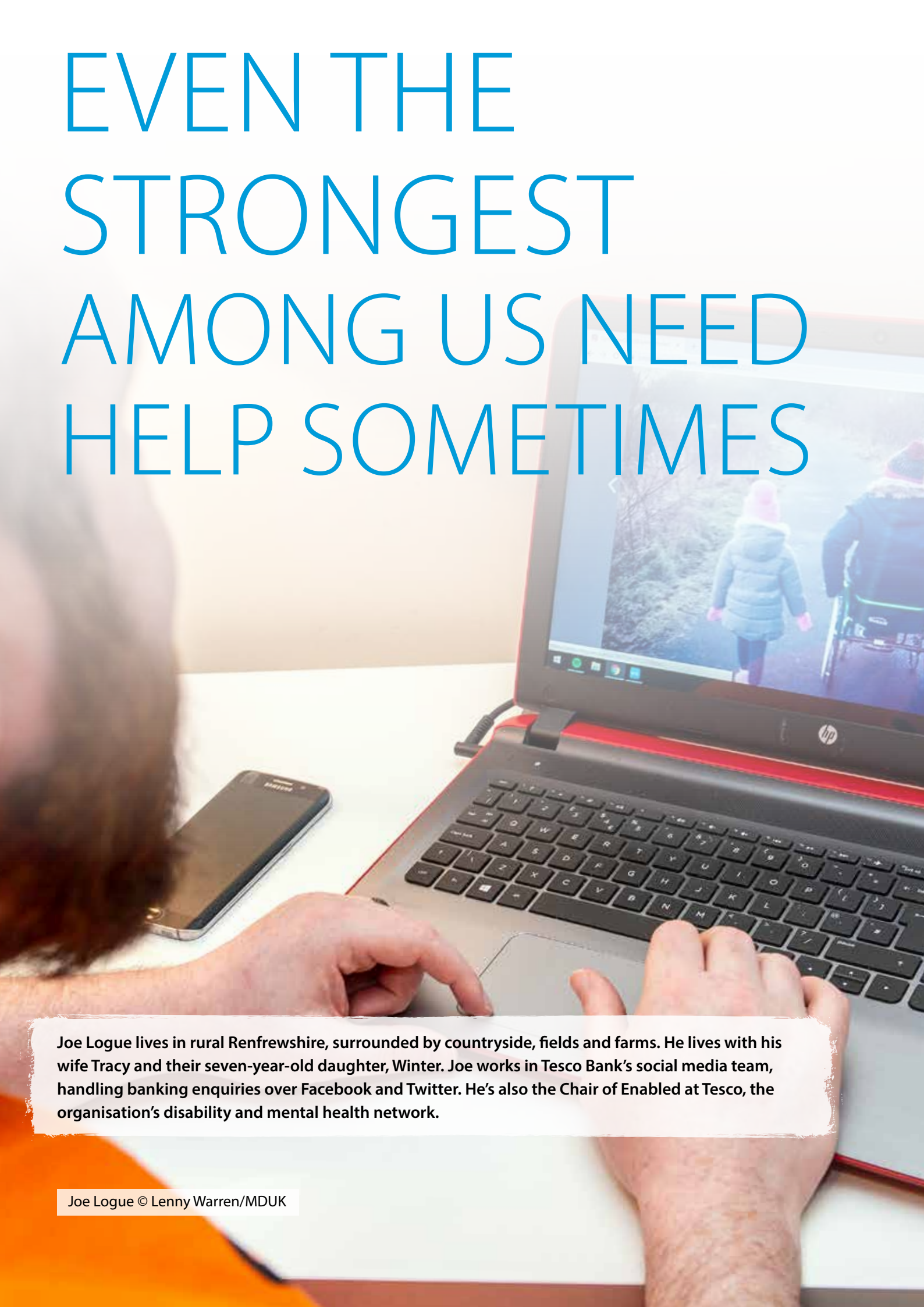
Our children need emotional and psychological help too

Mental health really matters. As parents, we're petrified of how our children feel, knowing they have a progressive muscle-wasting condition. I can't imagine how that feels and I'm Tommy's Mum. Without a service, an outlet to express his feelings, I fear depression, anxiety and, sometimes, even worse.

That's why MDUK's campaign to improve access to emotional support for adults and children living with muscle-wasting conditions is so important. Our children don't just need physical help, they need emotional and psychological help too. Being able to talk about their condition, about how they feel, and expressing their anger or frustrations is so important.

Find out how MDUK can help you get the emotional support you need at www.musculardystrophyuk.org/mental-health-matters

EVEN THE STRONGEST AMONG US NEED HELP SOMETIMES



Joe Logue lives in rural Renfrewshire, surrounded by countryside, fields and farms. He lives with his wife Tracy and their seven-year-old daughter, Winter. Joe works in Tesco Bank's social media team, handling banking enquiries over Facebook and Twitter. He's also the Chair of Enabled at Tesco, the organisation's disability and mental health network.

Joe Logue © Lenny Warren/MDUK

When he's not working, Joe enjoys writing poems and stories and using his experience of disability and mental health to connect with others. He's started a blog and an Instagram page named Dystrophy Dad, where he shares stories, poems and photographs illustrating the life of a person with Becker muscular dystrophy.

Joe shares with us his thoughts about what it means to live with Becker muscular dystrophy, and the emotional impact it has on him.

I was diagnosed shortly after birth, through a muscle biopsy. My grandfather had a spontaneous mutation of the condition, and my mother was a carrier, so it was expected that I would have the condition. My mother sat me down when I was three and explained that I was different and that when I grew up I would be just like my grandad. He was my hero, so I thought, why wouldn't I want to be like him?

I am still able to walk short distances using a walking stick, although some days are harder than others. At work, and on my worst days, I use my wheelchair. Adapting to the chair was a difficult transition for me but it helps if I view it as something I can use, rather than something I need to use. I find it hard not being able to keep up with my daughter, but we find things to do that aren't so physical, such as reading, creating stories together and playing video games.

The way it's affected my mental health cannot be understated

Muscle weakness is of course a major factor of the condition, but the way it has affected my mental health cannot be understated. I experience depression and anxiety but I see these feelings for what they are: transient, fleeting and far from the entirety of me.

With a progressive condition, you will mourn the life you haven't lived and with each stage you will experience the frustration of living in a body that doesn't want to co-operate with you. I have concerns for my own future and live with the knowledge that my child is a carrier.

I have the good fortune of having a loving wife who can tell when the condition is talking. I know

Tracy, Joe and Winter © Lenny Warren/MDUK

it isn't easy for her but we're in this together, as she likes to remind me.

My friends are used to it, so it's normal for them. If they see me struggling, they're quick to help, but I never miss out on social engagements due to my disability. Life has brought more interruptions than my condition ever has, so it hasn't impacted my friendships.

My workmates have been more than supportive, providing assistance when I need it and most recently banding together to raise £240 during 'Go Orange for a Day' for MDUK.

Even the strongest among us need help sometimes

Mindfulness and self-expression are my main coping strategies. I'm able to assess my own anxiety levels and know when I need to ask for help. Expressing my emotions through the written word has been most helpful; it gives me a sense that the pain I experience is not without purpose, and that I can take something destructive and create something beautiful.

Find out how MDUK can help you get the emotional support you need at www.musculardystrophyuk.org/mental-health-matters

I have been prescribed anti-depressant medication in the past, and found to be of great use. I urge anyone affected by this condition not to let the stigma of mental health prevent you from getting the help you need. Even the strongest among us need help sometimes.

The only support I feel I need, is the willingness of others to learn about my condition and not to see me as 'less' due to the fact I'm in a wheelchair. I am often spoken to in a patronising manner, with the assumption that a wheelchair is indicative of someone who is deserving of pity and 'a poor wee soul'. I am disabled but I have the same wants and desires as anyone else; I am fallible and that's a good thing. It's our flaws that make us human.

> **I wanted to make a difference and break this stigma**

Enabled at Tesco was established with the objective of destigmatising disability and mental health. This agenda extends to those with conditions, to carers and to those with family and friends affected by disability and mental health.

Several years ago, I experienced an anxiety attack at work brought on by the advancement of my condition. I was signed off for six weeks. This was the first time in my life that I felt this condition's impact on my mental health, and when I realised how important it was to look after your mind as well as your body. I knew from this point I wanted to make a difference and break this stigma.

When I became aware that Tesco Bank was developing a network for colleagues with disabilities, I knew I had to be involved. I put forward the suggestion that this new network would encompass both disability and mental health, as the two can be closely linked. I was later appointed to the position of Network Chair.

I now feel that my experiences have meaning and that by talking about them, I've encouraged others to do the same. My friend and team mate, who until that point had told few people, was inspired by my example to be more open about living with autism. This showed me the true power of sharing stories.

> **Muscular dystrophy will affect your mind in ways you may not expect**

Muscular dystrophy doesn't only affect your muscles, it will affect your mind in ways you may not expect. I would like MDUK and others to normalise this by encouraging people to talk and share their experiences, and ensure that mental health is referenced in any supportive literature given to those and the families of those who are newly diagnosed.

To those newly diagnosed, I'd say it isn't going to be okay and that's okay. For parents, I'd say, remind your child of what they can do, not what they can't. For children and those newly diagnosed I would say, you are not your disability, you can live a fulfilling life, you can form relationships and find love, and a life with a muscular dystrophy.

You can follow Joe on Instagram here: www.instagram.com/dystrophydad

AN EVER-CHANGING PROCESS OF GRIEF AND LOSS

Louise Halling, her husband, Mark and their seven-year-old son, Jacob, live in West Berkshire. Jacob was born in Australia, where the family lived for several years. Diagnosed with limb girdle muscular dystrophy 20 years ago, Louise talks about the emotional impact of the condition on her life, and on her family. She also talks about starting her own online counselling practice, and the reward it brings her and clients from all around the world.

I was diagnosed with limb girdle muscular dystrophy (LGMD) at 20, when it became apparent my left calf muscle had wasted. At the same time, my mum was diagnosed with LGMD, having been mis-diagnosed many years before. There was initially little impact on my life. I backpacked around India with friends and lived a full life at university.

My condition now affects every day of my life. My mobility is significantly impaired. I can still walk without aid around my own home – furniture- and wall-surfing is my mode of transport! Outside of the home, I am more restricted, although deeply thankful that I am able to drive an automatic car. For short distances, I use a rolator, and occasionally crutches where steps are involved. For longer distances, I need my mobility scooter (affectionately named, 'Brian') or someone to push me in a manual wheelchair.

My life revolves around thinking about and managing access everywhere I go. I do struggle with persistent pain, particularly in my neck and shoulders. My energy levels are well below normal and have been for a long time.

> **It is a cycle, which ebbs and flows like the ocean**

It's an ever-changing process of grief and loss. The emotional impact of having lived with this condition for half of my life is now immense. It's a life-long, ongoing, ever-changing process of grief and loss. All the emotions associated with grief are involved in learning to live with it – shock, sadness, anger, fear, depression,

Louise, Jacob and Mark Halling © Chris O'Donovan/MDUK

acceptance. It is a cycle, which ebbs and flows like the ocean.

The impact on my family is massive too. It's hard to watch a loved one suffer and struggle, and be powerless to change that. My husband knew when he married me 15 years ago that I had this disease and what it might mean. My son knows his mummy is different to other mums, and that there are lot of things that mummy can't do. It's hard. And it matters.

When I realised that my intrusive, daily, thoughts of 'I can't manage', 'I can't do it', 'I can't cope', and 'this is too hard' were beginning to impinge on my mental wellbeing, I reached out specifically for help with a low-dose antidepressant from my GP. For me, this medication helps me manage living with loss on a daily basis. It's not for everyone but it's helped me a lot.

Allow the grief to take place

I have also had a few seasons of counselling, which I have found invaluable and totally validating. After all, when we lose someone we love, we wouldn't hesitate to consider having grief counselling. So why should the loss of muscle function and independence be any different?

The shock of a new diagnosis is never easy; it's important to treat yourself as you would a best friend. Expect to feel completely overwhelmed and allow yourself the space you need to process the grief you feel and are likely to continue to feel.

I've found that the best possible way to cope and learn to live with this disease is allowing the grief process to take place. It's painful and challenging, but it helps me to reach a sense of acceptance and in that, a fullness of life.

It helps to be around people who are empathic, friends and family who, rather than jumping in with 'positive thinking' mantras or desperation to fix things, are able to say, like Alice in Wonderland, 'When you can't look on the bright side, I will sit with you in the dark'.

I also manage my condition by swimming at least three times a week, having chiropractic

for my neck pain, and acupuncture to target and strengthen my immune system.

My faith also sustains me, along with the associated practices of mindfulness, meditation, prayer and contemplation. Having a local and global community of 'soul friends', good friends and the support of my family are also invaluable to me. I qualified as a counsellor in 2008, and since

> **I love that I'm able to make a difference in the lives of my clients**

returning to the UK in 2015, I've taken the bold step of setting up a private practice. I launched a counselling business, which functions 100 percent online, via video call, and business is thriving!

I love what I do and I love that I am able to make a difference in the lives of my clients. I offer 55-minute sessions and try to see about two to three clients per day. I'm fortunate that I can do my entire job from one room and yet meet with people from all over the world at the press of a button. It's the ideal job for someone with a significant, life-limiting disability! And it gives me such a sense of purpose.

Over the last few years, I have seen and continue to see several clients with disabilities, or their family members or carers. For the sessions, all the client needs is a private, uninterrupted time and space with a decent internet connection. No need

to struggle out to yet another appointment, they can have a session from the comfort of their own home. There's also no power imbalance in terms of coming into another person's 'space'.

Before I began working in this way, I was anxious that it would be harder to build a real relationship with my clients, something that is very important to the counselling process. But quite the opposite: clients often feel empowered to be open and honest and the relationship goes deep and with real feeling in a way that I didn't necessarily expect.

> **This is a journey of loss**

I'm fully behind MDUK's Mental Health Matters campaign. In my opinion, the key for psychological support must be to recognise that for many people with muscle-wasting conditions – regardless of the circumstances – this is a journey of loss. Loss of muscle. Loss of independence. Loss of dreams for the future. Potentially even, loss of the future. Loss of a loved one. Loss of function. Loss of possibility. Loss of financial security in many cases. I believe grief has to be at the centre and forefront of any treatment.

HOW WE'RE HERE FOR YOU

We understand that muscular dystrophy or an associated condition changes everything. That's why our advocacy team is here for anyone who is affected, right from the moment of diagnosis and beyond, to take back some control of their lives and to live well with the condition. We understand the everyday challenges of living with a progressive condition, including the impact it can have on your mental health. Our team can support you with information and advice, together with emotional and practical support.

When you need access to what you're entitled to, get in touch with our advocacy team. They can help you to get statutory support such as social housing, care and equipment, or help you appeal unfair decisions on benefits such as Personal Independence Payments (PIP), Universal Credit and Attendance Allowance.

Here are some examples of people we've supported.

Rebecca tells of her relief after a tribunal ruled in her favour when she appealed their decision. She said she would have given up had it not been for the support she received from the advocacy team, as well as her partner, friends and family.

For a year I battled and battled

After being diagnosed with myotonic dystrophy three years ago, Rebecca had had to give up her job. After a re-assessment, her ESA entitlement was reduced from £125 per week to £72 per week.

Rebecca got in touch with us to support her as she appealed against a decision on her Employment Support Allowance (ESA). We provided additional information about her condition, and composed a supporting letter giving evidence that Rebecca's entitlement to ESA should not have been reduced.

It took over a year to get to an appeal tribunal. When that eventually happened in September 2018, the decision went in her favour. "For a year I battled and battled," she said. "The Appeal process is so difficult, especially when you feel like I felt.

"My condition affects everything I do and I am in

pain every day. Since I was diagnosed, my life has completely changed."

The advocacy team has seen a marked increase in benefits cases over the past few years. The team handles around 80 cases a month. of which 11 relate to statutory benefits.

There are 11 people in the advocacy team, some offering support from the charity's London office on the phone and online, with others supporting people in clinics around England, Scotland, Wales and Northern Ireland.

I had first applied for a Blue badge in February

Derrick was diagnosed with inclusion body myositis (IBM) in March 2014, after having noticed a weakness in his grip. As his condition has progressed, Derrick has started to use a wheelchair for visits to restaurants or to sit at the table when other chairs are too low. Increasingly he uses the wheelchair when he has had a fall: "I had a fall in January and had to use the wheelchair for seven days continuously, but I can normally get about the house using a walking stick."

He feels very supported by the charity who, he says, recently supported him when he applied for Attendance Allowance. He'd previous approached the team for help with his application for a Blue Badge.

"I had first applied for a Blue Badge in February 2014 but was refused and reapplied two years later in June 2016 and was again refused. So I asked MDUK to assist me, and they succeeded in getting me one.

"They have also sent me a copy of the *Adaptations manual*, which contains really helpful advice and information about specialist equipment I've needed to get.

Wonderful support from MDUK

"The wonderful support from MDUK has helped me understand how my condition is likely to progress and what steps I can take to adapt and adjust to

the slowly changing situation. Plus, they've helped me to keep mobile and able to live a reasonable life. I remain cheerful and carry out the exercises recommended by my various physios and helpers to maintain my independence for as long as possible."

Every day counts when you're living with a progressive muscle-wasting condition. Our advocacy team is here with free advice and support to help you get the care, support and equipment and to make every day count.

Call us free on 0800 652 6352 any time on Monday to Friday between 8.30am and 6pm. Or email info@musculardystrophyuk.org

LEAVE A GIFT IN YOUR WILL TO CREATE A future free 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 Catriona Parker on **020 7803 4834** or email **legacy@musculardystrophyuk.org**

www.musculardystrophyuk.org/giftsinwills

SMA TREATMENT SPINRAZA IN THE SPOTLIGHT

There has been much activity over the past months to push for access to Spinraza, the first drug for people with spinal muscular atrophy (SMA). Here's a summary of the latest news in the fight for access to this life-changing treatment.

Access update

In early March 2019, along with SMA UK, TreatSMA, clinicians and families, MDUK attended the third NICE committee meeting on Spinraza, to ensure the patient voice was well represented by those present. The outcome of the meeting will follow, so please keep an eye on our website for any news. We will also keep all SMA families updated by email.

It was announced in February that access to Spinraza would be extended on the NHS in Scotland for children and adults with SMA Types 2 and 3. Families in Scotland have welcomed the news that individuals and families are able to receive this life-changing treatment from April 2019.

It was approved through the new ultra-orphan pathway assessment process for the rarest conditions, which was set up in October 2018 by the Scottish Government. It follows the approval for people with SMA Type 1 to access treatment on the NHS in Scotland from May 2018.

We look forward to hearing more news in due course.

Minister meeting

We met with Health Minister Baroness Blackwood in March to discuss access to Spinraza and NICE's appraisal processes for future rare disease treatments. The Minister committed to working closely with MDUK when NICE's appraisal routes were reviewed.

Media coverage

The campaign for access to Spinraza has been featured in national, broadcast and regional media. This wouldn't have been possible without the support of families across the UK, who have shared their personal stories with us.

Some of the key coverage included an open letter, published by *The Guardian*, from 30 clinicians involved in the care of children and adults with SMA. The letter highlighted the clinicians' frustration at an effective treatment being out of reach. The signatories, including consultants, physiotherapists and nurses, joining MDUK and SMA UK in asking NICE to show flexibility.

There were also interviews with families and MDUK spokespeople on *BBC News*, *ITV News*, *The Mirror Online*, *STV News*, *the Scotsman*, *Metro Online*, *The Sun*, *Mail Online*, *ITV London*, *BBC East Midlands Today*, *BBC Look North*, *ITV Calendar*, *ITV Granada*, *BBC Radio York* and *BBC Leicester*.

We would like to thank all the individuals and families who have been campaigning so tirelessly for access to Spinraza, writing letters, attending meetings and generally making your voices heard. We will keep fighting alongside you to make this life-changing treatment available.

More at www.musculardystrophyuk.org/spinraza

PRESSING FOR THE BEST CARE FOR PEOPLE WITH MUSCLE-WASTING CONDITIONS

MDUK has awarded Centre of Clinical Excellence status to 17 centres UK-wide that support people with muscle-wasting conditions.

These awards recognise excellence across a range of criteria, and help to drive up the standards of clinical support for people with muscle-wasting conditions.

A panel of health professionals and patient representatives developed the criteria for the awards, while patients shared their views online and at Muscle Groups. The criteria helped determine which centres were delivering the very best care.

What are Centres of Clinical Excellence?

The Centres of Clinical Excellence awards' review began in 2012 and takes place every three years. It involves a rigorous assessment of services by experts, with our Services Development Committee leading the review process. The committee, chaired by Baroness Thomas of Winchester, includes leading neuromuscular clinicians, patient representatives and a specialist NHS commissioner.

Which centres have received Centres of Clinical Excellence status?

The following centres have been recognised:

- Addenbrooke's Hospital, Cambridge
- Alder Hey Children's NHS Foundation Trust, Liverpool
- Heartlands Hospital, University Hospitals Birmingham NHS Foundation Trust
- Bristol Royal Children's Hospital
- North Bristol NHS Trust
- Evelina Children's Hospital, London
- National Hospital for Neurology and Neurosurgery, Queen Square, London
- Great Ormond Street Hospital, London
- John Walton Muscular Dystrophy Research Centre, Newcastle
- Leeds Teaching Hospitals NHS Trust
- Oxford University Hospitals NHS Foundation Trust
- The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust, Oswestry
- Manchester University NHS Foundation Trust
- Sheffield Children's NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- Walton Centre NHS Foundation Trust, Liverpool
- Wessex Neurological Centre, University Hospital Southampton NHS Foundation Trust.

In addition to the 17 recognised as Centres of Clinical Excellence, there are other muscle centres that provide very good quality care but narrowly missed out on a few of the audit designation criteria.

Rob Burley, MDUK's Director of Campaigns, Care and Support, said the centres deserved the recognition for their role in ensuring people with muscle-wasting conditions had the best possible healthcare near where they live.

"We would like to congratulate all centres who have been awarded Centres of Clinical Excellence status. It is deserved recognition of the comprehensive service they provide for people with muscle-wasting conditions and the work they do in promoting best practice, ensuring patients have access to the best possible healthcare near where they live. Improved clinical care means faster access to treatments and potential cures.

"As the leading charity improving standards in muscle centres, we want to make sure everyone living with a muscle-wasting condition gets excellent care. We will continue to work with all centres to ensure this ambition is realised."

To find out more about the Centres of Clinical Excellence, Awards please get in touch with David Stephenson at d.stephenson@musculardystrophyuk.org or on 020 7803 4826.

LIVING INDEPENDENTLY WITH ALEXA

Alexa is a virtual assistant device that lets you instantly play music, control your home, get information, news, weather and more – using just your voice.

For hundreds of people like Arryn, who is 20 and lives in Stirling, owning an Alexa is life-changing. It gives him the independence to do the simple things most people take for granted. Like turning off the lights when he wants to go to sleep and switching on the TV without asking someone else to do it for him. Arryn has Duchenne muscular dystrophy and has just been awarded one of the new Joseph Patrick Trust (JPT) grants for smart home technology.

> **My bedroom is like my own home**

Arryn said, "Unless I am at college, playing Boccia or Powerchair football, my bedroom is like my own home, which I spend a fair bit of time in. Having the use of Alexa in my bedroom has really helped, where now I have the independence of being able to turn lights on and off, switch my TV on or off, change channels and games all by my voice.

"Alexa can even understand what I am saying when using my night-time ventilation! Also now my parents can 'drop in' on my device, allowing them to not just talk to me but actually see me as well – like a video call – which is great as there is no requirement for me to press any buttons as you would when using a mobile phone."

Arryn with his sister Mia

The JPT is MDUK's grant-giving arm, the aim of which is to promote independence and quality of life. It awards grants to adults and children with muscle-wasting conditions towards the cost of equipment not available through statutory services, including wheelchairs, scooters, and mobile arm supports, as well as communications-based assistive technology, including devices such as Alexa.

You can now apply for funding towards a range of household equipment, large and small, that can help make home life that little bit smoother.

The JPT meets four times a year to assess applications.

CORNISH MOTHER AND DAUGHTER POWERING AHEAD

Annette and Amy Lee-Julian share more than most mothers and daughters. They both have a real passion for the training and skills development needed to play Powerchair football and they both have the same muscle-wasting condition, Charcot-Marie-Tooth disease (CMT) Type 2.

Both found joy when they discovered what is now the fastest growing disability sport in the UK.

> **The social side is absolutely fantastic!**

The duo, who have been playing Powerchair football for five years, say the sport has given them independence and has changed their lives 100 percent.

"With severe disabilities, this is the only competitive sport we can take part in," said Annette. "The games are incredibly good fun and we get to meet hundreds of new people. The social side is absolutely fantastic."

Although the family live in Cornwall, they are happy to travel to Nottingham Trent University five weekends a year to play in the MDUK National Championship league matches. They also train in Cheltenham, where they play for Cheltenham Regionals and the South West All Stars National Team.

We're a very determined mother and daughter

Both Annette and Amy are the proud owners of 'Strike Force' chairs, which cost more than £9k each. They bought them with JPT grants. The two have also developed a brand new Cornish Powerchair Football Club where they are training eight 'newbies.'

"At the moment we have plenty of members but not the chairs! It's a huge effort to get funding for them but we are a very determined mother and daughter," said Annette.

It really changes people's lives

"Powerchair football is much more than just a game. It brings disabled people and families into a world they didn't know existed and opens their eyes to how life can be. The sport has created countless friendships, competitive rivalries, memories and even marriages – it really changes people's lives. MDUK is proud to support Powerchair football, and we wish all competitors the very best of luck for the rest of the season," said Ryan Sipple, MDUK's Sports Development Officer.

What is Charcot-Marie-Tooth disease (CMT)?
CMT is a group of genetic conditions affecting the peripheral nerves, which connect the brain and spinal cord to the rest of the body. It is commonly referred to as hereditary motor and sensory neuropathy (HMSN), which refers to its two primary features: it is hereditary and affects the function of the motor and sensory peripheral nerves. This leads to weakness and wasting of the muscles below the knees and often those of the hands. It can also cause numbness or loss of feeling in the hands and feet.

Amy and Annette

To find out more about the JPT's grants towards specialist equipment, please call Alice on 020 7803 4811 or visit www.musculardystrophyuk.org/jpt

To experience the thrill of the competition or the sheer joy of being part of a team, give Powerchair football a go. Find out more and where you can play at www.musculardystrophyuk.org/powerchairfootball

CHANGING PLACES UPDATES

Changing Places toilets differ from accessible toilets in that they have a hoist, changing table and enough space for two carers, as well as a wheelchair. Standard accessible toilets meet the needs of some disabled people but absolutely anyone who needs assistance to use the toilet needs a Changing Places toilet.

Every little helps…

Visit Tesco at Ryde Extra, Fareham or Aylesbury Superstore and you'll find a smart brand new Changing Places toilet. By the end of March 2019, Tesco had installed more than 30 of these in areas deemed to have the greatest need.

None of this would have been possible without the dedication of Changing Places toilet campaigners, pressing for facilities to be more widely available across the UK.

> **More Changing Places toilets are desperately needed**

Kerry Thompson, a campaigner from Milton Keynes, has played a key role in this.

"Sharing my story with Tesco and being part of this truly amazing project has been a privilege. Being involved from the start, I've seen how passionate everyone involved has been in bringing this scheme to life. For a company as big as Tesco to recognise the lack of Changing Places toilets is wonderful."

Why do these toilets matter?

With still relatively few Changing Places toilets available, disabled people are forced to sacrifice their dignity and independence every day.

This may mean they just don't leave home, or purposefully dehydrate themselves. In other extreme cases, people have opted to have surgery to remove the fear of needing a toilet when out and about.

What is the Changing Places campaign?

This dire situation, shared by over 250,000 people in the UK, resulted in the launch of the Changing Places campaign in 2006. In 2017, MDUK took over as co-chairs of the Changing Places Consortium, alongside PAMIS, a Scotland-based charity that supports people with profound and multiple learning disabilities.

MDUK and campaigners are pushing to make Changing Places toilets a mandatory requirement under Building regulations for all large public buildings, and a consultation is expected to be launched later this year.

Important news

In December 2018, the Government announced it would be consulting on changes to Building Standards, which would require all new publicly accessible buildings to provide Changing Places toilets. They also announced £2m funding for more Changing Places toilets in NHS hospitals and, last summer, the Department for Transport committed £2m to fund the installation of Changing Places toilets at motorway service stations. We'll be working with the DfT on this project, launching in the spring.

If you'd like to share your story, or get involved in the Changing Places campaign, do get in touch with Clare at c.lucas@musculardystrophyuk.org or 020 7803 4838.

MAKING LIFE THAT LITTLE BIT EASIER

Tiffany Watson got in touch with MDUK in 2018, to seek help with her first assessment for Personal Independence Payments (PIP). Emma Jeremy, MDUK's Advocacy and Care Co-ordinator, supported Tiffany through the process and after four months, Tiffany's claim was successful.

My disability won't define me

Tiffany was born with malignant hyperthermia and central core disease.

"I've never felt upset or negative about my disability purely because my parents never made it an issue or treated me any differently. But I do remember when I was 10, I sat between my parents opposite a consultant, who abruptly stated: "She'll be in a wheelchair by 20." Even at that age, I knew I would fight and show them my disability wouldn't define me.

"I'm still not in a wheelchair, but I do find these conditions challenging, both physically and mentally. My spine is hampering my lung capacity, and my swallowing is probably my worst, as it can be quite scary. In the near future, I'll be fitted with a permanent peg feed.

"I have severe arthritis in my joints, which is extremely painful, and I have two full metal ankle replacements. I get fatigue in the afternoons, which we joke and call 'zombie time'. My muscles are so tight that it causes headaches and stiffness around my joints.

"Now that my condition is getting worse, I also suffer with anxiety," says Tiffany.

I felt so elated to see a simple factsheet

At her annual appointments in Poole Hospital with the Dorset Neuromuscular Service, Tiffany sees several members of the team, including healthcare professionals Kathryn Docherty and Suni Narayan (who is also MDUK's Head of Clinical Development). At her 2018 appointment, Tiffany mentioned her PIP assessment had arrived. Kathryn immediately wrote her a supporting letter, and Suni suggested she contact the MDUK advocacy service.

"That was when I had my first call with Emma. From that call, to the numerous emails to and fro', I couldn't believe how amazing Emma was. She also wrote me a letter and enclosed factsheets about my condition. I felt so elated to see a simple factsheet, as I'd never seen one on CCD in 46 years.

The whole process of PIP was stressful

"The whole process of PIP was stressful, but Emma advised me which path to take throughout. My claim finally was successful and I know part of this was because of the help I had from all involved."

"I'd been receiving DLA [Disability Living Allowance] since 1997, when it was awarded

on an indefinite basis. So when I had to reapply for PIP, I felt extremely stressed, as I knew it would again be a fight. A couple of years ago, when I'd had to swap to ESA [Employment Support Allowance], they didn't recognise my conditions. I'd had to pay a specialist solicitor to help me, and the thought of having to repeat that, with more at stake, was scary.

This is when I made a complaint

"My first PIP appointment was cancelled one hour before the set time, and my second appointment was cancelled whilst I sat in the building, waiting to go in. This is when I made a complaint and finally my third appointment went ahead. The stress from the process was awful and definitely made me ill.

"The form was like a book, which had another book enclosed in it, which explained the form. My husband and I are both academic and we were perplexed. It took us a whole weekend and around 10 hours to complete. I was so lucky to have support and we both wondered how people would cope alone.

"The questions were not easy and it was hard to fully describe the whole picture. I had to leave a couple of sections blank, which made me more anxious about the final decision.

"If I hadn't got PIP, I truly believe that life would be very negative and my condition would deteriorate much faster. Getting PIP means having my car, which gives me freedom and the ability to make a limited situation easier.

"Using public transport can be tricky when you are disabled and suffering from anxiety. PIP also enables me to get any equipment I need and covers my yearly prescription fee for all my medication. It also pays for swimming to keep my muscles moving, and for the support of a trainer, who has helped me through five major operations.

"Emma was so professional and supportive throughout; she's an asset to MDUK. I'm so thankful for what MDUK has done for me. They make living with disability that little bit easier."

PIP's our most asked-about topic

"We in MDUK's advocacy team know that PIP applications and assessments can be daunting, especially if you're applying for the first time.

"Many people ask us about PIP – it's become our most asked-about topic – so we're all really experienced in supporting people through their first applications, reassessments and the reconsideration and appeals processes. We want you to get the support you're entitled to, and we can guide you so you have the best chance of going through the process without any problems.

"We're always thrilled to hear about cases like Tiffany's, which like many, ended with her getting the support she was entitled to. So if you're having difficulty getting the support you feel you should be getting, don't hesitate to get in touch with us.

"You'll find a warm, listening ear and someone who knows the ins and outs of these processes. And we'll always try our best to help you." Emma Jeremy, MDUK Advocacy and Care Co-ordinator

Here for you

Emma is one of a team of people at MDUK who can help you with your PIP assessment, or give you advice about getting the care, support and equipment you're entitled to.

MDUK is working on a new guide to PIP, as well as a benefits report. Both will launch later this year – we'll keep you posted.

FIND OUT MORE

Malignant hyperthermia and central core disease

Central core disease is one of the congenital myopathies, a group of conditions characterised by muscle weakness and wasting. It's a rare condition, caused by a mutation in the ryanodine receptor (RYR1) gene, which carries the instructions for a protein involved in calcium release in muscle. People with this mutation may also be susceptible to malignant hyperthermia, an acute reaction to certain anaesthetics or muscle relaxants used for general anaesthesia.

www.musculardystrophyuk.org/central-core-disease

MEETING PEOPLE NEAR YOU

Having muscular dystrophy or a muscle-wasting condition often means adjusting to a new and unexpected reality, so it can really help to meet others and talk about the things that matter to you. Muscle Groups are a great opportunity to do just that, near where you live.

Our network of local groups, known as Muscle Groups, meet regularly across the UK. The meetings give you a chance to hear about how MDUK can support you, and to meet others who also know what it's like to live with a muscle-wasting condition. We have a network of local Muscle Groups in 10 regions of England and in Scotland, Wales and Northern Ireland. Each region has three meetings a year, usually built around a theme or a topic that the Group members have identified, and relevant speakers. One of the three meetings each year is more of a social gathering.

Don't just take our word for it, here's what people with muscle-wasting conditions tell us about what Muscle Groups mean to them:

> Very interesting, open meeting with enthusiastic people

> It was fabulous for information and links to services

> Useful information and contacts

> Very constructive

> It makes you feel less isolated by meeting other people with the same condition

To find a local Muscle Group near you, visit www.musculardystrophyuk.org or get in touch with us on 0800 652 6352

MDUK RESEARCH UPDATES

LATEST NEWS AND UPDATES FROM RESEARCH INTO MUSCULAR DYSTROPHY AND ASSOCIATED CONDITIONS

Repurposed drug could be beneficial for OPMD

Repurposing drugs means taking an existing drug – developed to treat one condition – to treat another condition. The advantage of doing this is that the drug has already been tested in people. This means researchers have a good understanding of where the drug acts in the body and its side effects. This may reduce the time and costs associated with developing the drug for another condition.

A new study has shown that a drug previously used to treat high blood pressure can improve muscle strength in a mouse model of oculopharyngeal muscular dystrophy (OPMD). Although this is promising news, this drug was discontinued because of its side effects of sleepiness. By testing the drug in a clinical trial, researchers will be able to fully understand its safety and effectiveness in people with OPMD.

New FSHD mouse model treated with gene therapy

Researchers in the US have created a new mouse model of facioscapulohumeral muscular dystrophy (FSHD). Developing animal models of FSHD has proved difficult in the past because of the toxicity of the DUX4 protein that causes the condition. To overcome this, Dr Harper and his team used a genetic tool that allowed them to tightly control DUX4 levels in the mice.

The researchers also tested a gene therapy in the mice, to see if they would be a useful model for studying the effectiveness of potential treatments. This gene therapy delivered a copy of the follistatin gene, which is known to trigger muscle growth. The treatment increased the size of the mouse muscles that it was injected into, and improved the strength of these muscles. Although this type of therapy doesn't target DUX4, these results show that it still has a lot of potential for treating muscle weakness in FSHD.

Care recommendations for myotonic dystrophy type 1

An international team of experts has published the first set of care guidelines for adults with myotonic dystrophy type 1. It is hoped these will inform clinicians who may not be familiar with the condition, and help standardise and improve care. In addition, removing inconsistences in patient care will improve our understanding of the condition, and its

progression. This is important for drug development and clinical trial design. We are currently working with myotonic dystrophy experts in the UK to adapt these care guidelines for UK practice.

MDUK-FUNDED RESEARCH

Collagen VI registry now live

The Collagen VI Alliance, of which MDUK is a part, is supporting the development of a global patient registry for collagen VI-related dystrophies. We're pleased to say that good progress has been made and the registry is now accepting registrations in English.

Registries are very important for research into rare conditions such as collagen VI-related dystrophies, which include Bethlem myopathy, Ullrich congenital muscular dystrophy or an intermediate form of these conditions. Not only do registries help with clinical trial recruitment, but they also give a better understanding of the progression of a muscle-wasting condition.

If you'd like to join or learn more about the collagen VI registry, please visit collagen6.org or get in touch with the registry curator, Dr Alison Blain on 0191 241 8605 or collagen6registry@ncl.ac.uk

Improving genetic diagnosis

With funding from MDUK, researchers at Newcastle University have demonstrated that next-generation sequencing is faster and more precise than current genetic testing methods. They took DNA samples from 56 families with unexplained limb girdle muscle weakness and used next-generation sequencing technology to search for the underlying mutation. Mutations were identified in 14 different genes and in 23 families. This information will help these families to receive more appropriate care and guidance. However, there were still families in which the disease-causing mutation couldn't be identified. The researchers hope to seek further funding to explore other sequencing technologies that may help to diagnose these families.

CLINICAL TRIAL UPDATES

Positive results from LGMD gene therapy trial

Sarepta Therapeutics has announced preliminary results from a trial testing a gene therapy for limb girdle muscular dystrophy (LGMD) type 2E. Only three children have been dosed with the gene therapy so far, but the data looks positive and suggests that muscle damage has been reduced. Although this is good news, it's still early days and we don't know what effect the gene therapy will have on muscle function.

Positive results for Catabasis' Duchenne drug

Catabasis has shared new data supporting edasalonexent as a potential treatment for Duchenne muscular dystrophy. In the Phase 2 MoveDMD trial and open-label extension study, boys with Duchenne treated with edasalonexent had similar growth to unaffected boys in the same age range. This is good news, as many boys with Duchenne experience stunted growth owing to steroids. The drug is now being tested in a global phase 3 trial called PolarisDMD, which includes four UK sites.

Positive results from myasthenia gravis trial
A phase 2 clinical trial has shown that zilucoplan can reduce the severity of generalised myasthenia gravis. The trial was carried out at sites in the US and Canada by Ra Pharmaceuticals and included 44 patients. Based on these results, Ra Pharmaceuticals will test zilucoplan in a larger phase 3 trial. The company plans to confirm the design of this trial with the US Food and Drug Administration (FDA) and other regulatory agencies by the first quarter of 2019.

Report on Duchenne gene therapy trial
Solid Biosciences recently announced preliminary findings from its IGNITE-DMD trial, which has so far treated three boys with microdystrophin gene therapy. Muscle biopsies taken after three months showed low levels of micro-dystrophin protein. Although this is disappointing news, it's important to remember that IGNITE-DMD is a dose-escalation study, and these three boys received the lowest planned dose. These results confirm the need to test a higher dose of the gene therapy in future patients.

FDA priority designation for neuromuscular drugs
Since the beginning of 2019, the US FDA has granted Orphan Drug or Fast Track Designation (see below) to three drugs being developed for neuromuscular conditions. This is great news as these schemes provide certain benefits that help to lower the cost of developing the drugs.

Drug name	Type of drug	Company	Condition
ACE-083	Myostatin inhibitor	Acceleron Pharmaceuticals	Charcot-Marie-Tooth disease
PXT3003	Combination of three existing drugs	Pharnext	Charcot-Marie-Tooth disease
MYO-102	Gene therapy	Myonexus Therapeutics	LGMD type 2D

CYCLING FOR JONATHAN

Last October, Dr Sally Whittet, from North Curry, cycled from Manchester United's Old Trafford ground to Chelsea's Stamford Bridge, and raised over £10,000 for MDUK. She took on the impressive five-day, 220-mile challenge in memory of her godson, Jonathan Holden, who had Duchenne muscular dystrophy and died in July 2018 aged 28. He was an avid Man Utd fan, while she is a Chelsea supporter.

Former player and Ireland international Denis Irwin waved Sally off at Old Trafford, and ex-Chelsea and Scotland winger Pat Nevin welcomed her at Stamford Bridge.

"This cycle ride was my tribute to Jonathan. It won't bring him back, but the money I have raised could help others in the future. I hope that one day, there will be a way to prevent and treat this condition."

It was Sally who realised Jonathan had Duchenne

Sally and Jonathan's mum, Hazel, became friends at school when they were 12. Hazel and Phil, Jonathan's dad, also have two daughters – Kathryn and Alexandra.

"With Sally's children being a similar age to our older two, the families saw quite a lot of each other. It was Sally who realised Jonathan had Duchenne, although we were already concerned about his running/climbing ability so had arranged for him to see a physio. Jonathan had just turned three when he was diagnosed," says Hazel.

"Sally has been a huge support to us all over the years; even when she moved further away, she regularly came to see us all. She enjoyed a friendly rivalry with Jonathan over their football teams. Text messages on match days were not unusual!"

l to r: Jessie Keighley, Pat Nevin, Sally, Lorna Poultney and Laura Burge at Stamford Bridge

His love of all things sport

"A huge part of Jonathan's life was his love of all things sport," says Phil.

"I certainly appreciated having the excuse for all the extra sports channels. Jonathan enjoyed playing fantasy rugby and football and competing in my office competitions, always doing well and certainly better than his dad!

"Jonathan achieved excellent results at school and went on to study Computer Aided Product Design at Bournemouth University. He had a remarkable ability to quickly take in, analyse and then use information. He was always able to explain his workings when challenged. When he graduated, we were all very proud of his 2:1 and more importantly his overall achievement in spending the three years away from home."

Sally's amazing challenge

"We all thought Sally was amazing taking on her challenge, especially as she didn't even have a bike when she first mentioned it! Jonathan would have thought she was 'nuts' to take it on but would have also been surprised that anyone would want to do anything like that in his memory. Although Sally did also run the 1999 London Marathon in his honour," says Hazel.

And now the challenges will continue as Jonathan's older sister Kathryn and her fiancé too will be taking on the 2019 London Marathon for MDUK, in Jonathan's memory.

MACKIE'S OF SCOTLAND –
a fantastic and strong partnership

The strong partnership between one of Scotland's favourite food brands and MDUK is raising vital funds and helping to build awareness of the work of our charity. Mackie's of Scotland have even coloured their cows orange to support us.

The special relationship began in 2010 with a farm open day organised by Denis Emslie, Sales Director at Mackie's of Scotland. The event raised over £45k towards the work of the charity, and the company has been sponsors of the charity ever since.

Denis had a rare form of muscular dystrophy, and died in 2013. The connections with the condition continue with the Taylor family, closely connected to Mackie's through their joint venture company, Mackie's at Taypack. Managing Director George Taylor's brother Mark had Duchenne muscular dystrophy and died at the age of 28. Mackie's of Scotland produce 10 million litres of their famous ice cream each year. They make it on the family farm in Aberdeenshire, using fresh, whole milk and cream from their herd of 330 cows.

Firmly established as one of the UK's most popular take-home ice creams, Mackie's diversified into making crisps in 2009, and these are now available in over 20 countries. And in 2014, a tractor shed became a dedicated £600k chocolate factory on the Aberdeenshire home farm.

Mackie's is a fourth generation family business, founded in 1912 as a dairy farm. It diversified into making ice cream using surplus cream from the sales of semi-skimmed milk, in 1986. In 2009, they formed a partnership with the Taylor family, who are Tayside potato farmers, to produce Mackie's crisps.

A very impressive family-based company

MDUK's Head of Corporate Development, Nura Makki said: "We are absolutely delighted with the strong and ongoing partnership with Mackie's of Scotland. This is a very impressive family-based company, whose determination to support anyone with a muscle-wasting condition chimes completely with our own mission."

In 2017, Mackie's opened their first ice cream parlour, named Mackie's 19.2 in Aberdeen. The name 19.2 represents the distance in miles from the parlour to the family farm. In January 2019, the parlour transformed into a stunning bright vision with orange lighting, balloons and staff dressed in orange T-shirts to mark our annual fundraising event, Go Orange for a Day. The company even converted their logo to an orange-spotted cow for the day.

A charity close to our hearts

Mackie's Marketing Director, Karin Hayhow said, "Muscular Dystrophy UK is a charity close

To find out more about our corporate partnerships, get in touch with Nura at n.makki@musculardystrophyuk.org or 020 7803 4822

to our hearts because we have experienced first-hand the severity of the illness.

"MDUK is our official charity and we do what we can to support the fantastic work that it does for those that have been affected by muscle-wasting conditions.

Keen to get behind the cause

"Our parlour customers had great fun with the orange lucky dip that we organised for Go Orange for a Day, and were keen to get behind the cause."

Mackie's of Scotland also joined forces with the team at Mackie's at Taypack to self-publish their first recipe book, with 31 fun and tasty recipes – both sweet and savoury – that feature their products: ice cream, chocolate, crisps and popcorn.

The hardback book *Cooking with Mackie's* sold well at the 2018 BBC Good Food Show in Birmingham and the Royal Highland Show in Edinburgh, as well as at Mackie's 19.2.

In summer 2018, Mackie's at Taypack introduced special packs of new sausage and caramelised onion crisps – a delicious new flavour – with 7p from each pack going to MDUK.

George Taylor and his team also raised over £4,500 for MDUK by taking on an 82-mile cycle. They are looking to build on this, aiming to raise at least £10k.

MDUK's Regional Development Manager for Scotland, Dean Widd said, "These are simply wonderful corporate partners. There are just over 6,000 people in Scotland with muscular dystrophy and the money raised helps to fund our work into new treatments, and campaigns for better care and support."

Craig Marsden, Bonaria Fanara, Yvette Harrison, Zuzanna Gliwinska, Fiona Gillick

TOGETHER FOR RHYS

Graham, Laura and Rhys

A local family went all out to support MDUK at our Leicester Town and Gown 10k in March. Six-year-old Rhys fired the starting gun, dad Graham ran the race, and friends and family came to cheer everyone on.

"We were proud that Rhys had been chosen by MDUK to be the race-starter on the day! It's great to have this event on our doorstep and take part with others, to support MDUK. Having Rhys cheer me on always gives me a boost," said Graham.

"Being a local event for us meant that friends and family joined us on the day to support everyone as well."

Our lives changed in an instant

Graham and Laura Jones started their Family Fund, Together for Rhys, soon after Rhys was diagnosed with Duchenne muscular dystrophy at the age of two. They set up the Fund to raise awareness and raise money for MDUK's Duchenne Research Breakthrough Fund.

"When Rhys was diagnosed in 2015, we felt helpless and devastated. Our lives had changed in an instant.

"We were put in contact with a care advisor and we found it useful to talk to someone about the condition. The charity was also able to provide information and support to help us through this difficult time," said Laura.

Rhys is like any other cheeky six-year-old boy

"Right now, Rhys is like any other cheeky six-year-old boy! He loves his toy racing cars, dinosaurs and building with his Lego. He is a determined and inquisitive little guy, who always manages to do things his own way.

"Currently there is no cure, but Rhys is fantastic at just getting on with life, unaware of the challenges ahead.

Channel our energy into something positive

"We set up a Family Fund because we wanted to do something positive. We thought fundraising would allow us to channel our energy into something positive in what is an otherwise uncertain future.

"A lot of the time it's friends and family who

know Rhys the best who support us, as they are always willing to do what they can to help. But Rhys' story has also compelled complete strangers to help us, and it's always very humbling that people want to help and support us.

"Working with our MDUK Regional Development Manager, we can talk through ideas and plans for fundraising events. This really helps us make sure our events are a success and we can call on their support when we need it.

MDUK is there to support us as well

"MDUK also allows us to direct our funds raised into research areas that will hopefully benefit Rhys and other boys with the Duchenne. Having our own banner to fundraise under gives us ownership of how we fundraise, but it's also reassuring that MDUK is there to support us as well," said Graham.

"We are holding our first charity ball at the National Space Centre in Leicester on 11 May. It's by far our biggest and most ambitious event since we started fundraising. It's been hard work but also enjoyable and we expect it to be a fantastic night."

To buy tickets for what promises to be a fantastic night, please email: togetherforrhys@gmail.com

Family Funds

Starting your own Family Fund is a great way to fundraise for MDUK. Personalise your fundraising, bring your friends, family and local community together and you'll make a real difference to those living with muscle-wasting conditions.

Visit www.musculardystrophyuk.org/family-funds to find out more.

Family Fund: George's Genes

Leicester Town and Gown is the newest 10k in our series, which includes the Newton Oxford Town and Gown, and the Newton Cambridge Town and Gown. Known as the 'Runner's run', the scenic race takes you through closed streets, past universities, rivers and parks and many of the cities' historic buildings.

"Thank you to everyone who helped make our third Leicester Town and Gown our biggest yet, and to Rhys who pulled the horn! The sun shone as 312 runners crossed the line! So far our runners have raised a fabulous £7.5k towards our work, and we hope to reach £10k." Jessie Keighley, MDUK Event Project Manager, Town and Gown 10k series.

Daniel Sanders (pictured) was diagnosed with facioscapulohumeral muscular dystrophy when he was 18. He lives in Wellingborough with his wife, Emma, and comes to the Centre monthly.

"The physio keeps me flexible, and the stretches help. The physiotherapist tells me what I should and shouldn't do, and how far to push myself. Some of the stretches can be tough, but no pain no gain!"

WORKING TOGETHER TO IMPROVE ACCESS TO HEALTHCARE

MDUK is proud to be working with the Muscular Dystrophy Support Centre (MDSC), a unique multi-disciplinary centre and charity, based in Coventry. It offers integrated and individually tailored specialist therapies and support to people with muscle-wasting conditions.

Of the 70,000 people in the UK who have muscle-wasting conditions, around 12,000 live in the Midlands region alone. The Centre was established to provide physical therapies for people with muscular dystrophy to maintain independence and stay stronger for longer. Their services are making a difference to the physical and mental wellbeing of those who regularly visit the Centre.

The services are free

Correct physical therapy is vital for people with muscle-wasting conditions, as it helps maintain mobility and reduces the rate of muscle deterioration. People with these conditions get very little access to physical therapy from the NHS once they turn 18, which is why the service offered by the Centre is so valuable.

If you're an adult with a muscle-wasting condition, you can get free and continuous specialist physiotherapy and osteopathy at the Centre, as long as you have a referral from your GP or consultant. Core services are free but donations are always welcome as they help the Centre maintain its level and high standards of service. There are also complementary therapies and classes to support you or your carer in the other areas of life that may be challenging for you. There is a nominal charge for these.

Born out of a need

"The idea for the Centre was born out of a need. During the 2009 consultation between MDUK and the NHS on Access to Specialist Neuromuscular Care, a group of patient experts tabled the need for neuromuscular centres across the UK. They were determined to start a service in the Midlands as the only centre in the UK at that time was in Cheshire.

"It wasn't until the project was openly discussed at a West Midlands MDUK Muscle Group meeting that the group of like-minded individuals moved the project forward. The first step was finding a location so we started raising funds," says Ruth Hereford, MDSC's Chair of Trustees.

"We raised a total of £40k to get the Centre started. MDUK was helpful in curating the funds for us and facilitating the early meetings. The NeuroMuscular Centre in Cheshire was also very generous in sharing their valuable experience and knowledge with us, and with the help of both charities, we started the Centre in 2012.

"Initially, we offered about eight hours of physical therapies a week. As word spread, we started getting more referrals from consultants and GPs. We currently employ nine therapists, offer therapies four days a week, and our waiting list is growing!

"In the first four or five years we were in 'survival mode' and had the help of many volunteers and our dedicated therapists to get the Centre running and meeting the needs of our service users. We're now in the next phase of our development, looking at how we can reach more people, and how we can grow and move the Centre onwards.

Taking services out to more people

"As the Centre has grown, the Trustees have decided on a 'hub and spoke' model, to establish satellite clinics rather than expanding a central facility. This would take services out to more people, making them accessible to those who need them the most and reducing travel times as much as possible.

"The first satellite clinic was set up at an osteopathic clinic in Droitwich just over two years

ago. About a year ago, the Centre joined up with Acorns Children's Hospice in Birmingham to establish a second satellite clinic to provide therapies on a weekly basis in their therapy suite. And from early summer this year, the Centre will be working with Rainbows Hospice for Children and Young People in Loughborough to set up a third satellite clinic. The benefit to the Hospices is that their service users can also make use of the Centre's services there when they reach the ages of 18 and 30 respectively."

Partnerships like this are so important

The Centre also works closely with Murray's Muscles, a Droitwich-based charity that supports people across the Midlands with grants towards life-changing equipment. It's often during therapy sessions that the need for this equipment is identified.

"It's great when charities work together to use each other's resources in the most effective and economic way possible. It's always the service users who benefit. We're looking forward to working more closely with MDUK so care advisors – and soon advocacy and information officers too – can come to our centres to support service users with information and advice. We can't do it all, which is why partnerships like this are so important," says Ruth.

"Collaborating and working in partnership with other groups like the MDSC is essential to delivering our mission to make every day count, and to speed up access to treatments, support and better care for people with muscle-wasting conditions," says Catherine Woodhead, MDUK's CEO.

Bryan Gould, Ruth Hereford and David Salt

MEET SOME OF OUR THERAPISTS

Ulrike Uta, a specialist neurological and MDSC's co-lead physiotherapist, worked for the NHS for 12 years before joining the Centre in 2014.

"Our approach is person-centred, which means we work with service users on what is important for them. Most service users come regularly but others come back as and when they need to. For me as a therapist, it's wonderful that I can support people on an ongoing basis and work with their current needs. The service users are lovely; they're very keen, proactive and want to manage themselves."

Jane Field (a founding Trustee of MDSC) has been practising osteopathy for nearly 40 years.

Having a son with Duchenne, Jane brings a wealth of knowledge and understanding to the Centre and the therapy needed to maintain mobility.

"Osteopathy and acupuncture bring additional toolsets, widening the breadth of our specialist, integrated therapies and enabling us to offer a bespoke set of therapies to our service users. Seeing the maintenance of or even improvements in service users' mobility never ceases to make me feel that my job is worthwhile."

Muscular Dystrophy UK President's Awards

MDUK President Gabby Logan is inviting you to nominate someone you know for a President's Award this year.

Do you know someone who takes the time, care and commitment to make a difference in the lives of people living with muscle-wasting conditions? Whether they're a scientist in their early career, they've been working in the community for years, or have achieved something outstanding in their campaigning work, we want to hear from you.

You can nominate today at www.musculardystrophyuk.org/presidents-awards-2019
Voting closes 1 July 2019, full terms and conditions on our website.

The awards will be presented at our National Conference in October.

MDUK'S NATIONAL CONFERENCE
Join our President Gabby Logan to mark our 60th anniversary at this year's MDUK National Conference on Saturday 12 October at the Sofitel London Heathrow.
Book your place at www.musculardystrophyuk.org/national-conference-2019

THANK YOU FOR TAKING PART

By taking part in events across the UK, you're helping ensure we can be here for everyone affected today, tomorrow and beyond. Together we will bring forward the day when we beat muscular dystrophy.

Orange-themed menu

In November 2018, 50 guests gathered at The Ashmolean in Oxford to sample the food of Masterchef finalist, Nawamin Pinpathomrat's special orange-themed menu. An incredible £48k was raised to support research into nemaline myopathy.

Go Orange for a Day

Friday 1 February was the orangest, sunniest day yet! Over 220 groups and organisations across the UK turned their workplaces and schools orange to raise awareness and funds.

Q Trust Quiz

In November 2018, the Q Trust hosted their bi-annual quiz, compèred by broadcaster Evan Davis, and raised an incredible £44k for the MDUK Oxford Neuromuscular Centre. Over the years, the Q Trust's outstanding support of MDUK has had a huge impact on a number of projects.

Five-a-side football

In February, 10 property sector companies played in the inaugural 5-A-Side Challenge in London. MDUK Appeal Board member Tim Lumsdon from Marchmont Investments led the event, which raised £6k for MDUK.

BGC Charity Day

At the 2018 BGC Charity Day on 9/11, we were delighted that Sam Allardyce, Catherine Tyldesley, Jack Wilshere, Jon Richardson and Al Murray represented us at the event at BGC Partner's London office. We'll let you know the total amount raised when we hear later this year.

Celebrity Sports Quiz

Our 2019 Celebrity Sports Quiz at Lord's Cricket Ground raised a fantastic £75k. It was a fun and enjoyable evening hosted by Rugby World Cup legend, Will Greenwood, and attended by other sports stars such as Monty Panesar and Robin Cousins.

Microscope Ball

Last October, the 35th Microscope Ball brought the party spirit of Cuba to London at the Hilton Park Lane. Hosted by the popular comedian Ellie Taylor, the event brought together 740 influential members of the property industry and raised a staggering £353k.

Gifts in Wills Week event

In February 2019, we invited a group of our supporters, who've chosen to leave a gift in their Will, to visit Royal Holloway University's research lab. We wanted to show them how the charity invested in research and how their gifts might be used in the future.

If you or your business would like to support MDUK or organise your own event, please contact us at events@musculardystrophyuk.org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WHAT YOU CAN GET ON BOARD WITH

	DATE	EVENT	CONTACT	CONTACT DETAILS
MAY	5	Belfast City Marathon	Julie Harvey	j.harvey@musculardystrophyuk.org,
	10-12	Family Fund BIG Weekend	Fundraising team	volunteerfundraising@musculardystrophyuk.org
	11	Together for Rhys Ball, Leicester	Celia Hickson	c.hickson@musculardystrophyuk.org
	12	Newton Oxford Town and Gown 10k and Junior 3k	Jessie Keighley	www.townandgown10k.com/oxford
	15	MDUK East Midlands Neuromuscular Conference	David Stephenson	d.stephenson@musculardystrophyuk.org
	17	Question of Support Dinner and Quiz, Glasgow	Dean Widd	d.widd@musculardystrophyuk.org
	18	Lagan zipline	Julie Harvey	j.harvey@musculardystrophyuk.org
	19	Millers Dale Bridge Abseil, Derbyshire	Celia Hickson	c.hickson@musculardystrophyuk.org
	25	Stanley's Big Day Out, Manchester	Fundraising team	volunteerfundraising@musculardystrophyuk.org
	25	Edinburgh Marathon Festival	Dean Widd	d.widd@musculardystrophyuk.org
	27	London Vitality 10,000	Louise Moffat	l.moffat@musculardystrophyuk.org
JUNE	5	London to Paris Cycle	Fundraising team	volunteerfundraising@musculardystrophyuk.org
	8	Volunteer engagement and training day	Joel Rackham	volunteering@musculardystrophyuk.org
	8	Heineken Race to the Tower, the Cotswolds	Rory Criddle	r.criddle@musculardystrophyuk.org
	8 June and 6 July	Pedal Paddle Peak, Lake District	Rory Criddle	r.criddle@musculardystrophyuk.org
	22	Nightrider Glasgow	Dean Widd	d.widd@musculardystrophyuk.org
	23	Total Warrior, Leeds	Fundraising team	volunteerfundraising@musculardystrophyuk.org
JULY	13	Dixons Carphone Race to the Stones, Oxfordshire	Jessie Keighley	j.keighley@musculardystrophyuk.org
	13	Nightrider Liverpool	Charles Horton	c.horton@musculardystrophyuk.org
	27	Snowdonia Velocity zipline	Charles Horton	c.horton@musculardystrophyuk.org
AUG	4	Prudential RideLondon-Surrey 100	Lauren Rouse	l.rouse@musculardystrophyuk.org
	17	Three Peaks Challenge, Yorkshire	Fundraising team	volunteerfundraising@musculardystrophyuk.org
SEPT	8	Simplyhealth Great North Run, Newcastle-upon-Tyne	Kiera Santry	k.santry@musculardystrophyuk.org
	18	MDUK Charity Shoot, Berkshire	Lorna Poultney	l.poultney@musculardystrophyuk.org
	21	Firewalk, North London	Louise Moffat	l.moffat@musculardystrophyuk.org
	22	Scottish Half Marathon and 10k, East Lothian	Dean Widd	d.widd@musculardystrophyuk.org
	26	Mount Kilimanjaro trek	Fundraising team	volunteerfundraising@musculardystrophyuk.org
	26	Microscope Ball, London	Lorna Poultney	l.poultney@musculardystrophyuk.org
	28	Skydive for MDUK, North West	Charles Horton	c.horton@musculardystrophyuk.org

OCT	5	Bournemouth Marathon Festival	Nicole Beebee	n.beebee@musculardystrophyuk.org
	12	MDUK National Conference, Sofitel London Heathrow	www.musculardystrophyuk.org/National-Conference-2019	
	12 and 13	Tyne Bridge Slide	Fundraising team	volunteerfundraising@musculardystrophyuk.org
	13	Royal Parks Foundation Half Marathon	Louise Moffat	l.moffat@musculardystrophyuk.org,
	14–20	Bake a Difference Week	Fundraising team	volunteerfundraising@musculardystrophyuk.org
	18	Luke's Gala Dinner, Bristol	Nicole Beebee	n.beebee@musculardystrophyuk.org
	20	Great South Run, Portsmouth	Ashleigh Venables	a.venables@musculardystrophyuk.org
	20	Newton Cambridge Town and Gown 10k	Jessie Keighley	www.townandgown10k.com/cambridge
NOV	2	MDUK Scottish Conference, Glasgow	www.musculardystrophyuk.org – details to follow	
	14	Q Trust Chef's Dinner, London	Lorna Poultney	l.poultney@musculardystrophyuk.org
	16	Christine Ogden's 15th Annual Concert for MDUK, Bolton	Christine Ogden	www.musculardystrophyuk.org/events
	28	Spirit of Christmas concert, Oxford	Nicole Beebee	n.beebee@musculardystrophyuk.org
DEC	5	Spirit of Christmas concert, Gloucester	Nicole Beebee	n.beebee@musculardystrophyuk.org

If you have any questions please get in touch with us 0300 012 0172

MUSCULAR DYSTROPHY SUPPORT CENTRE ANNUAL OPEN DAY – SATURDAY 8 JUNE 2019

Health and wellbeing

Meet our therapists, try taster sessions of osteopathy and complementary therapies and participate in sessions on caring for your mind, spirit and body. It's also an opportunity to hear about the Centre's plans and share your ideas for the Centre's development. It's free to attend and lunch and refreshments are included.

Register at mdscopenday2019.eventbrite.co.uk or call 024 761 00770

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