Muscular Dystrophy UK's lifestyle magazine

Issue 2 – 2017

Target MD

Surrey model, Gems Woodall, and her charity ball

Stories of our amazing supporters

Target Research: news and updates

Muscular Dystrophy UK
Fighting muscle-wasting conditions

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The magazine for supporters of Muscular Dystrophy UK, written and produced entirely in-house.

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On the cover

Gems Woodall (right) and her sister-in-law Sally Godfrey at Gems' glamorous charity ball in Surrey. (Read more on p8.)

Hello

Hello and welcome to the second edition of *Target MD* in 2017. This time, we've focused on some powerful stories of our supporters. You'll read of some outstanding achievements, of some extraordinary ways to live every day, and some gritty determination to fight for what is right.

We also bring you updates on our campaigns, and information on new resources available for people living with muscle-wasting conditions. You'll find a reflection on your incredible support at some of our recent fundraising events. We can't thank you enough for the huge difference you make in the fight against muscle-wasting conditions.

If you'd like to take part in any of the upcoming events, our teams will welcome you. They always do a great job of supporting you too.

Our National and Scottish Conferences are scheduled for 7 October in Birmingham and 11 November in Glasgow, respectively. These are great opportunities not only to make new friends or connect with old ones, but also to hear research updates and take part in workshops on practical aspects of living with a muscle-wasting condition.

Have a look at the info on page 30, and book your place. And if you're not a Friend of MDUK, join today – the benefits include a 50 percent discount on your conference ticket prices.

As always, please keep in touch and tell us what you'd like to read about in future editions. We want to bring you the magazine you want to read.

I'd love to hear from you.

Ruth

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About us

Muscular Dystrophy UK supports 70,000 children and adults with muscle-wasting conditions to live as independently as possible. We accelerate the pace in the development of effective treatments and cures.

Helpline

If you'd like to speak to someone about living with a muscle-wasting condition, please call our friendly Care and Support team.

They are available from
8.30am to 6pm Monday to Friday,
on **0800 652 6352** (Freephone helpline)
or **info@musculardystrophyuk.org**

Photo © Anne-Marie Briscombe

Thank you for your ongoing support

Everything we do, as you'll read in the pages ahead, relies on the support of generous people like you. People who understand what it will take to beat muscle-wasting conditions.

Join us – we can do this, together.

Please contact our Fundraising Team to find out about all the ways you can get involved.
Call **0300 012 0172** or email
fundraising@musculardystrophyuk.org

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MEDICOTECH

Let's accelerate access to new treatments

I'm keen to share with you how you can help us accelerate the steps to new treatments being available in this country. However, I first want to recognise that we are living through difficult times with loss and suffering caused by terrorist attacks and other painful events. Our deepest sympathies to all those who have suffered in recent weeks and months.

In terms of new and emerging treatments, our support and commitment to research over many years has made a vital contribution to today's progress. Our supporters can be very pleased with what you've helped us achieve in raising research funds to back the most promising research by excellent scientists across the country.

In this edition of *Target MD*, you can read of some clinical trials now underway in a range of conditions.

As potential treatments come through clinical trials (although some are ineffective and fail), regulatory approval is needed and the price of the drug has to be affordable. I commented in the Spring edition of *Target MD* on changes to the NICE policy for the evaluation of rare disease drugs. These are intended to reduce the overall cost of new drugs given the relatively high cost of some of these drugs and the budgetary problems faced by the NHS.

We have urged the NHS and the Department of Health to hold tough negotiations with the drug companies to reduce costs. Further, effective treatments can also generate savings by reducing the impact of the condition and allowing more people to consider training and employment. This may well lead to reductions in the long-term cost of care, and family members may find they can continue in employment and contribute to tax revenues.

However, NHS budgetary pressures are compounded by political uncertainties following the June election and the start of 'Brexit' negotiations.

We would welcome your help in this crucial task. Add your voice to our work in the Parliaments and Assemblies, attend a regional Muscle Group and support our work in research and campaigns. We are stronger when we act together. Let's ensure the decision-makers understand the impact of muscle-wasting conditions and the need for new treatments to be available without delay.

As ever, our huge thanks for all your support.

Robert Meadowcroft, CEO

New support in Westminster

Ahead of the recent general election, we promoted Muscular Dystrophy UK's priorities to increase the number of our parliamentary supporters.

Together with patients and families living with muscle-wasting conditions, we contacted election candidates across the UK to seek their backing for our *Manifesto for Muscle: Seven steps to fight muscle-wasting conditions*. This backing included pledges on support for fast access to new treatments, improvements to specialist healthcare and independent living.

From successful candidates who backed our pledges, as well as re-elected MPs who have regularly highlighted muscular dystrophy and the charity in Parliament, we now have over 60 MPs ready to support us.

Have a look at our website to find out if your MP signed up to the *Manifesto for Muscle*. If you can't see your MP's name on the list, you can get in touch with them – using the contact details on the Parliament website – to ask if they will support you and Muscular Dystrophy UK's campaigns.

If you have any questions or want to find out more, please contact Jonathan Kingsley at j.kingsley@musculardystrophyuk.org or 020 7803 4839

"Stanley is our happy little boy. He's one of the brightest and most loving children I know."

Laura Deal

Our happy little boy

It's something no parent should ever have to endure, but here Laura Deal reveals what it's like knowing her little boy may never grow up:

"My little boy, Stanley, talks about digging for dinosaurs when he is older. He's perfected his roar and, although at just four years old he hasn't quite mastered the word 'palaeontologist', if there's anything you want to know about the *Tyrannosaurus Rex* he has all the answers. But while, as a mother, I love that he has those dreams, the truth is, it's unlikely Stanley will live past his 16th birthday.

"Every day my little boy's tiny body grows weaker, and his muscles more tired. And one day, they will just stop working – all of them, including his heart.

"The agony I feel today couldn't be more different to the happiness I felt when I found out I was pregnant. My partner Rob called friends and family with the good news. His boys, Robbie, then 12, and Alfie, nine, were so excited about becoming big brothers.

"When Stanley came into the world, I couldn't believe it – he was here, he was ours. As biased as it sounds, Stanley really was the perfect baby – happy and smiley. As he neared his first birthday, we started to notice he wasn't meeting his milestones.

"While other babies his age were crawling, some even taking their first tentative steps, Stanley was only shuffling on his bottom. And he couldn't even pull himself to stand.

"Friends told me not to worry. But Rob's sister wasn't so sure. She'd had a little boy a month after me and the differences between the two cousins were clear. She said we should take Stanley to see a doctor. I didn't want to admit she was right, but I knew, if Stanley needed help, I had to get it for him.

"So, we took him to the doctor, who immediately referred us to Addenbrooke's Hospital in Cambridge. I was terrified, and over the next few weeks, Stanley endured test after test – blood samples and MRI scans.

"The doctors had so many questions. 'Did Stanley's kicks feel strong when he was in the womb?' But he was my first baby; I had nothing to compare it with, no way of knowing how to answer.

"I took time off from my job as a teacher and Rob juggled his shifts as a fireman. In April 2014, just before Stanley's second birthday, the hospital called us in. There were two consultants and a nurse waiting for us.

"'Stanley has congenital muscular dystrophy, and the prognosis isn't good,' is what the consultant said. He explained that while Stanley was as clever as any other little boy, the condition would cause the deterioration of all the muscles in his body.

"I sat there in silence, unable to muster a single word. We wondered about Stanley having a family, going to university. The doctors said Stanley would never be strong enough to walk. 'At present his condition is incurable,' they explained.

"The nurse booked us in for another appointment and Rob and I left the office, our faces wet with tears, our bodies shaking with sobs. All I could think was we were going to lose our baby boy.

"In the months that followed, Stanley started physiotherapy and, knowing he'd need to use a wheelchair one day, we started adapting the house.

"Dealing with the practicalities was far easier than the realities of what was to come. Rob struggled too; he couldn't sleep, some days he couldn't even get himself dressed.

"Stanley, our happy little boy, kept smiling and showed us we had to stay strong. He'd happily tell everyone about his 'wibbly wobbly legs that were like jelly'.

"We vowed not to let anything hold him back, and were determined to do something to change the odds for him. So we got in touch with MDUK, and started raising money for research to find a cure.

"Since then, we've enrolled Stanley into a clinical trial that monitors the strength of his heart.

"He's too young to understand what's happening, but at some point we'll have to tell him. I'm still clinging to the hope that they'll find a cure. And that my precious, perfect little boy will get to live the long, happy life he deserves."

words: Kira Agass and Lucy Banwell
Originally appeared in Woman magazine

Gems is an unstoppable force of nature

A model and mother-of-two, Gems Woodall has raised £2,500 for Muscular Dystrophy UK by holding a glamorous ball.

Gems, from Godalming in Surrey, is now less than £2,000 away from her target of raising £10,000 this year for MDUK.

She and her brother Dan Godfrey (pictured with guitar) both have limb girdle muscular dystrophy, which causes weakness in the arms and legs.

Dan is a talented musician. He supported his sister at the ball and performed a few songs.

Gems said:
"To perform at the ball was a huge deal for Dan, as his arms are much weaker now. If he pushes himself too hard, he really does pay for it. I am so proud of Dan for all he has endured and his fighting spirit."

Gems fundraises for the charity via her own fashion and beauty magazine, where all profits from sales go straight towards funding vital research into potential treatments.

She set up *Creative Portrait Magazine* two years ago after she found herself confined to her bed and in constant pain because of her condition.

She wanted to remain in the creative field and realised she could raise much-needed funds through sales of the magazine, which she puts together from her home. It now has thousands of readers worldwide.

A passionate campaigner for increasing diversity in the beauty and fashion industry, Gems said: "By March we had already hit over £8,000! I am so very excited to know that we will smash our target this year and help raise funds for MDUK.

"When I can't move or sit up or eat independently, it gets me through those hard times, knowing that I am achieving my goals in life, regardless of the position I have found myself in due to my diagnosis."

The ball, which was held at the Guildford Holiday Inn, was the first of *Creative Portrait Magazine's* annual fundraising events and next year there will be a debut fashion show.

Sal Lalji, External Affairs Advisor, who was there on the night, praised Gems' fundraising efforts:
"Gems is, quite frankly, an unstoppable force of nature! We're very grateful to Gems and her brother Dan for all their support. The ball was a wonderful evening and it was lovely to see the fantastic turnout."

Independence regained

Cambridge mum and grandmother, Sharren Donaghey (pictured with her grandchildren) was diagnosed with limb girdle muscular dystrophy about 10 years ago. She was in her early 50s.

While the muscle-wasting condition gradually and significantly limited her mobility, a grant from the Joseph Patrick Trust (JPT) has enabled Sharren to 'live my life again'. In February 2017, Sharren received a grant towards the cost of a self-folding scooter.

"I had always had bad posture. When I was about 50, I thought I'd improve my fitness and go to a Pilates class. I wasn't at the same level of fitness as those in the classes, so I had some private lessons at home with a Pilates instructor. After three or so sessions, she told me she thought something was wrong. She suggested I go to my GP and perhaps a neurologist.

"I was quite amused that she would say something like that, but I did as she suggested. My GP laughed at me and told me not to be silly, but referred me to a neurologist anyway. After some tests and a muscle biopsy, I was diagnosed with limb girdle muscular dystrophy. It was quite a shock.

"As I've got older, the condition has got worse and worse. I can't walk very far, and struggle to lift anything. I started to think about a scooter and – looking to the future – realised I needed a self-folding scooter.

"That's when I came to Muscular Dystrophy UK, applied to the JPT and got a grant.

"Having the scooter means I can join in with things a lot more. I've always loved visiting markets with my family, but I haven't been able to do that for a number of years as the walking was too tiring. Over the last bank holiday weekend, I was able to go around our local market for the whole day – everyone else was exhausted, but I was fine!

"I can also take my scooter on a ship or on a plane. So in the summer, I'm going to visit my sister who lives in France. I haven't been able to do that for about 10 years.

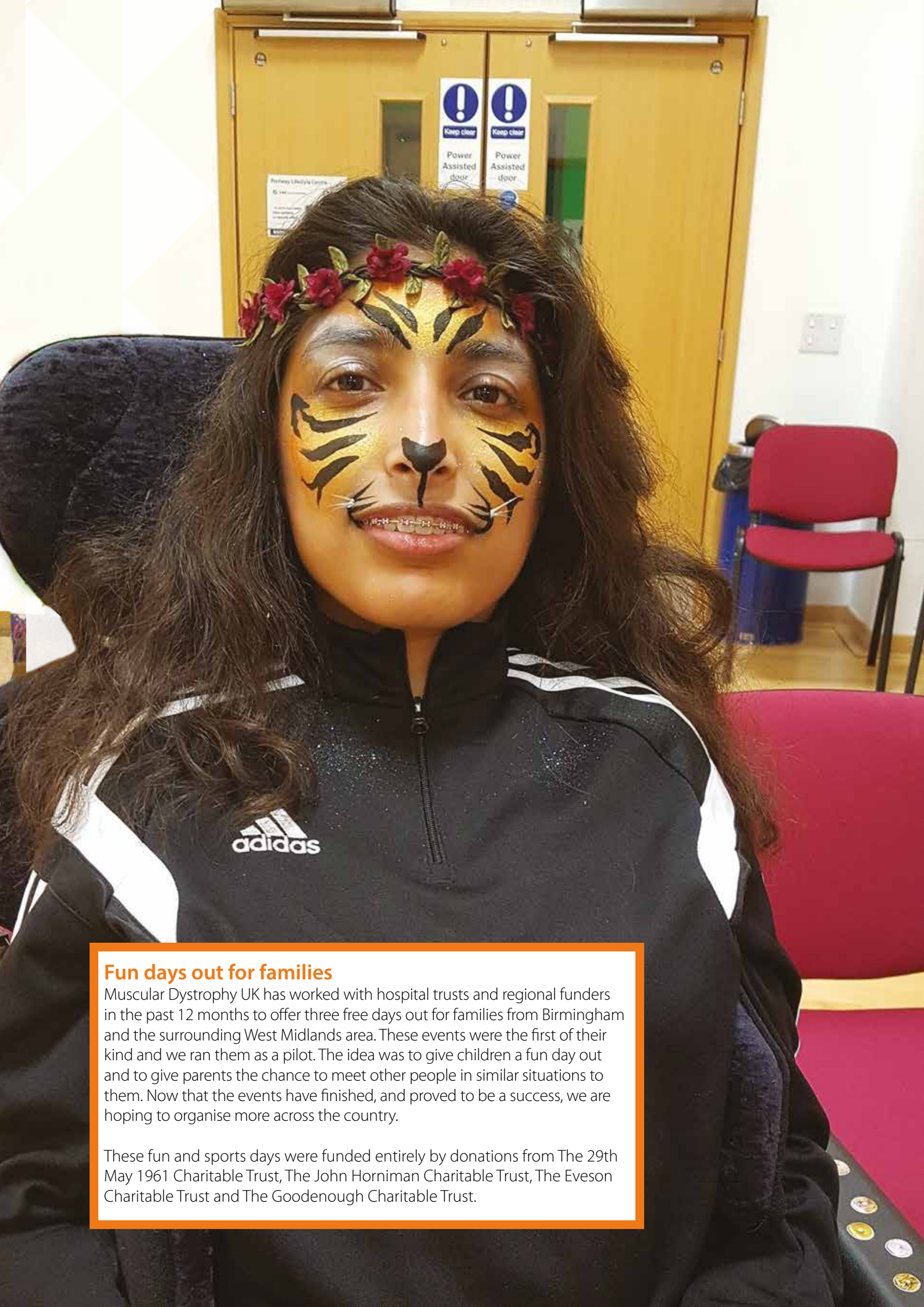
"The scooter has enabled me just to get on with my life."

About the Joseph Patrick Trust (JPT)

Muscular Dystrophy UK is committed to improving quality of life for people with muscle-wasting conditions and enabling independent living. Through the JPT – the grant-giving arm of the charity – we empower people by providing funds towards the cost of specialist equipment for children and adults with muscle-wasting conditions.

Grants are awarded for equipment not available through statutory services, including wheelchairs, scooters, and mobile arm supports. The Grants Panel is also keen to award grants towards communications-based assistive technology.

Find out more at **www.musculardystrophyuk.org/jpt**



Fun days out for families

Muscular Dystrophy UK has worked with hospital trusts and regional funders in the past 12 months to offer three free days out for families from Birmingham and the surrounding West Midlands area. These events were the first of their kind and we ran them as a pilot. The idea was to give children a fun day out and to give parents the chance to meet other people in similar situations to them. Now that the events have finished, and proved to be a success, we are hoping to organise more across the country.

These fun and sports days were funded entirely by donations from The 29th May 1961 Charitable Trust, The John Horniman Charitable Trust, The Eveson Charitable Trust and The Goodenough Charitable Trust.

We're all tigers

Wolverhampton sisters, 20-year-old Sanah (pictured above right and opposite) and 17-year-old Zaynab Rauf (pictured above left) both radiate joy and enthusiasm. They brought their *joie de vivre* to MDUK's recent fun and sports days in Birmingham. They loved the opportunity to meet other young disabled people and – in Sanah's case – to find a new passion: Powerchair football.

"It was good to meet other families, and people with spinal muscular atrophy (SMA). I'm going to join a Powerchair football team soon because at the sports day I had the opportunity to try it and really enjoyed it," said Sanah.

"It was good to meet new people and have fun at the MDUK events. They were very informative, there was a nice atmosphere and all the people were loving and caring," added Zaynab.

Both sisters were diagnosed with SMA Type 3 as young children. Their parents, Imtiyaz and Abdul, were devastated. Sanah said her mother found it really hard to take it all in.

"It's hard to be told it's a condition that gets worse as you grow. But my mom and dad dealt with it.

"I can't walk so I use a powered wheelchair to help me do everyday things and go out of the house.

"I'm studying creative media, and I love music, art and photography. Many people miss moments in life and in photographs you get to freeze the beautiful moments that can hold so much, and which last forever. I love self-expression, I love watching people dance – I think it's one of the most beautiful things ever.

"If I were to be an animal, I'd be a tiger. They are strong and powerful. Also, people perceive disabled people as weak but we are all tigers, fighting every day and doing our best."

Zaynab is the second youngest in the Rauf family. She has two older sisters: Sanah, Hina (19) and a brother, Abdul (14).

A student at sixth form college, Zaynab aspires to go to university to study speech and language therapy or social work. She says SMA affects her physically, including her ability to walk.

"I'm very independent and I can do everything myself like getting myself ready, transferring into and out of my wheelchair, and so on. I'm grateful that I can do all this.

"I have a YouTube channel called Zay Zay's World, where I have uploaded a couple of videos. I love watching stand-up comedy – my favourite is Michael McIntyre. In my spare time, I like to listen to music, chill, colour."

To find out more about our fun and sports days, please get in touch with our Outreach, Commissioning and Professional Development team. Contact Hannah Chalmers at **h.chalmers@musculardystrophyuk.org** or **020 7803 4826**.

Bradley and Abbi are the

Pride of Birmingham, in partnership with TSB, honours unsung heroes of all ages

Bradley Addison – Young Fundraiser of the Year

Thirteen-year-old Bradley (pictured below), who has Duchenne muscular dystrophy, has been recognised for his fundraising and commitment to Powerchair football after helping the Villa Rockets win a league and cup double.

Bradley's mum, Sarah Thompson, said that the family was delighted by the news.

"Bradley was over the moon, he couldn't believe that he'd won, or even that he'd been nominated.

"He couldn't stop smiling. He got very tearful over it, actually.

"He's a very sporty child. Sometimes people can't comprehend that a person in a wheelchair could be so sporty, but he loves everything about it.

"He has an encyclopaedic knowledge of the players in all of the football teams and things like that, and he loves Aston Villa. His dream is to work for them when he gets older, if there's the opportunity.

"It's good to know that because of this award, people might get to find out more about Powerchair football. It has really helped Bradley because he meets other people with the same condition and he gets to play sport.

"It's the only time I see him smile, when he's playing football."

Powerchair football is the fastest growing disability team sport in the country with over 1,000 people playing on a weekly basis.

More than half of the people playing have a muscle-wasting condition. Muscular Dystrophy UK sponsors the National Powerchair Football League.

Find out more at **www.thewfa.org.uk**

Pride of Birmingham

who do extraordinary things to help others.

Abbi Bennett – Young Fundraiser of the Year

Nine-year-old Abbi (pictured below) was named Young Fundraiser of the Year at the 2017 Pride of Birmingham Awards. The Bournville schoolgirl received the prestigious honour for helping to raise £147,000 for Muscular Dystrophy UK. TV presenter and campaigner Katie Piper hosted the star-studded Awards dinner and handed Abbi her stunning trophy.

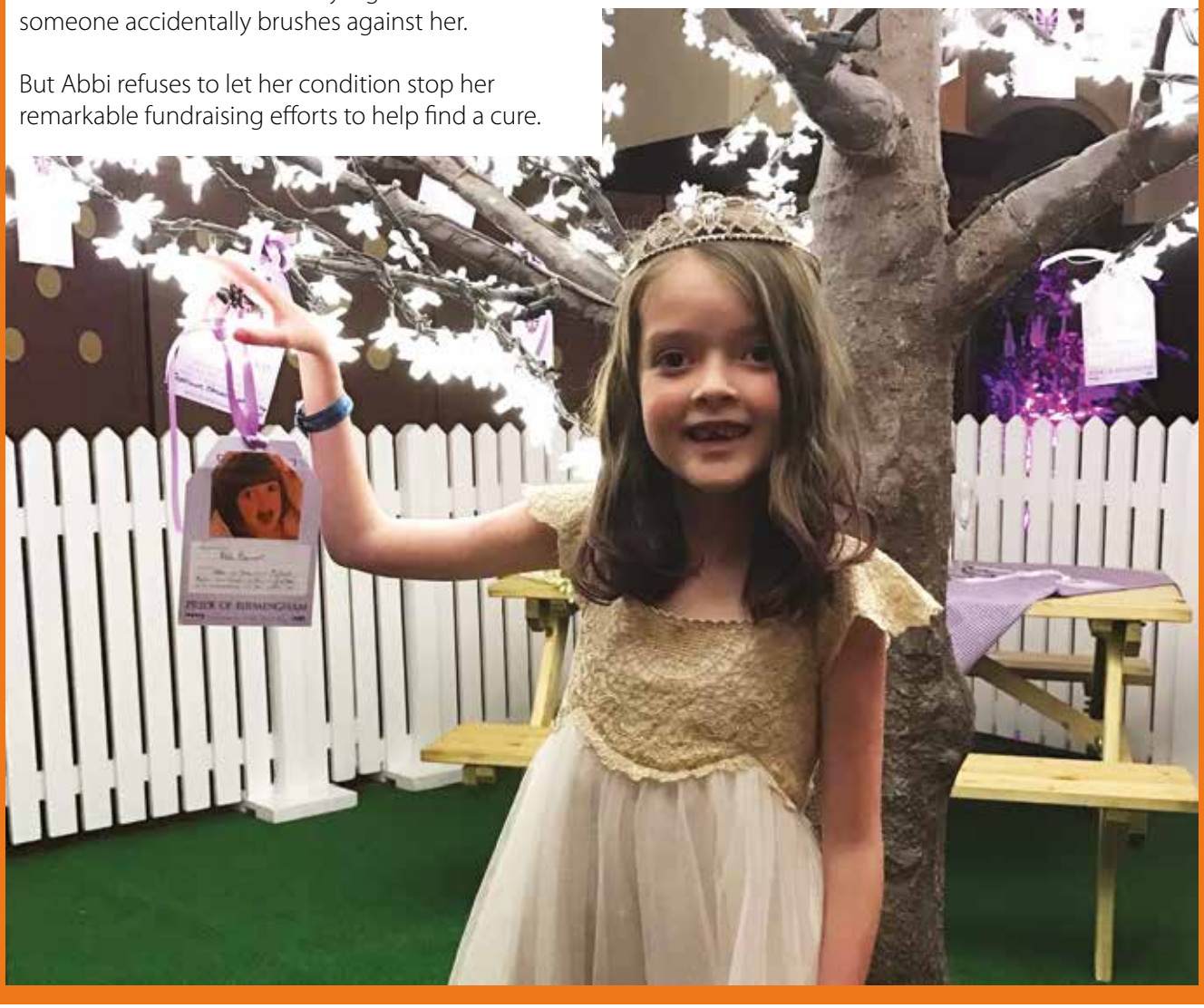
Abbi, who was diagnosed with Ullrich congenital muscular dystrophy at the age of two, is so weak she can be knocked off her feet by a gust of wind or if someone accidentally brushes against her.

But Abbi refuses to let her condition stop her remarkable fundraising efforts to help find a cure.

Abbi gets involved in charity events organised by her parents, Gary and Sarah:

"I'm really grateful for people who give money to charity. We raise money for all the little boys and girls and adults who have the same condition as me to help them."

The Pride of Birmingham judges said: "She is an absolutely inspirational little girl and the amount of money she has helped to raise is truly incredible."



Driving change

Dumfriesshire father, David Gale (pictured above), lost his adapted vehicle during the upheaval around benefits reform. He put together a petition and successfully led a call for the government to stop removing people's vehicles before their appeals had been heard.

David, who has Becker muscular dystrophy, had to return his Motability car last October. As the family's sole breadwinner, he had to use his savings to buy a new car so he could get to his job as a civil servant 30 miles away in Carlisle. He appealed the decision and won back his right to apply for a Motability vehicle. However, because of the inaccurate assessment, payments for his replacement car were leaving him out of pocket.

David started a petition in March to make sure this situation changed. Backed by Muscular Dystrophy UK, his petition secured 750 signatures in five days, and reached close to 51,000 by the end of April. That's the same as the number of people who have, since 2013, lost access to their government-funded Motability vehicles during the switch from the Disability Living Allowance (DLA) to the Personal Independence Payments (PIP).

Following extensive coverage of the story, Motability said they would let people keep their vehicles for six months after being told to return them. This is a major win but Muscular Dystrophy UK will continue campaigning for an overhaul of both the rules and implementation of the assessment process.

David said:

"I need my car to get to my job in Carlisle and support my family. Facing reassessment, losing my car and spending hard-earned savings I can't get back on a replacement vehicle has been a waste of my time, energy and money. We urgently need change so that thousands more people can avoid the distress I have been put through."

Baroness Celia Thomas CBE, Vice-President of Muscular Dystrophy UK and Liberal Democrat spokesman on disability, said:

"The high number of successful PIP appeals for enhanced rate mobility demonstrates that Motability is struggling to cope with the delays in the appeals' system.

"David is to be applauded for standing up for the thousands of people who have been reassessed wrongly and have lost their vehicles, independence and, often, large sums of money because of the inconsistency of reassessments and long wait for appeals. The PIP reassessment process has been brutal and unfair for thousands of people. I urge the Government to sort this problem out."

Target Research

Welcome to the research pages of *Target MD*.

You may remember from our last edition that the European Medicines Agency (EMA) was reviewing spinal muscular atrophy (SMA) drug, Spinraza. Well, I'm delighted to report that the EMA has now approved this drug as a treatment for SMA types 1-3. You can read about this in more detail on p17.

You can also read the highlights of the Tenth UK Neuromuscular Translational Research Conference that was recently held in London. It showcased recent findings in neuromuscular research and was attended by a large number of scientists from all over the world.

I hope you enjoy my research round-up and please do get in touch if you have any questions about the topics covered. The next full edition of *Target Research* will be published in November.

Dr Jenny Sharpe
Editor, *Target Research*

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Scientific research articles

Study reveals developmental aspect to CMT
Charcot-Marie-Tooth disease (CMT) is considered to be a neurodegenerative condition, as the peripheral nerves usually deteriorate during adolescence or adult life. However new research studying CMT 2D mouse models suggests that problems might occur much earlier and that the development of the nervous system is affected.

Genome editing in Duchenne mouse models
Researchers in the US have shown that genome editing can correct the underlying genetic mutations in mouse models of Duchenne muscular dystrophy. It increased the amount of dystrophin protein in the heart and muscles of the mice, leading to an improvement in muscle function. Although these are encouraging results, the overall safety and specificity of genome editing needs to be improved before it can be tested in people with Duchenne muscular dystrophy.

Early heart treatment important for people with Duchenne or Becker
A phase 3 study suggests that people with Duchenne or Becker muscular dystrophy should begin ACE inhibitor therapy when heart fibrosis (scarring) is first identified and before heart weakness occurs. ACE inhibitors are drugs that widen the blood vessels, making it easier for the heart to pump blood around the body. People with Duchenne and Becker muscular dystrophies are often prescribed ACE inhibitors but there is currently no clear consensus on when they should start them.

photo © yodiyim/Fotolia

Update on clinical trials

Promising results for OPMD gene therapy
Benitec Biopharma has developed a gene therapy that can silence (switch off) and replace the mutant PABPN1 gene that causes oculopharyngeal muscular dystrophy (OPMD). This reduced muscle scarring (fibrosis) and improved muscle strength in mouse models with OPMD. Benitec and its collaborators are now developing a next-generation gene therapy potentially to take forward into a phase 1/2 clinical trial for people with OPMD.

Orphan Drug Designation for Resolaris
Resolaris is a drug being developed by aTyr Pharma that aims to reduce damaging inflammation in several muscular dystrophies, including limb girdle muscular dystrophy (LGMD) and facioscapulohumeral muscular dystrophy (FSHD). It now has Orphan Drug Designation for both LGMD and FSHD, which it is hoped will speed up its development and get it to patients more quickly.

Increasing muscle mass by inhibiting myostatin
Blocking the myostatin protein allows muscles to grow and become stronger, which could potentially be beneficial for people with muscle-wasting conditions. US pharmaceutical company, Acceleron, is currently trialling a myostatin inhibitor called ACE-083 in people with facioscapulohumeral muscular dystrophy (FSHD) and has recently announced plans for a trial for people with Charcot-Marie-Tooth disease (CMT).

Update from Summit Therapeutics
Summit Therapeutics has released an update on its utrophin modulation programme. Utrophin modulation has the potential to treat Duchenne and Becker muscular dystrophies, and is currently being tested in boys with Duchenne in a phase 2 clinical trial. Summit has said that recruitment for this trial is likely to finish in the second quarter of 2017. Initial results are expected during the first quarter of 2018.

EMA gives green light to SMA drug

In April, the European Medicines Agency (EMA) recommended approval for nusinersen – now to be known as Spinraza – as the first-ever treatment for spinal muscular atrophy (SMA). This approval – which was signed off in June by the European Commission – is for a broad licence, meaning that Spinraza can be marketed in Europe for children and adults with SMA types 1, 2 and 3.

Spinraza is a drug that addresses the underlying genetic cause of SMA. It increases the amount of SMN protein, which people with SMA do not have enough of.

What happens next?

The decision on whether to make the drug available to families in the UK is taken by NICE in England and the Scottish Medicines Consortium (SMC) in Scotland. Northern Ireland is formally linked to the NICE process, and Wales will often implement recommendations made by NICE.

In July, we expect to hear if NICE will evaluate the drug. The manufacturer also needs to apply to the SMC, which they have said they will do in the summer.

Expanded Access Programme

While Spinraza's manufacturer, Biogen, sought approval from the EMA for all types of SMA, it set up an Expanded Access Programme (EAP) to make the drug available for free to infants with SMA Type 1.

However, while doctors are doing all they can, the drug is very intensive to administer. Owing to a lack of capacity to accommodate all eligible infants, very few have been able to begin treatment so far.

Muscular Dystrophy UK is working with SMA Support UK, SMA Trust and Treat SMA to push for access to the EAP for all eligible infants with SMA Type 1, no matter where in the country they live.

Roisin and Eunan O'Neill's 16-month-old daughter Katie (pictured right) was diagnosed at four months with SMA Type 1, and began treatment with Spinraza in December 2016 under the EAP in Northern Ireland.

Roisin said:

"We follow many children online who have been on the trial drug longer than Katie and have had more time for the drug to work, and their progress is amazing. Some are holding up their own heads, sitting up, some even standing and walking.

"This has given me and our family such hope, compared to the devastation this time last year when she was diagnosed and there was no treatment available. We feel extremely blessed Katie is receiving the drug.

"We just hope that Spinraza can reach as many people as possible and give them a chance as well. There's no time to waste with SMA. It waits for no child and no parent."

Get involved

Muscular Dystrophy UK is committed to pressing for access to Spinraza, and to working with fellow patient groups, clinicians and Parliamentarians to make this happen. Find out how you can get involved in the campaign by visiting our website: **www.musculardystrophyuk.org/news/news/make-your-voice-heard-in-the-campaign-for-access-to-spinraza/**

Highlights of the 2017 Neuromuscular Translational Research Conference

The tenth UK Neuromuscular Translational Research Conference was held in London in March 2017. Jointly organised by Muscular Dystrophy UK and the MRC Centre for Neuromuscular Disease, the conference showcased recent findings and developments in neuromuscular research and was attended by eminent international scientists.

A keynote speaker at the conference was Professor Ronald Cohn from the University of Toronto. He presented some of his group's research using the pioneering genome editing technique called CRISPR. His group created different mouse models of Duchenne and Becker muscular dystrophy by using CRISPR to remove certain exons of the dystrophin gene.

Professor Cohn also showed some remarkable videos of a mouse model of merosin-deficient congenital muscular dystrophy (MDC1A). After receiving a CRISPR-based treatment, the MDC1A mouse was no longer paralysed in its back legs and was able to run around. This CRISPR treatment was designed to increase the activity of the LAMA1 gene, which compensated for the faulty LAMA2 gene in the mouse.

Another highlight of the conference was the overview given by Dr Richard Finkel from Nemours Children's Hospital, Florida, on therapeutic strategies being developed for SMA. He showed results of a gene therapy trial, as well as data from the Spinraza trials that he helped to run in the US. He also showed some videos of children who took part in these trials and who are now reaching milestones never seen in SMA Type 1, such as sitting up, crawling and even walking. Dr Finkel concluded his talk with future considerations for the SMA field, now that there is an approved treatment available. For example, newborn screening should be explored as earlier treatment of SMA gives a better outcome.

Professor Carsten Bönnemann from the National Institute of Neurological Disorders and Stroke, USA, gave an interesting presentation on a very rare and severe type of neuropathy called giant axonal neuropathy (GAN). He is currently leading a phase 1 clinical trial testing the safety of a gene therapy for GAN. This uses an adeno-associated virus to deliver a functional GAN gene into the body. The trial is ongoing and initial results are expected in 2018.

The conference also included talks and posters on a range of muscle-wasting conditions. We were delighted to hear that two of our MDUK-funded researchers won prizes at the conference for their posters: Dr Maryna Panamarova, who presented her research on a mouse model of facioscapulohumeral muscular dystrophy (FSHD), and Dr Maximilien Bencze, who presented his research on muscle fibre death in Duchenne muscular dystrophy.

You can read more about these MDUK-funded projects on our website:
www.musculardystrophyuk.org/progress-in-research/research-projects

(l to r) Dr Alison Stevenson, Senior Grants Manager and Dr Jenny Sharpe, Research Communications Officer at the UK Neuromuscular Translational Research Conference

MAP Nemaline

The MAP Nemaline Family Fund was established by the Park family in 2015 following their daughter Meriel's diagnosis with a very rare condition: nemaline myopathy. Meriel (pictured above) is now eight.

Nemaline myopathy is one of the congenital myopathies, in which changes in the muscle cells make them less able to contract. Fewer than 50 people in the UK have this condition.

"Meriel loves life, is full of fun and won't let anything stop her doing things. She loves school, being with her friends and making up new games in the playground like 'Zooterboarding' – a combination of a scooter and her 'walker' frame tied together.

"A huge sports fan, Meriel can often be found kicking a ball about with older brother Miles (10) from her 'walker' frame, or discussing football with him (Alexis Sanchez being a bit of a hero). Ellie Simmonds is another hero, as is, of course, Prince Harry. He presented her with a WellChild Award in 2015.

"We first connected with Muscular Dystrophy UK about three or four years ago when we looked at the possibility of setting up a restricted fund for research in to Meriel's condition. We set up MAP Nemaline, and MDUK has been an enormous support and help to us as a family over the years."

The family hopes that by raising awareness of this little known muscle condition, it will be possible to directly fund research to make life for children diagnosed with nemaline myopathy in future generations a little easier. MAP Nemaline's support so far has enabled two research projects to begin, and it recently received a further boost of £11,000 from Team MAP Nemaline.

The Team of more than 20 runners took on the Oxford Town and Gown 10k and the Junior 3k in May. Meriel started the race, joined by her friend Lulu and her brother Miles, after he ran the Junior 3k.

Find out more about nemaline myopathy and MAP Nemaline at www.musculardystrophyuk.org/map-nemaline

Alex Polizzi (pictured below with Meriel) presenter of Channel 5's *The Hotel Inspector* and friend of the Park family, ran the 10k with Team MAP Nemaline.

"Anyone thinking of taking part in a Muscular Dystrophy UK Town and Gown 10k should just do it! It's for a fantastic cause, and they will gain the immense benefit of doing some exercise themselves! There may well be some ultra-competitive types powering round, but there will also be the occasional runner, like me, who likes a challenge but not too enormous a one!"

Visit www.townandgown10k.com or go to page 28 to find out how to get involved in the 2017 Cambridge Town and Gown 10k on 22 October.

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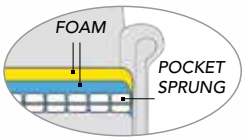

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New resource to help with home adaptations

People often tell us of challenges they face in adapting their homes: thinking of current and future needs, and understanding what is possible. Muscular Dystrophy UK's second edition *Adaptations manual: for children and adults living with muscle-wasting conditions* addresses many of these.

The College of Occupational Therapists reviewed and endorsed the guide.

Revised by occupational therapists (OTs) who work closely with families living with muscle-wasting conditions, the guide includes examples and practical information. It also outlines the process of making adaptations to your home.

"From the arguments for and against specialist baths, to the need for vertical rise seats, the manual has all the information and resources OTs and people adapting their homes will need."
Corinna Keaney, an OT and Muscular Dystrophy UK Advocacy and Information Officer, who led on revising the manual

"MDUK's *Adaptations manual* has proven to be an invaluable resource to my family as we prepare to adapt our home to make it more accessible for our son, Luke, as his needs change.

"I thought I had a good understanding of what we needed, but the manual has helped me think about lots of things I wouldn't have thought about. This could save us from additional costly alterations in future.

"The information is so practical and easy to understand. The authors really did think of everything when it comes to adapting your home. It has made me feel more prepared and more confident in discussing Luke's changing needs with his OT, with the architect and with everyone else involved in adaptations.

"You can pick and choose the parts that are relevant to you. I can definitely recommend that if you're thinking of adapting your home, have a read through the manual and take it from there."
Claire O'Hanlon (pictured above with her son Luke who has Duchenne muscular dystrophy)

To order your copy or to find out more, contact us at info@musculardystrophyuk.org

Campaign updates

Campaigner steps down as MP

A champion for improving access to specialist neuromuscular care and treatments, Dave Anderson (pictured) stood down from Parliament before this year's general election.

Many of Dave's close relatives have had myotonic dystrophy. Throughout his time as an MP, he brought this very personal experience in raising awareness to MPs of the care and support needs of people with muscle-wasting conditions.

Dave chaired the All Party Parliamentary Group for Muscular Dystrophy for over 10 years. He led a groundbreaking inquiry into access to specialist neuromuscular care, which culminated in the publication of the *Walton Report* in 2009.

The report's recommendations persuaded NHS decision-makers to invest in key aspects of specialist neuromuscular care and support, and increased the number of NHS-funded care advisors.

Dave was also at the forefront of the successful campaign for access to Duchenne muscular dystrophy treatment, Translarna, which NICE approved in July 2016.

"Through my time working with Muscular Dystrophy UK, I have met numerous patients and family members who are battling courageously to raise standards of neuromuscular care. It has been my privilege to give them a voice in Parliament," Dave said.

In 2011, Dave's tireless campaigning earned him the Dods Westminster Charity Champion Award.

Campaign win for Trailblazers

The commencement of section 165 and 167 of the Equality Act 2010 in April 2017 was a result Trailblazers had campaigned for since the Act came into force.

This significant change in law brings three new key protections to disabled people in England and Wales.

Taxi and private hire vehicle drivers will be obliged by law to:

- transport wheelchair users in their wheelchair
- provide passengers in wheelchairs with appropriate assistance, and
- charge wheelchair users the same as non-wheelchair users.

Any taxi drivers who do not follow these rules and don't have a medical exemption will face a possible £1,000 fine.

These new requirements will complement the rules already in place. These prevent discrimination against the use of assistance dogs, and underline Government's wide-ranging commitment to support transport networks for everyone.

To join Trailblazers, where you'll get to make friends and campaign on issues that are important to you, visit www.musculardystrophyuk.org/trailblazers

Working with Clinical Commissioning Groups (CCGs)

Muscular Dystrophy UK campaigns to ensure that the NHS funds best-practice healthcare for people with muscle-wasting conditions. Our supporters work with different commissioners across the country to deliver improvements to NHS care.

Whether it's pressing for funding for new care advisors or improving hospital referral pathways, we want to make sure everybody, no matter where they live, gets the right care when they need it.

Anisa Kothia, whose son Yusef has Duchenne muscular dystrophy, works with North Kirklees CCG:

"I feel very passionately about being the voice for my son and other parent-carers to get the right services across North Yorkshire.

"By attending meetings with my local CCG, I can push for GPs and physios to complete the MDUK online training modules for neuromuscular conditions.

"Recently, I was invited to meet up with the CCG bodies to help them improve respiratory services in

Kirklees. This means that people in the region will get easier access to cough assist machines and we hope they will fund a specialist respiratory care nurse for adult care.

"Unfortunately, I have learned through my experience that we will only receive high-quality services and care if we shout out loud. The commissioners only learn about the effectiveness of the services by listening to patient experiences. It is important that we attend CCG meetings so that the services, which are fundamentally important to us and our children, are planned correctly and effectively.

"The future for quality of healthcare for our children and families is in our hands, and we need to work together with the CCG to fight for the right care."

To find out more about working with CCGs, visit **www.musculardystrophyuk.org/news/news/your-campaigns-with-commissioners**

Information resources to help you live more independently

Muscular Dystrophy UK has developed a range of helpful information resources for people living with muscle-wasting conditions:

- **care plans** – to give you a tailored approach to your healthcare
- **alert cards** – for 16 different muscle-wasting conditions, outlining their vital and specific issues
- **factsheets** – up-to-date and accurate information about muscle-wasting conditions
- ***Living with ...*** – in these postcards, individuals and families share their stories of living with a muscle-wasting condition
- **welfare factsheets** – about welfare, financial or practical issues relating to life with a muscle-wasting condition
- **top tips** – our Advocacy Ambassadors share their top tips of seeking and securing financial and practical support.

To find out more, or to order your copies of any of these resources, please call **020 7803 4800** or visit **www.musculardystrophyuk.org/information**

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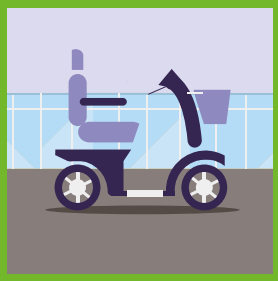
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Here for you: clinic support

One of our new commitments for you

Receiving a diagnosis of a muscle-wasting condition can be devastating, leaving you feeling isolated. At a time like this, it is important to know that the charity is here working with your clinicians to ensure you receive the best health and social care and advice.

As part of our new commitment – Here for you: clinic support – we now have health and social care professionals on our staff to do just that. Offering tailored support in local communities, they are working alongside teams in clinics around the UK to ensure you get access to all the resources and community support you need, as well as the best of specialist healthcare.

Three of the advocacy officers will be offering MDUK services in clinics in Wales, Northern Ireland and Scotland, and will soon be joined by roles in London, Newcastle and Oxford.

Suni Narayan, Head of Clinical Development (who also works clinically as a physiotherapist and care advisor based in University Hospital Southampton NHS Foundation Trust):
"I will be leading on this exciting new venture to develop these roles to provide support and advocacy services locally.

"Over two years our aim would be to evaluate the support provided by the advocacy officers and based on the success of this roll it out to other centres."

Jackie Munro, Advocacy and Information Officer, trained as a social worked and is based in Scotland:
"I will be working with the teams across Scotland, getting to know individuals and their families and offering advocacy support and information about MDUK."

Rebecca Brown, Advocacy and Information Officer, is based in Wales:
"My role is unique because it's so varied and I get to help people with problems daily. Often it just helps to know that you are not alone. I have a muscle-wasting condition and I remember feeling very isolated and not knowing who to go to for information or support when I was diagnosed. I want to help change that."

Corinna Keaney, Advocacy and Information Officer, is an occupational therapist based in Northern Ireland:
"Muscle-wasting conditions are rare. We know that many people feel isolated because there just aren't the community services available, and some healthcare professionals may not always understand muscle-wasting conditions. Part of my role is to bridge that gap – provide practical support to families where required and assist with the upskilling of healthcare professionals."

Find out more about this new commitment at www.musculardystrophyuk.org/about-us/new-commitments-for-you/clinic-support


Suni Narayan


Corinna Keaney


Jackie Munro


Rebecca Brown

London Marathon

On a warm Sunday in April, 93 remarkable people ran 26 miles through London and raised £250k to help beat muscle-wasting conditions. In other words, each #TeamOrange runner – some first-time runners, others seasoned veterans – raised more than £100 for every mile. An extraordinary feat. And each runner had a reason to take the marathon on. Here are just some of them:

"My son Alfie, 10, was diagnosed with Duchenne at the age of three, and we've supported MDUK since then. Until May 2016, he was still able to walk short distances. Knowing he was likely to be unable to walk by summer 2017, he set his own challenge of walking a marathon over the summer holidays to raise money for MDUK. Sadly, at the end of May his legs gave way beneath him and in falling to the ground he broke his left leg. This made him entirely dependent on his powerchair and put paid to his plans of walking his own marathon.

"After a tough summer of physio, Alfie got himself back on his feet and on 18 September he walked a Mile for Muscles. It took him four hours and 15 minutes, and huge amounts of grit and determination. Inspired by Alfie, I ran my first Marathon in April. I loved the race and I enjoyed all the cheering from the volunteers, it was amazing. I was knackered at mile 20 but when you see them cheering for you it spurs you on. Each step in those final miles around London did hurt and I had to dig deep to finish the course but that fails to compare with Alfie's efforts to walk that mile. It's very emotional for me because of everything it means. I had such amazing support. We raised over £4,000 and it has been overwhelming how great everyone's been. The messages of support have been phenomenal!"

Rachael Yates (pictured above), who took on the London Marathon after her son, Alfie, took part in Move a Mile for Muscles for MDUK

"The Marathon was fun. It was definitely challenging. There were times when I was doing it when I thought, 'I can't believe I'm actually running the Marathon.' The supporters were great and I loved going past the cheer points, particularly at mile 19 when I really needed to dig in. It really helped to have people encouraging me. I didn't realise how generous people were going to be. I've raised £6,300, which is a lot more than I expected. The charity has been really helpful and supportive, particularly with all the updates and advice on blogs and social media. I support MDUK because my brother Jason died when he was very young from SMA Type 1."

Stacey Langdon, who ran her first London Marathon this year

"I lost my first husband to muscular dystrophy when he was just 35. I wanted to run in memory of him, as well as for my daughter Jade, who has just been diagnosed with FSHD at the age of 22. As of yet there are no drugs and no cure for this progressive muscle-wasting condition, which leaves us feeling gutted and helpless. Hopefully by running the marathon and raising money and awareness, one day – just one day – there may be a breakthrough. I've had an awesome experience running the Marathon and raised over £6,000! This is the least I can do for my family and all others living with the condition out there."

Jackie Smith, who ran her first London Marathon this year

"My nephew Ross has Duchenne muscular dystrophy. He was diagnosed at two and a half and now he's 20. We've done a lot of fundraising: we've raised about £40,000 over 20 years, and I've run the marathon about four times for MDUK, usually with some friends. This year, I got to a point where I had to walk, but I really wanted to finish. It was an amazing crowd as ever. I saw the MDUK volunteers cheering at all three points and they were fantastic – it's really great to hear them shouting your name. The charity really helped me with the fundraising as well, and told me to let them know if there was anything I needed. It's such a good cause and I'm very happy to be involved. Would I run it again? Why not!"

John Pike, a seasoned marathon runner

Fundraising

Oxford Town and Gown

Runners packed the city streets of Oxford on Sunday 14 May for what was the most successful Town and Gown race in our event's history. Some 4,400 runners lined up for the 10km with over 300 runners taking on the shorter 3k Junior Fun Run. The total raised by our amazing runners has passed £160k and more is still coming in. Huge thanks to all who supported us on the day.

On page 19 see how Team MAP Nemaline got involved in supporting the Oxford Town and Gown 10k.

Photo credit: Sussex Sport Photography

Leicester Town and Gown

Thank you to all who took part in our inaugural Leicester Town and Gown 10k on Sunday 5 March. The weather was wet, but spirits were high as runners took on our park and university course. They also raised over £10,000 for Muscular Dystrophy UK – thanks to everyone who braved the wet weather!

Photo credit: Sussex Sport Photography

Cambridge Town and Gown

Inspired and don't want to miss out on the next Town and Gown? Fear not, our third run of the series will be returning to the beautiful city of Cambridge on Sunday 22 October 2017. This year we are aiming to have 2,000 runners at the start, so join us now and help us beat muscle-wasting conditions faster. Just like last year, the 3k Junior Fun Run is also back at Cambridge. Hope to see you there – it's a perfect chance to get the whole family involved and make a day of it!

Sign up for only £22 at
www.townandgown10k.com/cambridge

Photo credit: Sussex Sport Photography

Sports Quiz

Thank you to all those who joined us at Lord's Cricket Ground on Thursday 9 March 2017 for our Celebrity Sports Quiz. A big thank you to our celebrity guests for coming along and supporting us on the night. Our President and quizmaster, Sue Barker OBE, and our host for the evening Martin Bayfield, did a great job and helped us to get those all-important auction bids.

Our guests raised an incredible £104,000. This could enable us to encourage the brightest young scientists to stay in the field of neuromuscular research by supporting a research student through their PhD.

All of us at Muscular Dystrophy UK would like to say a huge thank you to every person who took part in our 2017 **Go orange for Day** and made Friday 27 January our brightest day of the year! It was the second year in a row that we held the event and it was another roaring success!

Over 180 different companies, schools and clubs took part and more than 38,000 people across the UK dressed in orange. This was a truly amazing show of support – and orange!

Thanks to everyone who took part. You have all helped to raise awareness of muscle-wasting conditions, educate others and raise vital funds for research and support. The day raised £36k – that's enough to fund over eight months of groundbreaking research, or to give 20 grants towards the cost of specialist equipment.

Fancy getting your office or school to **Go orange for a day** in 2018? Put Friday 2 February 2018 in your diary and register to take part at **www.musculardystrophyuk.org/go-orange**

Photo credit: Robert Kneschke/Fotolia

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*Friends of MDUK get **50 percent off** conference tickets, as well as a whole host of other great benefits: the charity magazines sent to their doors, discount off holidays, specialist insurance, and more (see below.)

Friends of MDUK

When Hayley Lloyd and her 11-year-old son Tommy (pictured below) went on holiday to Spain last year, finding accessible accommodation was a priority.

"I booked the holiday through a travel agent and explained about Tommy's condition (he has limb girdle muscular dystrophy). The agent advised me I would need to contact the hotel directly regarding Tommy's disability to check if they could help with an appropriate room.

"The hotel was a recommendation from a friend who had stayed there before.

"Luckily the hotel staff were wonderful and had allocated us an apartment right next to the amenities (restaurant and swimming pool). Tommy is still walking at the moment, but struggles with long distances so the resort was just perfect. Essentially for Tommy, the room had a disabled bathroom, which was so helpful.

"We had a fabulous accessible holiday and as a result would definitely return there again."

Become a Friend of MDUK and you'll get £40 off one holiday booking with Handiscover each year. Handiscover does all the research for you into accessible holiday accommodation. They check all of the accommodation listed on their website to ensure it meets your needs.

Friends of MDUK

As a Friend of MDUK, you'll join us in the fight against muscle-wasting conditions, while enjoying a whole range of great benefits for you and your family. You'll get discounts on holidays, specialist travel and car insurance, and a massive 50 percent off Muscular Dystrophy UK's conferences, as well as a subscription to the charity's flagship publications.

It costs just £15* a year to become a Friend of MDUK. Join today: visit **www.musculardystrophyuk.org/friends** or call **0300 012 0172**.

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