Muscular Dystrophy UK's lifestyle magazine

Issue 2 – 2018

Target MD

Powerchair football – what a season!

Target Research: news and updates

Stories of our amazing supporters

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
Bradley Bates, who has SMA, plays Powerchair football for West Bromwich Albion PFC. Read more on p34.
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Hello

Hello and welcome to our summer edition of *Target MD* of 2018. As always, you'll read stories from a range of amazing people making every day count.

You'll read a round-up of the action-filled Powerchair football season that's just ended. And you'll meet Nicola and Katie, who talk about not only what it means to live with a progressive muscle-wasting condition but also about the things that really matter to them. Like sport, travel, pets, as well as family and work.

You'll meet Dr Ros Quinlivan, and you'll see her passion for and dedication to her work and the huge difference that makes. She works alongside MDUK in numerous ways to improve quality of life for everyone living with muscle-wasting conditions, and has been instrumental in a number of positive changes and developments.

You'll also read of the amazing fundraising efforts of a number of people across the UK. And about some campaigns that are making real change. We can't thank you enough for the huge difference you make in the fight against muscle-wasting conditions.

Thanks to those of you who took part in our survey by telling us how we can make this the magazine you want to read. Watch this space!

I love hearing 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

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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From the CEO

This is my last article in *Target MD*, as I step down from the role of CEO in September and I've shared some reflections later in this brief overview.

I want to start by highlighting encouraging news of potential treatments together with some disappointing news of a drug being discontinued after it failed to demonstrate a benefit in clinical trial.

Gene therapy is regarded as a promising therapeutic route for Duchenne (and potentially other conditions including limb girdle muscular dystrophy) after successful trials in animal models. Three trials are currently underway in the US using gene therapy, and preliminary results were announced by Sarepta from their trial at the Nationwide Children's Hospital in Ohio.

These are early days but the results offer genuine hope if they can be sustained over a longer period and in a larger group of boys. There are more details in the *Target Research* pages and you can also talk to our Research team – led by Dr Kate Adcock, our new Research Director – for additional information.

In the UK, we are funding the UNITE-DMD gene therapy study which will recruit boys in 2019. We are working with partners in France and I know the researchers are encouraged by the US results. Every day counts and we will not let up the pressure in the search for treatments, improvements in NHS care and support for independent living. Your fundraising and support enable us to accelerate this vital work.

Finally, it has been a great privilege and honour to be with the charity since 2006. I have met many committed and wonderful people who have given many years to our cause. Some of those, like Professor John Walton and Lord Richard Attenborough, enabled the charity to make a national impact. Other very determined people, like Alan Richmond and Jim O'Hagan, for example, have made an enormous contribution through local Branches, in their communities and, of course, for the charity nationally.

The baton is passed to the next generation and we can be confident we are heading towards the day when there will be effective treatments available for many of the muscle-wasting conditions. The first licensed drugs are now available to treat some causes of Duchenne and SMA. Also, families affected by severe mitochondrial disease can now access the groundbreaking IVF technique mitochondrial donation at the Newcastle Centre.

This progress in treatments underlines the impact of our research and our work with the NHS and regulatory bodies such as NICE and the Scottish Medicine Consortium.

Muscular Dystrophy UK has achieved so much and is making a huge difference today in the fight to beat muscle-wasting conditions. There is much more we need to do, of course. I know the charity will not slow down until the fight is won and I will continue to be a proud supporter. It has been a real privilege and an honour to lead the charity.

Thank you so much for all your support.

Robert Meadowcroft, CEO

KATIE
on sport, animals and her new, different life

Katie Hammond lives in Hampshire with her three cats, three rabbits, guinea pig and tortoise. A Patient Safety Care Coordinator/Staff support advisor at University Hospital Southampton, Katie is a keen swimmer who enjoys socialising, camping and trying new places.

"I swim once a week. I really enjoy swimming and recently took part in the local swimathon. I joined a disabled swimming group two years ago and find I am much more comfortable attending a private session, without being stared at."

Katie was diagnosed with facioscapulohumeral muscular dystrophy (FSHD) as a child:

I was showing the obvious signs in my shoulders, and my eyes didn't close properly. My walking wasn't affected and I didn't really understand. I quite enjoyed going to see the doctor as I enjoyed going on the giant rocking horse in the waiting room!

My mum recalls being 'gutted' when she found out I had FSHD. I was the active child, always running and playing sport. When I was in secondary school, I was appointed one of four sports prefects in a school of about 1,400 pupils.

I also ran 10k races for charity and loved cycling and playing football with my brother. When I was at college, we did lots of sporting challenges – I loved it all!

After leaving school I worked full-time as a lifeguard until I started college and completed a BTEC National diploma in Public Services. After various roles with the NHS, I decided to go to university and train as an Operating Department Practitioner. I started that job in 2011 and loved every minute.

I began to struggle with the job as it involved moving patients, transferring patients, pushing beds and trolleys around. I was getting very tired with the increased muscle weakness. I even stopped going out with friends as I was too tired and found I wasn't enjoying life much; only working and sleeping.

In 2016, I saw a job advert for patient safety and applied. It was a promotion, and I didn't hold out much hope, having disclosed my disability. But I was given the job and the fact my walking was getting worse didn't even crop up. My management team has now purchased a mobility scooter to help me get around. They don't question my ability to complete the role.

I stopped seeing my MD consultant many years ago,as he said 'there's nothing we can do', and that was before my condition really deteriorated. I felt alone and scared and didn't know what was normal.

It's very daunting and difficult when, with everything you love from running and cycling, you're suddenly struggling to walk and not even being able to get on a bike without falling off. I developed bilateral foot drop, thigh weakness and worsening balance.

My family struggled as well, as the happy active daughter/sister they knew and loved had gone and this broken, non-functional, unhappy mess was left behind.

I didn't really know what was happening to me or why, but when the new neuromuscular care advisor started in Southampton, I was given an appointment to see her. She made everything make sense and was such a ray of sunshine in my darkest hour.

I've been to two MDUK Muscle Group meetings and find it really interesting to hear how other people are affected by their condition and to learn of the different conditions. It's nice to meet people in similar frustrating circumstances.

I've had to accept that I'll never be the same and I had to learn to grieve for the old me and let go. I am now a stronger person and I have my smile back. Life isn't over, it's just beginning in a different and more challenging way.

Having muscular dystrophy can often mean adjusting to a new and unexpected reality, so it can really help to meet others and talk about the things that matter to you. To find an MDUK Muscle Group meeting near you, visit www.musculardystrophyuk.org and search for local muscle groups.

FSHD

We're driving research into FSHD by supporting two preclinical projects as well as the UK patient registry. Between 2,000 and 2,500 people in the UK have FSHD, which particularly affects the muscles of the limbs, shoulders and face. It can be diagnosed at any age. If you'd like to speak to someone about your condition, our helpline is here for you on 0800 652 6352 or info@musculardystrophyuk.org

SPIRIT BEHIND
The Dream Stone

A new children's book – *The Dream Stone* – is now available to buy with all royalties supporting the MAP Nemaline family fund at Muscular Dystrophy UK (MDUK).

The book is based on the true story of Meriel Park, a young girl with nemaline myopathy, who set herself a challenge a couple of years ago – to reach the top of Mount Snowdon. This became her 'Dreamstone Triathlon' challenge.

Anna-Marie, Meriel's friend and carer, wrote the book with the help of Meriel at every stage. They helped with everything from suggestions when Anna-Marie suffered 'writer's block' to creating illustrations for the story. Meriel's brother, Miles, also helped with the illustrations.

The debut novel chronicles their epic expedition on Mount Snowdon, and shows that disability should never be a barrier to your dreams.

The book is available to buy from Blackwells at: blackwells.co.uk/bookshop/product/9781999954307

(l to r) Miles, Anna-Marie and Meriel

Nemaline myopathy

We're funding research internationally to improve our understanding of nemaline myopathy and to accelerate the path to treatments. Nemaline, or rod, myopathies are a group of conditions which fall under the umbrella of congenital myopathies and are characterised by rod-like structures in the muscle cells. Around one in 50,000 individuals are estimated to be affected. If you'd like to speak to someone about your condition, our helpline team is here for you on 0800 652 6352 or info@musculardystrophyuk.org

DEEP IN THE HEART OF YOUR BRAIN:

notes from an exhibition

Jacqueline Donachie, Moira Jeffrey and Nicola White

Deep in the Heart of Your Brain was the title of Jacqueline (Jackie) Donachie's 2016 show at Glasgow's Gallery of Modern Art in Scotland. Central to the exhibition was *Hazel*, a compelling film connecting the experiences of sisters where one sibling has inherited the gene for myotonic dystrophy and one has not, to a wider discussion around relationships, age and appearance. Jackie is interested in the capacity of artworks to influence research and care in the field of genetics, and has collaborated for many years with researchers in Glasgow and Newcastle.

Jackie raises questions around health, ability, and the assumptions made both by 'the outside world' and within family dynamics. Art can be a powerful way of articulating lived experience – everyone has a story to tell, to share. The book contains full transcripts of Jackie's frank interviews with sisters, as well as a new, commissioned work of fiction by award-winning author Nicola White, and an essay by journalist and lecturer Moira Jeffrey looking at life stories, epiphany and sisters.

Jackie, who doesn't have myotonic dystrophy and her sister Susan does, interviewed 11 similar pairs of sisters from all over the UK. She asked them all the same questions.

"My goal was to give an insight into what it means to live with myotonic dystrophy. It's not medical. I wanted to talk about things that aren't related to the condition, and to present the normality of these women's experiences and to write down their words. I didn't want to make something that was over-emotional.

"I wanted to know about their fashion likes and dislikes. How each would describe their sister; their worst thing; what one thing they would change.

"A lot of the women talked about how under-recognised the condition was and how little people knew about what it means to have it; how people don't understand. That frustration was shared by all the sisters.

"It was quite an emotional process for me, particularly talking to other unaffected sisters. I found it quite difficult, quite moving. I talked with another sister about what it might be like to have a sister who doesn't have the condition.

"Affected sisters are used to talking about their condition. Unaffected sisters don't need to think about it as much.

"Through my book, I want people to learn about the condition. I'd like professionals, who deal with the medical side of the condition, who look at the cells, to see myotonic dystrophy as just something that people have. That people are not defined by their condition; they have interests, they are sisters, they have lives beyond hospital appointments."

This publication is an excellent resource for scientists, artists, and families living with myotonic dystrophy, looking at the complexities around disability, care, relationships and ageing.

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Myotonic dystrophy
We're accelerating progress in myotonic dystrophy research by supporting six research projects and the UK patient registry. About 9,500 people in the UK have a form of myotonic dystrophy. It is a group of inherited conditions that show muscle weakness and myotonia. If you'd like to speak to someone about your condition, our helpline team is here for you on 0800 652 6352 or info@musculardystrophyuk.org

MAKING DREAMS COME TRUE

Nicola Upfield lives in Hampshire with her husband Gary and rescue dog, Bones. A season ticket holder at Portsmouth Football Club, Nicola enjoys reading, watching films and travelling whenever she can:

Although I had a degree in history, I wanted a secure job that would pay enough to allow me to visit nice places. So I decided on accountancy, despite the fact that maths was never my strong point!

It was a hard slog – 15 exams in under two-and-a-half-years – but it's been worth it. I work in the audit department so going into various different business to evaluate their systems as well as looking at their finances. I get to meet lots of different people.

As I've become less mobile I have become more office-based and my managers have been really supportive about that. My whole team are really helpful on a day-to-day basis and all look after me.

I was diagnosed with a mutation of the FHL1 gene in 2010, when I was nearly 25. I was always really sporty and athletic when I was younger – a member of Portsmouth Athletic Club, I ran in the national cross country championships for both club and county.

My friend and I had decided to do the Great South Run to raise money for charity but I'd noticed I was carrying my foot strangely and couldn't raise my left arm very high when running. I visited my GP a few times, and although he suggested swimming, my parents paid for me to see a physio. After six months nothing had improved so he wrote to my GP requesting a referral to the hospital as soon as possible.

I saw a Neurology Consultant who took five minutes to diagnose me with a muscle-wasting condition.

It then took a number of years to get to my specific diagnosis, but I'm told there are only a handful of documented cases to refer to and even between these cases the symptoms vary quite a lot.

My condition affects all my muscles. The weakness has progressed sporadically; my left arm is virtually useless on its own – the right has to pick it up and put it where it needs to be as I can't raise it from my side. I have foot drop in both my feet so I wear splints on both legs.

I walk with a hiking pole (I'm too tall for a normal walking stick), I have appalling balance and I can no longer get up on my own if I fall. I'm unable to get up a kerb without help and my husband helps me dress in the mornings. Because of the contracture in my muscles, I can't bend in all the right ways to get certain types of clothes on.

I get anxiety going to unfamiliar places and I'll only go if I have someone with me who's very close to me and aware of my needs. When we go away or out for the day we take a wheelchair because I can't walk any distance anymore and uneven surfaces are my enemy.

We moved to a bungalow the same year we married and had to completely renovate it. But it was worth it to get a bungalow on a flat road, with a flat entrance and close to a bus-stop!

We were all pretty devastated when I got my diagnosis, finding out that it's only ever going to get worse, and that there's no cure or treatment (something health professionals tell you pretty quickly).

My boyfriend of about five months said whatever happened he didn't care, he'd push me wherever I needed to go. Eight years down the line, Gary is still my rock.

I was so chuffed I didn't use my stick all day at our wedding because everyone just knew to hold on to me! I have a great support network of close family and friends and my mum in particular is amazing.

I first heard about MDUK when I met my consultant at Southampton University Hospital. He introduced me to the Neuromuscular Co-ordinator and Specialist Physiotherapist, Suni Narayan. She's also MDUK's Head of Clinical Development, and has been amazing for both practical and emotional support. She also introduced me to some brilliant people with similar struggles.

I can't say enough good things about her – everyone needs a Suni!

MDUK has helped me in a number of ways: to apply for Personal Independence Payments (PIP), which fund my hydrotherapy sessions; they arranged occupational worker visits when I moved, to help me get some much-needed adaptations in my house; they helped me in getting a better quality of foot supports, more suitable to my needs, and they're there for me with general advice and emotional support.

Being diagnosed with muscular dystrophy makes life a lot harder but I have learnt to make the most of what I've got. Don't get me wrong – I have real down days but I feel sorry for myself for a bit then dust myself off and get on with it. When you have great people supporting you it does make it easier.

In 2015, I realised my dream of going on safari in Africa with my husband and two of our closest friends.

Last year we spent three weeks in Thailand for our honeymoon – travelling around on sleeper trains and ferries, visiting national parks, elephant sanctuaries and island hopping.

It wasn't easy and there were a few 'just laugh it off' situations but it was so worth it. My highlight – being lifted off a speedboat on to a ferry in the middle of the sea by two lovely Aussies!

MDUK is always here for you with information, advice and support. To find out more, call us free on 0800 652 6352 or email info@musculardystrophyuk.org

Muscular Dystrophy UK
Fighting muscle-wasting conditions

Take the leap!

Make Today Count 2018

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Join Muscular Dystrophy UK's Make Today Count event in September and help beat muscle-wasting conditions. If you are lucky enough to be our 1,000th jumper, you'll get your jump filmed for free!

Choose a date in September at a range of sites across the country and make your day count.

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www.musculardystrophyuk.org/maketodaycount

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HEART AND MUSCLE
Dr Ros Quinlivan

"Even if we don't have curative treatments for muscle-wasting conditions, you can actually make quite a big difference to improving life."

Dr Ros Quinlivan is a Consultant in Neuromuscular Disease at the MRC Centre for Neuromuscular Diseases, Queen Square in London. She's not only devoted her career to improving the lives of people living with muscle-wasting and other neuromuscular conditions, but has been instrumental in transforming clinical care for this patient group UK-wide.

"When I ran my first muscle clinic in 1991, we only had physiotherapy on offer. We'd also thought that after the dystrophin gene was discovered in 1987, we'd have treatments available in five to 10 years. We still don't have a cure but things have moved a long way in clinical care and research.

"I've seen huge changes: the introduction of a home ventilation service, an explosion in genetics and molecular science with the discovery of new genes and proteins – as well as different conditions – and an explosion in pharmaceutical trials and potential treatments. The introduction of steroid treatment in Duchenne has also had a huge effect – the adult patients I see today are so much better than the adults I used to see many years ago."

Ros has been involved with MDUK and worked closely alongside us since becoming the first MDUK-funded Marjorie Crowe Research Fellow at Guy's Hospital in London in 1990, working across adults and paediatrics. She's seen a lot of change at the charity too.

"MDUK has been hugely influential in improving services across the country. Through MDUK's campaigning, the NHS now funds care advisor posts.

The NHS has invested around £5.6m in 81 new posts.

"Through the NorthStar network, MDUK has standardised care across the UK for Duchenne patients. The NorthStar database has provided excellent information about the benefit of steroids, and the different regimes (daily vs intermittent). Now we're trying to use this model to standardise care for adults across the UK, by developing the NorthStar adult database to look at the natural history of adults with Duchenne. We don't know what the impact of steroids will be in the long term, so it's important to gather that information for the future.

The Adult NorthStar Network, set up by MDUK, brings together specialist health professionals and adults living with Duchenne to make vital improvements in care and support. One of its goals is to create the first formal document outlining best-practice care for adults with Duchenne.

"The charity has also been involved in negotiating with commissioners and getting the South West Neuromuscular network up and running.

"Through the *Invest to save* campaign, MDUK has made a big difference in the resourcing of centres. In 2007, Robert [Meadowcroft] and I were trying to improve services in the West Midlands. We'd had many meetings to get our service recognised as a specialist service.

"We felt these services would give patients better care and could prevent emergency admissions for chest infections, for example. The West Midlands specialist commissioners checked the costs of emergency admissions in the region and were surprised to see they had cost £6m.

"MDUK started developing the *Invest to save* report and started working on a service specification. We presented it at a meeting in London in 2011, where specialist commissioners agreed to do a more formal audit, looking at emergency admissions between June 2009 and June 2011 at 12 hospital sites."

The results of this audit, led by Professor Mike Hanna, were published in 2012. They found that patients experienced poor services and fragmented care across multiple centres in the region.

In response, MDUK developed an approach, for which they received a significant grant to drive forward services for people with neuromuscular conditions, which saw:

- investment in 46 NHS-funded specialist roles
- the launch of the London and South East neuromuscular network
- an ambulance flagging system for people in London living with neuromuscular conditions
- a series of alert cards to inform health professionals about key issues relating to your condition in an emergency, and to co-ordinate care

A re-audit in 2017 of unplanned hospital admissions for people with neuromuscular conditions found that since 2012:

- A&E is still the most common admission route to hospital
- people known to a specialised neuromuscular service had fewer admissions to intensive care units than those who were not
- the proportion of preventable hospital admissions related to a known neuromuscular condition had been reduced
- the mortality rate in hospitals had gone down
- the number of readmissions among people with neuromuscular conditions was reduced
- hospital stays were shorter among admissions for people known to a specialised service.

(Nine Trusts participated in this re-audit.)

- online training modules for GPs and physiotherapists
- personalised neuromuscular care plans.

"While these findings are encouraging, there is always room for improvement. Our next key focus areas is London and the South East coast, where there are no care advisors and no local specialist services."

The Neuromuscular Complex Care Centre (NMCCC)

"After starting a monthly transition clinic with GOSH, it was difficult for me to manage patients who were going to different hospitals for their heart and respiratory care while coming to my hospital for their neuromuscular service.

"It was hard to co-ordinate their care, and we consultants felt it would be best to have all the care under one roof. We worked on a business case and it was approved in the spring of 2012.

"The building started that year and was completed in 2013, and then we recruited the staff and trained them. It was like opening a whole hospital from scratch!

"The NMCCC has six beds. When we opened in the Spring of 2014, we opened for day access. Soon after, it opened two nights a week, rapidly building up to five nights a week.

"The NMCCC is now open seven days a week, and has a very high turnover of patients.

"The consultants from neurology, cardiology, respiratory medicine and gastroenterology meet once a week to discuss patient care together with the therapists, and we all meet monthly to develop care pathways.

"Depending on the need of the patient, they will come in annually, or every three to six months. Some come in as day cases, especially if they are too unwell to come to a clinic – the NMCCC is a better environment for this group. We're very careful to pre-screen all admissions so that no-one comes in with a chest infection.

"The NMCCC has transformed how we provide patient care."

By putting her career into muscle conditions, Ros has made – and continues to make – a huge and positive difference to the lives of so many individuals and families living with muscle-wasting conditions.

To find out more about the work MDUK is doing to improve specialist healthcare, visit www.musculardystrophyuk.org/get-the-right-care-and-support
If you'd like to know more about the NMCCC, speak to your consultant.

INFO DAY ROUND-UP

In April, nearly 200 people came to our information day in Cambridge to hear about research progress to meet with others living with similar muscle-wasting conditions.

Research and clinical professionals focused their talks on limb girdle muscular dystrophy, facioscapulohumeral muscular dystrophy (FSHD), myotonic dystrophy, mitochondrial disease and Duchenne muscular dystrophy. Those who came along had opportunities to meet the speakers and ask questions too.

"Always good to hear from the experts together with patients who raise the questions."

"Thank you, it was our first conference. Very informative and good to meet other people and hear up-to-date information."

Dr Alessandra Ferlini came from the University of Ferrara in Italy to speak about the Nanodelivery of drugs in Duchenne muscular dystrophy.

We created a Facebook live event for this, and you can still view the film on our Facebook page at facebook.com/musculardystrophyuk.

Keynote speaker, Professor Patrick Chinnery from the University of Cambridge, gave an overview of an exciting research initiative set up by the National Institute for Health Research (NIHR). The NIHR BioResource brings together health data from over 100,000 patients, who volunteer to join it. University researchers, as well as those in industry and the NHS can then access and use this data for their research.

If you have a muscle-wasting condition and would like to find out more, please visit the BioResource – Rare Disease website or email rarediseases@bioresource.nihr.ac.uk.

If you'd like to take part in similar events later in the year, join us at our National or Scottish Conferences.

National Conference, London, Saturday 13 October 2018
Book here: www.musculardystrophyuk.org/events/natconf18

Scottish Conference, Glasgow, Saturday 3 November 2018
Book here: www.musculardystrophyuk.org/events/scotconf18

Target Research

Welcome to the research pages of *Target MD*
It's my pleasure to share with you some exciting research news stories from over the last few months. There are some updates from clinical trials and MDUK-funded research, as well as summaries of scientific articles that have been published in journals.

You'll also find results from the first drug trial for congenital muscular dystrophy (CMD), which took place in the US. It's a huge challenge to run trials for very rare conditions like CMD, so it's great to see that this trial was a success. Hopefully this will attract more companies into the CMD field and accelerate research into treatments.

I hope you enjoy this research round-up and please do get in touch if you have any questions about the topics covered.

Jenny

Dr Jenny Sharpe, Editor, *Target Research*
020 7803 2885, research@musculardystrophyuk.org

Progress in MDUK-funded research

Potential gene therapy for Duchenne and Becker muscular dystrophies
The dystrophin gene is one of the largest genes in our bodies, and it plays an important role in muscle movement. Because of the gene's size, it's challenging to incorporate it into a gene therapy. MDUK-funded researchers have overcome this problem by developing an artificial chromosome that contains the entire dystrophin gene. This could lead to a potential treatment for Duchenne and Becker muscular dystrophies.

New myotonic dystrophy research
Falls can be a concern for people with muscle-wasting conditions. They can cause fractures that reduce mobility and weaken muscles further. New research suggests that people with myotonic dystrophy are more at risk of falls than the general population. Some of this data was collected using the UK myotonic dystrophy registry, which is co-funded by MDUK and the Myotonic Dystrophy Support Group. Findings from this study will help to raise awareness of falls, especially among healthcare professionals, and improve the care of people with myotonic dystrophy.

Neuromuscular Translational Research Conference
The 11th UK Neuromuscular Translational Research Conference was held in Cambridge in April 2018. Jointly organised by MDUK and the MRC Centre for Neuromuscular Disease, the conference showcased recent developments in research and was attended by eminent international scientists. We were delighted to see lots of MDUK-funded researchers both presenting their work and networking and learning from others.

You can read our full conference summary at www.musculardystrophyuk.org/news/news/highlights-of-the-2018-neuromuscular-translational-research-conference

Clinical trial updates

First CMD drug trial completed
The first drug trial for congenital muscular dystrophy (CMD) has been successfully completed in the US. The phase 1 trial showed that omigapil was safe in children with COL6-related or LAMA2-related CMD. Omigapil is an oral drug that protects cells from dying.

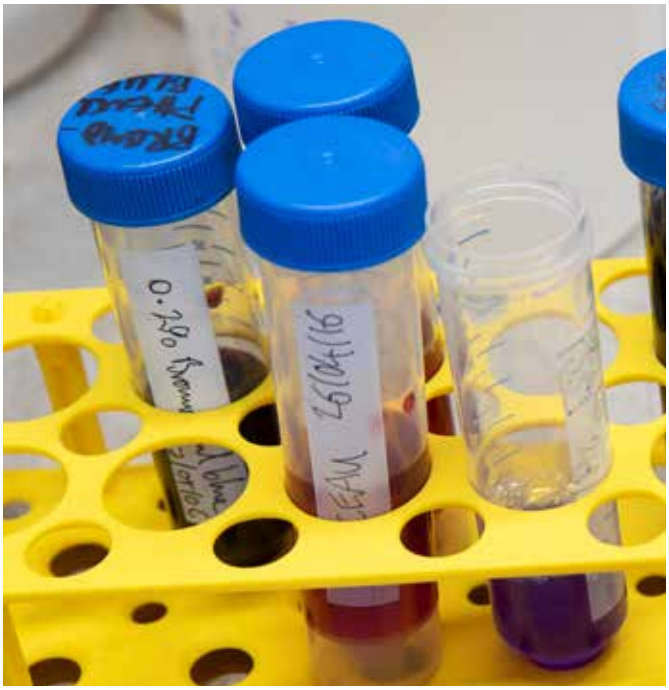
The trial wasn't designed to demonstrate efficacy, so we don't yet know whether omigapil has any beneficial effect on the muscle. Nevertheless we're pleased it was a success, and look forward to hearing more about a future phase 2 trial. We'll keep you posted.

First results from Duchenne gene therapy trial
Sarepta Therapeutics has announced positive preliminary results from its ongoing Duchenne gene therapy trial. The US trial is assessing AAVrh74.MHCK7.microdystrophin – a harmless virus carrying a shortened version of the dystrophin gene. Muscle biopsies taken from the first three children treated showed a significant increase in dystrophin protein. So far there have been no serious safety concerns. Although it's still early days, we're delighted by this news and look forward to seeing how the trial progresses. We'll keep you updated.

FSHD drug receives US Fast Track Designation
A drug that could build muscle mass in people with facioscapulohumeral muscular dystrophy (FSHD) has received Fast Track Designation from the US Food and Drug Administration (FDA). This will help to speed up its development and regulatory review. The drug – called ACE-083 – works by stopping certain proteins from reducing muscle growth. ACE-083 is currently being evaluated in people with FSHD as part of a phase 2 trial.

Positive results from myotonic dystrophy trial
AMO Pharma has released the results of its trial testing tideglusib in people with congenital and childhood-onset myotonic dystrophy. Tideglusib is an oral drug designed to block an enzyme called GSK3β, which is overactive in people with myotonic dystrophy.

Over the 14-week treatment period, most trial participants felt less tired and were better at performing day-to-day tasks. The drug was also well-



tolerated. AMO Pharma intends to further evaluate tideglusib in trials in the US, Canada and UK. We'll let you know more as soon as further information is released.

Summit stops development of utrophin drug
We are disappointed to hear that Summit Therapeutics has stopped the development of its utrophin modulator, ezutromid. After reviewing results from the PhaseOUT DMD trial, Summit has reported that while ezutromid was safe, it unfortunately did not provide a benefit to participants. This is understandably disappointing to families. However we have to remember that not all trials will be successful and there are others in the pipeline. The learnings from a negative trial can also be valuable to other researchers, and we welcome Summit's plans to make its data more widely available.

Early results from SMA trial
PTC Therapeutics has released initial data from its phase 2/3 trial testing RG7916 in babies with spinal muscular atrophy (SMA) Type 1. RG7916 is an oral drug that increases levels of the SMN protein. The drug has been well-tolerated so far. All participants are still able to swallow, and none has needed to have a tracheostomy (surgical procedure to aid breathing) or permanent ventilation. We'll keep you updated on the trial's progress.

If you have any questions about research or clinical trials, do get in touch with our Clinical Trials Information Service at research@musculardystrophyuk.org or 020 7803 4813.

Scientific publications

Mini-muscles could facilitate drug development
Researchers at University College London have grown artificial 'mini-muscles' in the laboratory. They took skin cells from people with Duchenne, limb girdle and congenital muscular dystrophies and turned them into stem cells called iPSCs. These were then grown into tiny muscles with their own nerves and blood vessels, much like a real muscle.

The mini-muscles showed some distinctive features of muscle-wasting conditions, which means they could be used for drug screening. They could also be used for more basic science studies to understand more about muscle-wasting conditions.

MDUK is funding a research project to build on this exciting work. You can read more about it at www.musculardystrophyuk.org/grants/making-mini-muscles

Muscle gene linked to cot death
A recent study – partly led by MDUK's Chair, Professor Mike Hanna – has linked some cases of sudden infant death syndrome or 'cot death', to mutations in a gene involved in muscle contraction. These mutations also cause neuromuscular conditions that aren't lethal, so it's likely that there are other risk factors involved in cot death. Further research is needed to fully understand the causes of cot death and the role that this muscle gene might play.

Study identifies potential treatment for CMT
A protein called HDAC6 regulates transport of important 'cargo' up and down our nerve cells. This keeps the nerves functioning properly, so they can pass signals to muscles and other parts of the body. Researchers in Belgium have found that a drug blocking HDAC6 can improve cargo transport within nerves of a mouse model of Charcot-Marie-Tooth disease (CMT).

The drug improved nerve health, giving the mice greater muscle function. Although this research is in relatively early stages, it could lead to a potential treatment for CMT.

Exercise study
A study has found that intensive exercise during adolescence could be associated with earlier symptom onset in dysferlinopathies (limb girdle muscular dystrophy type 2B and Miyoshi myopathy).

This finding could influence exercise advice for children and young people who have the condition but have not yet experienced symptoms. But the researchers have stressed that exercise has many health benefits and anyone who already has symptoms of dysferlinopathy should not avoid exercise. If you have any questions about this, do get in touch with your clinical team.

You can read these articles in full at www.musculardystrophyuk.org/news/research

MICROSOFT AND MDUK: accessible gaming

Microsoft, the global technology giant, recently announced the Xbox Adaptive Controller designed for gamers with limited mobility.

At MDUK, we worked with Microsoft on the product launch and one of our campaigners, Vivek Gohil, was among the first disabled people in the UK to test it out.

At the same time, we're also calling on the wider gaming industry to take more seriously the needs of those with disabilities. Our *Changing the game* report, out in May, identified the key issues disabled gamers faced and recommended some urgent action. You can find the report on our website.

"Microsoft's new Xbox Adaptive Controller is a welcome first step towards a more inclusive video gaming culture. It will make a real difference, particularly to people with a progressive muscle-wasting condition. However, our report highlights that there is still much more the industry needs to do."
Nic Bungay, MDUK's Director of Campaigns, Care and Information

After surveying more than 100 people with muscle-wasting conditions, Trailblazers found that:

- almost three in five people said gaming was their favourite or regular pastime, owing to limited access to other leisure activities
- eight out of 10 believe the gaming industry doesn't consider the needs of disabled gamers
- around one in four require extra technology to play video games
- more than one in three people said they couldn'ot play video games because of their disability.

The report calls for a number of changes, including the development of controllers that can be adapted to different levels of disability.

Microsoft's Adaptive Controller has been designed primarily to meet the needs of gamers with limited mobility. It will be available to buy later this year in the Microsoft Store.

"We realised that lots of people were excluded from the experience of Xbox. With the regular controller, some of the buttons are hard to get to; it works for a certain number of people, but a certain number are simply unable to reach all the buttons. The Adaptive Controller is our first attempt to make sure that people can customise a controller to suit their needs."
Hector Minto from Microsoft

"What we want to do now is challenge Microsoft and the wider industry to continue focusing on the needs of disabled gamers and create a much more positive and inclusive gaming environment for everyone."
Lauren West, Trailblazers Manager

To find out about Trailblazers, MDUK's network of young disabled people who campaign on issues that are important to them, visit www.musculardystrophyuk.org/trailblazers

HELP MAKE UK TAXIS ACCESSIBLE

photo © rcfotostock/Fotolia

A change in the Equality Act in April last year means taxi drivers now face fines of up to £1,000 if they refuse to transport wheelchair users or attempt to charge them extra. But this only applies to vehicles listed on Section 167 lists, which councils need to create.

"I'm a regular taxi user, but have had more bad experiences than good," says Trailblazer Nirav Shah (pictured below).

"Drivers have refused to take me, or have claimed that their ramp doesn't work. I have also had some drive off and leave me on the pavement, and companies quoting twice what a metered fare would normally be."

Nirav's story, unfortunately, is not uncommon – but with the majority of local authorities failing to create government-recommended paperwork designed to protect wheelchair users, many drivers who discriminate cannot be held to account.

The paperwork in question is a Section 167 list. The government recommends that every council compile a list, which includes a register of accessible taxis and cabs in the area.

The problem is, only drivers listed on these can face fines of up to £1,000 for overcharging wheelchair users or refusing to transport them – and two-thirds of councils haven't completed their lists.

Disability rights campaigner Doug Paulley, who submitted Freedom of Information requests to every local authority, says, "This new research provides a mixed bag of results: while some councils have made an effort to create a list, many have fallen foul of the complex fine print in the rules, leaving most passengers unable to use the new legislation.

"Councils alone can't unpick the confusion. We need to see a stronger lead from the Department for Transport if disabled people

are to get the tools they need to challenge overcharging and unsafe practices."

The current system has proven unworkable – which is why MDUK is joining Doug in calling for the Department for Transport to make the lists mandatory. With one in six councils who have created a list not meeting the criteria, we're also urging all authorities to ensure their lists are legally compliant.

"Taxis are often the only way that disabled people can get from A to B when public transport isn't an option but the new legislation simply isn't working to help ensure they can do so safely and fairly," says Nic Bungay, MDUK's Director of Campaigns, Care and Information.

"Doug's research robustly demonstrates the impossible situation that many disabled people find themselves in.

"Passengers, taxi drivers and councils alike are crying out for clearer guidance, and we need to see the taxi lists made mandatory, to make this well-intentioned law workable."

Doug's comprehensive research of 340 councils shows 42 have no intention of ever creating a list. It also reveals that 12 authorities have no wheelchair accessible vehicles in their respective areas and a further 109 have fewer than 10 – while only 18 out of 66 authorities with fully accessible fleets have so far created a Section 167 list.

"Companies should not be allowed to get away with this (discrimination), and the Department for Transport needs to act.

"Disabled people have enough to deal with as it is; we do not have the energy or the time to be worrying about taxi companies overcharging. We are people, and we just want to be treated equally," says Morvenna Richards, who has myofibrillar myopathy.

Wheelchair user Vicki Dennis (pictured) agrees.

"I have have never made a complaint, because I don't know how; it needs to be clearer, and there needs to be more of a process.

"I won't go in a London black cab now as it's difficult to know if you have a driver who will act with care. There is training in place, so I don't understand how there can be problems."

Put pressure on your local council to create a list, if they haven't done so already. See our interactive map, and download our template letter, at: www.musculardystrophyuk.org/news/news/call-on-your-council-to-get-the-new-taxi-law-working

To find out how to get involved in the Trailblazers campaign for accessible taxis, get in touch with l.west@musculardystrophyuk.org or call 020 7803 4846.

SPINRAZA FOR SMA TYPE 1
in Scotland

Children with SMA Type 1 will have immediate access to a life-changing treatment, with a landmark decision announced recently to make it available on the NHS in Scotland. There is disappointment, though, for those with other types of SMA – the same treatment will not be offered to them.

Spinraza is the first and only treatment for patients with SMA. When the Scottish Medicines Consortium (SMC) recommended that it should be made available on the NHS in Scotland for children with Type 1 SMA, it didn't approve the treatment for those with Types 2 or 3.

MDUK has been working in partnership with other SMA charities, SMA Support UK and The SMA Trust, to push for access to Spinraza for all patients with the condition. Without it, life-expectancy for those with SMA Type 1 is rarely longer than two years, but with treatment, many children can learn to crawl and even walk.

Together, the charities welcome the news that Spinraza will be available to SMA Type 1 patients, but will now be pushing for a reassessment of the treatment for all types of SMA. We're also encouraging the SMC, the Scottish Government and NHS Scotland to introduce a reformed appraisal process for ultra-orphan medicines as quickly as possible. Meanwhile, applications for patients with Type 2 and 3 SMA are being made on a case-by-case basis by treating hospitals in Scotland.

Robert Meadowcroft, MDUK Chief Executive, said:
"Spinraza brings hope to many families, and we welcome the news that it will be made available by NHS Scotland to children with SMA Type 1. But we won't rest until all patients with SMA have access to this treatment, and it is now vital that robust data are provided by Biogen to support the argument for access for all people with SMA, as we turn our focus to encouraging the SMC to reassess the drug for other types. SMA is a devastating and often cruel condition, and while it is not a cure, Spinraza can buy families more time. No parent should have to see their child gradually lose the ability to move, breathe and swallow, particularly while there is a treatment out there which could help."

Spinraza proved so effective in a clinical trial for children with SMA Type 1 that the trial was stopped early so that all children affected could access the treatment. Children in Scotland got the treatment via a temporary special compassionate access scheme, with pharmaceutical manufacturer Biogen providing the drug for free and the NHS in Scotland funding the costs of administering the treatment. At a special meeting earlier this year, families affected by the condition made a final plea to the SMC to approve Spinraza.

Dr Sheonad Macfarlane, MDUK's Scottish Council chair, shared her family's experience of living with SMA at the SMC's PACE (Patient and Clinical Experts) meeting earlier this year. Her nine-year-old daughter, Eilidh, has SMA Type 2. She said:
"I understand the decision that has been made, and it is wonderful news for families of children with SMA Type 1. However, many others with the condition will miss out, and naturally this is a huge disappointment. It doesn't end here, though, and we will keep fighting until all patients with SMA have access to this life-changing treatment."

Pictured left are Amy Cameron and her two-year-old son, Zac. He has SMA Type 1 and has been receiving Spinraza through the temporary scheme. The mum from Clackmannanshire in Scotland, said:
"Spinraza gives children with SMA the chance to reach amazing milestones that were never before possible. We are delighted that children like Zac will have access to this life-changing treatment, which has made such a difference to our lives. Since receiving Spinraza, Zac can swing his legs out when we hold him on our knee, and can also hold his head up when I pick him up. He's never done this before – it's a complete miracle. The effect Spinraza has on families cannot be underestimated, and it should be available to all who need it."

To find out more about the SMA charities and their work, visit www.musculardystrophyuk.org / www.smasupportuk.org.uk / smatrust.org

Spinal muscular atrophy (SMA)
Through our funding partnership with the SMA Trust, we're improving standards of care and investigating a potential therapy for SMA. There are three main types of childhood-onset SMA – Types 1, 2 and 3 - as well as the adult-onset Type 4. SMA can affect crawling and walking, arm, hand and neck movement, as well as breathing and swallowing. If you'd like to speak to someone about your condition, our helpline team is here for you on 0800 652 6352 or info@musculardystrophyuk.org

TOWN AND GOWN SERIES:

Race founder recalls how his son inspired Town and Gown

With the 37th race set to be run and over £1m to be raised, one little boy's legacy remains at the heart of Oxford's Town and Gown. Thousands of runners will take to the streets of Oxford for the annual 10km run for Muscular Dystrophy UK and at the helm, sounding the starting gun, will be event founder Mike Cleaver.

Mr Cleaver, from Stonesfield, near Witney, started the event back in 1982, as a cause close to his heart. His son Daniel was diagnosed with a rare form of muscular dystrophy, a muscle-wasting condition, at just six months old.

The 71-year-old said: "It was a very strong feeling, a very determined feeling to do something. When you have a personal reason connected to it, it drives you to do things as much as you can."

Mr Cleaver rallied friends to stage the first Oxford Town and Gown, held then in Blenheim Park, Woodstock, and had around 700 participants taking part. He recalls heavy snowfall just days before the event and an organising team of just 10 responsible for making it happen.

Mr Cleaver also looks fondly back at the first event with Daniel also there, aged just three years old but riding through the grounds in his electric wheelchair.

He said: "It was phenomenal. Obviously it was pre-computer days, so everything was done the long way, such as the registration which was done the day before because we didn't think we would be able to cope on the morning."

He added: "We had all the entries and cheques coming through to the house, I remember them covering the dining room table."

For the first three years, the event was staged in Blenheim Park. Then with support from Kidlington Runners it moved to University Parks. Last year was a record year with 4,476 runners.

Over the years, a number of famous faces have participated, such as then-Oxford United manager Jim Smith, Williams Formula One racing team founder Sir Frank Williams and Eddie'the Eagle' Edwards – whose false start caused some fun.

Mr Cleaver looks back on 1988 as a particular highlight in the event's history. It was the year ITV staged a 24-hour telethon which covered the race and included Mr Cleaver running with Daniel, then aged 10, in a wheelchair.

The TV show, which can be seen in part on the Oxford Mail website, includes both coverage of the race and an interview with the Cleaver family, including Daniel's sister Jennifer. Daniel died two years later in 1990, aged just 12.

In 2008, with the event still growing, Muscular Dystrophy UK took on the Oxford Town and Gown. Mr Cleaver said: "I can't believe it really, all those years have gone by and it is still the same. Oxford is obviously a fantastic venue."

He added: "I am so proud of it, and that Daniel has inspired thousands of people and the amount of research it has helped. It has now raised well over £1.5m. I am so proud it has all come together the way it has and all because of one little boy who passed away in 1990. It is humbling to know it is still happening today."

by Naomi Herring
Originally published in the Oxford Mail and reproduced with permission

Oxford Town and Gown 2018

"I wanted to try and come up with a way of raising money on a bigger scale with a large sporting event. It was around the time of the first London Marathon, so I thought that was the way to do it. Because we were in the University catchment area, I came up with the name Town and Gown."

When Mike (pictured opposite) sounded the horn to start the 37th Oxford Town and Gown on Sunday 13 May, just short of 5,000 runners had signed up.

This was our most successful and largest event yet. We saw a peak in businesses, schools and colleges entering teams, and this community spirit really shone on the day.

Thank you to all the runners who supported us and together raised over £171,000 to help beat muscle-wasting conditions.

Leicester Town and Gown 10k

Thank you to all who took part in our second Leicester Town and Gown 10k on Sunday 11 March. Because of adverse weather, we had to make the tough decision to move the date from 4 March, but the event was still a big success. Thanks to the 325 runners signed up for the race who not only moved their Mother's Day plans so they could join us, but also raised more than £11,500 for MDUK's work!

Keep an eye on our website to find out the date for next year's Leicester Town and Gown 10k at www.townandgown10k.com/leicester

Cambridge Town and Gown 10k

Inspired and don't want to miss out on the next Town and Gown? Fear not, the seventh Cambridge Town and Gown will be returning to the beautiful streets of Cambridge, on Sunday 21 October. This year we are aiming for our biggest and best race yet, with a target of 2,500 runners at the start. The junior 3k race is also back, so sign up today – it's the perfect way to get your whole family involved in a great event, for a wonderful cause.

Sign up for just £25 at www.townandgown10k.com/cambridge

#TEAMORANGE AND BEYOND

London Marathon 2018

Sunday 22 April saw 114 brave runners take on the incredible challenge of running the Virgin Money London Marathon 2018 – the hottest on record. All our #TeamOrange runners had been training and fundraising for months, together raising over £310,000 to support the fight against muscle-wasting conditions. A huge thank you to our sizzling team for all their amazing hard work!

Fancy joining our 2019 London Marathon team? Find out how at www.musculardystrophyuk.org/events/londonmarathon

Celebrity Sports Quiz

We were bowled over by the generosity of those who supported our annual Celebrity Sports Quiz in March this year, and raised an incredible £93,000. A huge thank you to all those who joined us in the Long Room at Lord's Cricket Ground, including our celebrity guests. A special mention to our host for the evening, World Cup-winner Martin Bayfield, as well as our wonderful quizmaster, Hayley McQueen. Thank you to Paul Kelly who spoke movingly on the importance of Powerchair football in his and his son Patrick's lives. We're also grateful to sponsors Fever Tree who provided guests with delicious drinks during the reception, and to our Committee whose hard work makes the event possible.

To get involved in any of our national or community fundraising events, visit www. musculardystrophyuk.org/get-involved or call our fundraising hotline on 0300 012 0172

RideLondon and Pedal, Paddle, Peak

Wishing good luck to our squad of #TeamOrange cyclists taking on the massive 100-mile RideLondon challenge on Sunday 29 July and hoping to raise over £20,000 for MDUK.. And to the 80 Pedal, Paddle, Peak participants, who are taking on a challenge in the Lake District – paddling across the Ullswater Lake and climbing the magnificent Helvellyn Mountain – on 14 July. They aim to raise £50,000 to support the fight against muscle-wasting conditions.

To get involved in any of our 2019 challenge events, visit www.musculardystrophyuk.org/events or call our fundraising hotline on 0300 012 0172.

FUNDRAISING ACROSS THE UK

Mackie's Crisps

Mackie's Taypack, Scotland's favourite snack makers, have chosen MDUK as their first official charity partner.

"This is a cause close to our hearts that affects thousands of families each year and has affected our own. It's why Mackie's Crisps is proud to support Muscular Dystrophy UK. Every pound we raise will support families through the challenges of daily life with a progressive muscle-wasting condition," says George Taylor, Managing Director.

The company has been raising funds and awareness by selling promotional packs of specially-created Sausage and Caramelised Onion flavour crisps. They've also published a Mackie's-themed recipe book, entered a team into the Edinburgh Marathon Festival and have more events planned.

World's Toughest Mudder

This November, Keith Pryce-Jones from Smethwick in the West Midlands, will travel to Atlanta, Georgia in the USA to compete in World's Toughest Mudder. This is a 24-hour timed event, in which Keith aims to cover 60 miles of obstacles.

While this would be a huge challenge for anyone, it is an even bigger one for Keith, who was diagnosed with Type 2 myotonic dystrophy after his father was diagnosed with the same condition. Keith has previously completed over 25 Tough Mudder's while proudly wearing his (very muddy) MDUK T-shirt.

Great runners for the Great North Run

Sinéad and Carrie, a head teacher and teaching assistant from Sheffield, are among 135 #TeamOrange runners tackling the Great North Run for MDUK in September. They are doing this in support of nine-year-old Alec, who attends their school and has Duchenne muscular dystrophy.

Sinéad and Carrie aren't natural long-distance runners; the most they've run in one go is 10km so the half-marathon will be a huge challenge for them. Both have been doing some amazing fundraising and getting their school behind Alec.

To get involved in next year's Great North Run, please get in contact with us on 0300 012 0172 or volunteerfundraising@musculardystrophyuk.org

Running through 2018

Simon Blunden, an architect from Kendal, is running every day in 2018 to support the son of a close friend, Greg Savage, who was diagnosed with Duchenne muscular dystrophy in 2015.

Simon has set his sights on running more than 2,000 miles over the 12-month period, an average of 5.5 miles each day, to raise funds for MDUK's Duchenne Research Breakthrough Fund.

Simon and his wife have recently completed the designs for Greg's home adaptations and work began in May. Simon will be running from his home in Kendal to Greg's house in Leeds to check on progress.

41 Club

Phillip Ellis from Bangor in Northern Ireland has chosen MDUK as his Presidential Charity as he takes on the role of 41 Club National President this year.

Phillip's grandson Enzo was recently diagnosed with Duchenne muscular dystrophy, and he wants to leave a lasting legacy and support research. The 41 Club has members all across the UK and forms part of the Round Table Family.

There are around 800 local 41 Club branches across the UK and Ireland which are active in their communities, supporting local charities and strengthening existing friendships.

The partnership with MDUK was recently launched in style at a Titanic-themed gala evening in Belfast and hopes to raise over £20,000 for our Duchenne Research Breakthrough Fund.

"Enzo was recently diagnosed with Duchenne muscular dystrophy aged just four, and I've experienced just how devastating the diagnosis is for the family.

"Hearing that Enzo has a life-limiting condition was a complete shock and we had never even heard of Duchenne; it was so much to take in."

To get involved in any of our national or community fundraising events, visit www. musculardystrophyuk.org/get-involved or call our fundraising hotline on 0300 012 0172

Keith Pryce-Jones, World's Toughest Mudder

Sinéad, Alec and Carrie

Enzo and Philip Ellis

George Taylor of Mackie's Crisps

POWERCHAIR FOOTBALL – what a season!

It's been a thrilling season in the Muscular Dystrophy UK Powerchair Football National Leagues; two new champions were crowned in both divisions, and both won by one point! The action has been fantastic to watch and it's been a pleasure to hear from players throughout the season on their experiences as the fixtures were being played.

Muscular Dystrophy UK Premiership round-up

Krishan Solanki

West Bromwich Albion PFC celebrated Premier League success after winning the Muscular Dystrophy UK Powerchair Football Premiership for the first time in its history. The 'Baggies' won by a single point ahead of Aspire PFC after a nail-biting finish to the 22-game season.

It's the first time the team has won the league in nine years of competing. The feat was also made even more impressive by the fact four of the squad's six members had never played together before this season!

Coach Chris Gordon also plays on the team.

"We've always been a team that is pushing the top two places in the league, but we've never actually made it to the top, so this is a massive achievement.

"We needed to win our last match on the Sunday to win the league and we did. But up until then it was an emotional rollercoaster. We also had the extra pressure of knowing that there was a league title at the end of it, but we managed to get the job done. We had some good celebrations.

"The trophy was there, so the players and their families all posed with it for photos. We had a bottle of champagne and it all got a bit Formula 1 as we enjoyed spraying it around!"

Sam Bull from the Wheelchair Football Association (WFA) agreed it had been another great season.

"The passion and drive of the players highlight just what the sport has given to them. To feel part of a team and the roller-coaster of emotions when winning or losing forges friendships that last long after the final whistle."

Muscular Dystrophy UK Championship

Kai Gill

It's come to that part of the year where Powerchair football leaves Lee Westwood Sports Centre at Nottingham Trent University for four months. I know, I can't believe how quick it has gone.

Well, what's happened during the season? Plenty of spin kicks, corking goals and cracking saves… but new champions of both leagues. West Brom were crowned Champions of the Muscular Dystrophy UK Premiership and Sevenoaks were crowned Champions of Muscular Dystrophy UK Championship.

On 12 and 13 May the final fixtures of the Muscular Dystrophy UK Championship 2017/18 campaign were played. The important game of the weekend was between first-placed Leeds and second-placed Sevenoaks. What a game it was – end-to-end football, let me tell you that! But Sevenoaks scored a goal just before half-time. The second half was a nail-biter and the crowd were cheering on both teams. Sevenoaks took home the three points putting them above Leeds by one point.

On Saturday, Muscle Warriors PFC faced Electric Eels. Following previous fixtures it was hard to predict who would win, but the Watford side came out and led 3-0 at half time. Following a tactical change and new plan Electric Eels held their defence for a long period before Muscle Warriors scored. But Electric Eels created a set piece and found a gap in the Warriors defence and the score ended 4-1 to Muscle Warriors.

Later in the day, West Bromwich Dudley faced Wessex Warriors in a great and very close game. Dudley led at half time 1-0 after a brilliant goal, but a lapse in defence saw Wessex score to equalise at full-time.

On Sunday, Nottingham Forest PFC faced Muscle Warriors in what was going to be a close game for both sides and would confirm who sat above who in the table. Muscle Warriors led at half time 2-0. Forest tested Muscle Warriors defence on a few occasions but struggled to get the ball across the goal line.

Later in the day, Electric Eels faced Bolton Bullets with some fantastic football from the Hull and East Yorkshire side which saw them score seven goals to finish the season in a comfortable sixth position.

It's time for a break away before trials and pre-season training begins. Thanks to MDUK for giving me the opportunity to write about Powerchair football for a second consecutive season – I've thoroughly loved it.

If this has given you the bug to come and try the sport, find your local club by visiting -our Powerchair Football page at www.musculardystrophyuk.org/powerchairfootball or The WFA at www.thewfa.org. To follow Kai's pre-season thoughts and updates, visit his blog at www.kaigillblog.wordpress.com

MDUK has partnered with The WFA in England and the Scottish Powerchair Football Association to sponsor the three main national leagues in the UK: the MDUK Premiership and Championship in England, and the MDUK Premiership in Scotland.

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