

# Target MD

**Quality of life:  
supporters share  
their stories**

.....

**#RoadtoRio**

**Meet Ollie Hynd**

.....

**Target Research:  
news and updates**





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Registered Charity No. 205395 and Registered Scottish Charity No. SC039445

Target MD is printed by Pureprint Group using their pureprint environmental print technology, a guaranteed, low carbon, low waste, independently audited process that reduces the environmental impact of the printing process. Pureprint Group is certificated to Environmental Management System, ISO 14001 and registered to EMAS, the Eco Management and Audit Scheme. Enclosed into a biodegradable polybag.

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#### On the cover

Paralympian swimmer Ollie Hynd (see p4)  
 He's pictured here with Iris Jaworski (4) who has congenital muscular dystrophy for a swimming session with a difference





# Hello



Hello and welcome to Target MD Winter edition. As always, it comes to you with stories of outstanding people, sharing a few insights into their lives. You'll see there's a Target Research in the centre of the magazine too.

With 2016 being a Paralympic year, our Chief Executive, Robert Meadowcroft, talks about disability rights and sport, as well as our supporters whose sights are set on Rio (see p5). He also talks about quality of life, the theme of this magazine edition.

Quality of life means different things to different people. I asked our supporters what it meant to them, and their stories fill the feature pages.

For some, it means getting the right information to ensure their child's school experience is equal to their peers. For others, it means being able to work and have a social life. For others still, it means meeting and supporting other families living with the same muscle-wasting condition, or finding their voice through campaigning for change.

If we can support you to maintain or improve your quality of life, do get in touch with us.

Have a look on p24 and see what motivates some of our **#TeamOrange** supporters to join in and fundraise for us. If you'd like to take part, our events team would love to welcome you. They always do a great job of supporting you too.

As always, contact me and tell me 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.

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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 progress in scientific research to fund treatments and cures.

## Helpline

If you'd like to speak to someone about living with a muscle-wasting condition, please call our 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**

## Join us online

Get all the latest news and updates by joining our social media networks.

### Online forum

[community.muscular-dystrophy.org](http://community.muscular-dystrophy.org)  
Join our friendly online community.



[www.facebook.com/musculardystrophyuk](http://www.facebook.com/musculardystrophyuk)  
Join the 22,000+ community on our Facebook page.



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Keep on top of our breaking news by following us on Twitter.



[www.youtube.com/c/musculardystrophyuk](http://www.youtube.com/c/musculardystrophyuk)  
Watch our videos on YouTube.



[instagram.com/musculardystrophyuk](https://www.instagram.com/musculardystrophyuk)  
Share our pictures on Instagram.

## Save the dates for our conferences 2016

Our 2016 National Conference and AGM will be on Saturday 1 October at the Park Plaza in Victoria in London

Our 2016 Scottish Conference will be on Saturday 22 October at the Beardmore Hotel and Conference Centre in Glasgow



## Rio 2016 calling

**Some of our supporters across the UK have achieved outstanding success in disability sport, and their dreams of competing in Rio 2016 look likely to become reality. We will be following their progress so keep an eye on our website for updates.**

Ollie Hynd MBE (pictured above) from Nottinghamshire is a gold-medal-winning Paralympic swimmer, who holds British, European and World records across his events.

Now 20, Ollie was diagnosed with neuromuscular myopathy as a young teenager. He has been an ambassador for Muscular Dystrophy UK since

2012, and is keen to encourage more young people with muscle-wasting conditions to benefit from sport.

"Having a dream has played a huge part in helping me overcome the challenges I face each day. Since I achieved my first goal [at London 2012], I've also inspired others to go on to make their dream a reality."

Chloe Ball Hopkins (19) also has her sights set on Rio 2016. Diagnosed with nemaline myopathy at the age of four, she took up sport at school, and it changed her life. Until recently, Chloe held the world record in Compound/Recurve W1 archery.

"I would love to get the Paralympic gold, or even silver or bronze. Just to make the Games would be an amazing experience," said Chloe.

Also hoping to add Paralympic gold to their already impressive haul are Stephen and Pete McGuire – Boccia champions from Scotland - and Freya Levy, an award-winning wheelchair basketball player from Essex.

**Do you have Rio 2016 in your sights? Please tell us about your involvement in disability sport, and the journey ahead. Write to us at [targetmd@muscular dystrophyuk.org](mailto:targetmd@muscular dystrophyuk.org) or call us on 020 7803 4836.**

# Disability rights and Rio

**While we back the most promising research and want to secure fast access to new treatments and excellent NHS care, our work is not simply about research. We are equally committed to enabling all those living with a muscle-wasting condition to enjoy the best possible quality of life.**

Through the Trailblazers group, our advocacy and campaigning teams, we are determined to identify and help to remove societal barriers and discriminatory practices that prevent people from living as independently as they wish. Indeed, Article 19 of the UN Convention recognises the right of people with disabilities “to full inclusion and participation in the community” and this is mirrored by rights set out in the Equality Act in the UK. Ensuring access to these rights in practice is often a huge challenge and at times a real struggle, of course.

For many people, inclusion and participation involve education and employment and a good number of young people move into a career after a successful period studying at university or college. For others, the first step into employment may be a period of work experience and we are able to offer the opportunity of a place on a Work Experience programme for a number of young people based here in our office.

We know other people may decide to pursue self-employment or follow their

interests in other directions. This can be through one of a wide range of leisure activities and this may include getting involved in sport, of course.

For Ollie Hynd, the McGuire brothers, Freya Levy and Chloe Ball-Hopkins, they have focused on competing at an international level in sport. Each of their stories speaks not only of medal hopes in Rio but also of their responsibility as elite athletes and role models for young disabled people.

If I can say a few words about Chloe, I first met her five years ago when she came into our office in London. As a 15-year old, Chloe was a talented tennis player with her sights set high and she had been invited to do the coin toss at the 2011 Ladies’ Final at Wimbledon. In the build-up to her Centre Court appearance, Chloe carried out a number of media interviews and gave extremely articulate answers to some quite intrusive questions about living with muscular dystrophy.

It was clear Chloe took very seriously her responsibility as a spokesperson for Muscular Dystrophy UK and, indeed, wanted to share her personal story to help other young people who might face similar barriers to those she had had to overcome. She has talked with great honesty about how she was bullied at school about her disability and needing to use a wheelchair, and was told she couldn’t take part in sport.

I’ve since met Chloe on many occasions over the years and I know her passion for living life to the full. Her aim today is to be selected for the UK archery team and to compete at the 2016 Rio Paralympics.

The competition will be tough and many others will want to beat her but I know for sure that Chloe will give it her best shot. Her philosophy is there are no limits to what can be dreamed and achieved. I think that’s a pretty good philosophy for all of us to adopt and it reflects the determination and ambition of Muscular Dystrophy UK.

Good luck Ollie, Stephen, Pete, Freya and Chloe, and all the young athletes who hope to get to Rio and show the world what they can do!

Robert Meadowcroft, CEO







## Families supporting each other

Many people with muscle-wasting conditions have told us what they needed most at the point of diagnosis were information and support. Add in fundraising for research, and these are the foundations on which one of Muscular Dystrophy UK's new Family Funds was established.

Mums Sian Rixon, Emma-Jayne Ashley and Sarah Ruane, along with grandmother Linda Atkinson, met up in Manchester last year to work out how best they could support each other.

They had identified a gap in information for children with congenital myotonic dystrophy, so decided to start a website aimed at families.

They also wanted to create a sense of community for the group, where families could get together, and fundraise.

"We spoke to MDUK about our ideas, and were told about the new peer support volunteer programme. That seemed a perfect way to support newly-diagnosed families and people in need. So we all signed up to be trained (by MDUK and Samaritans) as peer support volunteers," said Emma-Jayne.

"MDUK also told us about Family Funds, and the possibility that we could restrict our funding to research into congenital myotonic dystrophy. This too was a perfect fit for us so we started the Congenital Myotonic Dystrophy Fight Fund.

"We do a lot of fundraising for research, through the Fund. We've seen support from so many people, who have planned some great fundraising events," said Sian.

"MDUK has opened their arms to us, and given us such helpful support. I feel honoured to be part of such a wonderful team," said Emma-Jayne.

### Meet Dregan

Dregan Turner (16) lives in a tiny village on the banks of the River Humber with his mum and dad – Pete and Emma-Jayne – and brothers Xander (13) and nine-month-old River (pictured above). After a number of incorrect diagnoses, Dregan was finally diagnosed with congenital myotonic dystrophy when he was 15.

**"Our goals to ensure Dregan's quality of life changed with this diagnosis, almost instantly.**

"We want to make sure he enjoys life, has many new experiences, is as happy and healthy as we can keep him.

"At the point of diagnosis, we were lucky to be given access to a neuromuscular care advisor, and she was really helpful.

"Just two weeks after diagnosis, we were told about an MDUK information day in Basingstoke, on myotonic dystrophy. Pete and I went along and it was amazing, scary, upsetting, heart-breaking, and full of information and support.

"It was a shock just two weeks into diagnosis, however it was exactly what we needed at that time in our lives.

"MDUK is supporting us in our quest to get congenital myotonic dystrophy better known as a condition.

"Since the Fight Fund came about, we've been in constant contact with the charity, and now feel like we're part of something worthwhile. I get amazing support from everyone we come in contact with.

"Meeting up with Sian, Linda and Sarah in Manchester was one of the bravest things I've ever done! I'm not a social butterfly, and had never met anyone with the condition, or with children or grandchildren with the condition.

"The Fight Fund will fund research into the condition and our fundraising has already had a great beginning," said Emma-Jayne.

## Meet Emmie

Emmie Rixon is just like any other four-year-old. She lives in Southampton with her family (pictured right), mum Sian, dad Allan and older brother, Finn (5).

Emmie was diagnosed with congenital myotonic dystrophy when she was just 20 days old. She can walk, but struggles to run and cannot jump. While her speech and fine motor skills are delayed, her understanding is age-appropriate.

"It was really upsetting when we got the diagnosis. I cried at the time, and can remember two occasions since then that I've cried. What I needed most at that time were my family, and the support of Emmie's doctors. I learnt very quickly to stand up for myself around doctors.

"We cope with the reality of Emmie's condition on a daily basis, and made a conscious decision to treat her the same way we treat Finn. My focus is to make sure she is socially adept and can get on in life, while Allan wants to make sure she is physically active too.

**"We want Emmie to have the best quality of life. It's about having the opportunity to achieve your potential and the ability to balance what is necessary with what is wanted.**

"We've always given Emmie the same opportunities as her brother has: swimming lessons for example. Setting up the Fight Fund provides us with exactly what we need, and we put a lot of energy into fundraising for research.



"We've organised a Christmas walk, and have three riders in the London to Brighton bike-ride. As part of our Cyber Races initiative in November, we had 12 people run for us, one of whom was Allan with a pumpkin on his head!" said Sian.

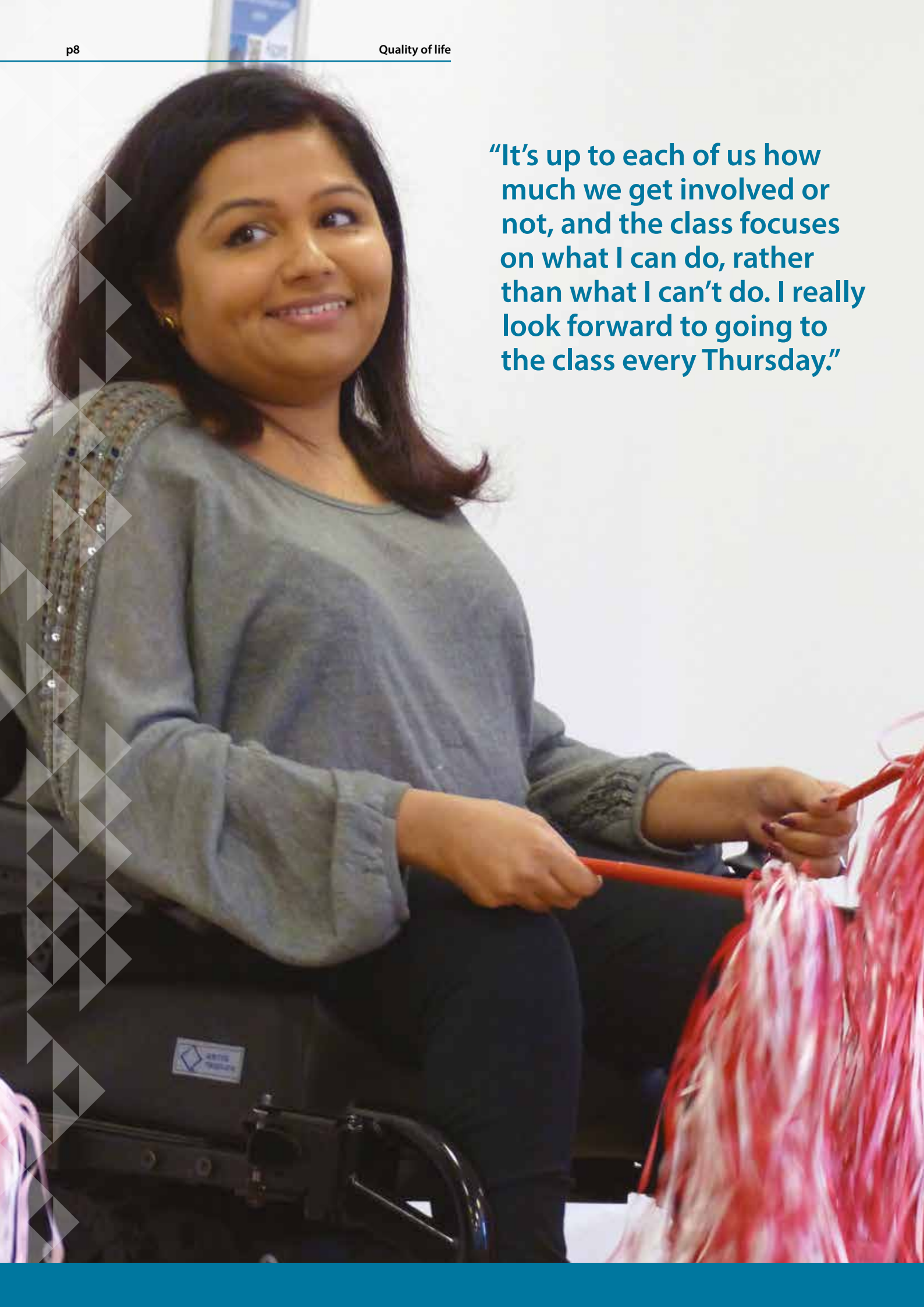
**To find out more about the Congenital Myotonic Dystrophy Fight Fund, visit: [www.cmmd.uk](http://www.cmmd.uk)**

**Setting up a Family Fund is a great way to fundraise for Muscular Dystrophy UK, to keep our vital research moving forward.**

**To find out more about our other Family Funds, visit: [www.muscular dystrophy uk.org/family-funds](http://www.muscular dystrophy uk.org/family-funds)**

**If you'd like to speak to someone about living with any muscle-wasting condition, please get in touch with us and we'll put you in contact with our peer support volunteers. Call 0800 652 6352 or email [info@muscular dystrophy uk.org](mailto:info@muscular dystrophy uk.org)**



A woman with dark hair, wearing a grey long-sleeved top and dark pants, is seated in a wheelchair. She is smiling and looking towards the right. She is holding two red sticks, likely for a craft project, and is working on a piece of red and white striped fabric. The background is a plain white wall. On the left side of the image, there is a decorative pattern of grey triangles. The text is overlaid on the right side of the image.

**“It’s up to each of us how much we get involved or not, and the class focuses on what I can do, rather than what I can’t do. I really look forward to going to the class every Thursday.”**



# Salsa in Stanmore

Every Thursday afternoon, at the Aspire Leisure Centre in Stanmore, a group of people come together to shimmy and salsa. Led by instructor, Rachel, the seated dance class offers an hour of fun, movement, music and social interaction – all of which have benefits far beyond the physical.

Tanvi (pictured opposite), who has spinal muscular atrophy (SMA) joined the class about a year ago.

“If I didn’t have a disability, I would dance – I really love music. I’ve always had an interest in exercise, and dance classes bring exercise to life.

**“The physical benefits of seated dance are important – keeping active and trying to maintain strength – and these classes give me a fun way of doing that. However, the fun factor and the social side of exercise are just as important.**

“With this class, I’ve got to meet new people and I’ve made new friends – and we all understand each other. Rachel has specialist knowledge of disability, so she tailors the classes for people with limited mobility.”

Other people who take part in the salsa classes had this to say:

Claire has been a wheelchair user for 12 years. For many years, her illness and disability left her feeling isolated. That all changed when she joined the dance class earlier last year.

“I had felt so isolated – to the point where I could not remember how it was to be around people. I now have a circle of people around me and I look forward to seeing them every week. We are like a family.

“It is so nice to come and switch off and not to have to deal with the hard bits of being disabled. This class has been really good for me emotionally and psychologically.

“I only found out about the class last year – I wish I had known about it sooner.”

Ann has been on painkillers for some time for her spinal injury and brain tumour. The seated dance classes have helped her enormously.

“Since I’ve been doing these classes, my balance and co-ordination are improved, I’ve been able to reduce my painkillers, and I’ve been sleeping so much better.

“I also no longer feel isolated. Having met new people, I know that I’m not alone.”

Vivienne has rediscovered her love of music and dancing.

“Before I was diagnosed with transverse myelitis, I was the first one up and dancing whenever there was music playing. With this class, I feel the benefit of the endorphins and increased serotonin – and the music is lovely too.”

**“Somehow group classes feel less intense than if you’re exercising on your own. You make friends of all ages. It is fun to do something with music – for me it’s more like a hobby than anything to do with my disability,” said Tanvi.**

## Local opportunities for sport

Trailblazers’ report on access to grassroots sports, produced following the London 2012 Olympics and Paralympics, called for increased opportunities for young disabled people to participate in local, grassroots sport and exercise.

The report recognised that engaging in sport did far more than bring physical benefits; social and psychological benefits were equally important.

**Read the report here:**  
[www.muscular dystrophyuk.org/trailblazers](http://www.muscular dystrophyuk.org/trailblazers)



# My limitless adventures

Sulaiman Khan (pictured above) describes himself as 'a young creative type from London, who happens to have muscular dystrophy'. He graduated BA (Honours) in Advertising & Brand Communication in 2012 at UCA Farnham.

Sulaiman recently got his first job, as a researcher for a communications agency based in Waterloo in London. Here, he writes about the value of work to his quality of life, especially as someone with a disability.

"I have a very active professional, voluntary, personal, and social life. I love going to new places, meeting new people, developing new skills (and learning new things) and learning about new cultures.

"To most people, quality of life might mean being able to spend your time exactly

how you want without the constraints of working life. To me, it means being able to spend time on the finer things, and having a working life is part of that.

"Quality of life means having a fully-rounded life, with work, friends, family, and also some of those finer things. It means having the same opportunities that everyone else has – including the chance to contribute to society by being able to work for a living.

**"Quality of life can often be thought of in medical or clinical terms when it comes to people who have a disability, but there is so much more to it than merely surviving and not being in too much discomfort or pain.**

"For instance, as humans, we thrive on interaction. Having a busy social life is a big factor

in my quality of life. It keeps me sane and whole to be able to spend time with friends, attend events, meet new people, and learn new things. It strengthens my physical and mental wellbeing.

**"If it weren't for the busy schedule of professional, voluntary, personal and social activity, I would be lying down in bed almost 24/7. That's just no way to live.**

"Being able to go out and meet people can sometimes be extremely fatiguing for me, but without it, I would have a very poor quality of life indeed. In my final year of university, my wheelchair was out of commission for a month, so I wasn't able to go out and do normal activities. This hugely affected my physical and mental health, and caused me anxiety as I had an impending dissertation. On the flip side,



experiences like that have bolstered my motivation to find work and have an active social life. The alternative doesn't bear thinking about.

"This experience has made having gainful employment such a big factor in my quality of life. In the ugly alternate universe, where I don't have a job or the motivation mentioned, I wouldn't have the money for social activities, treating myself and contributing towards my goal of financial independence. I wouldn't have the fulfilment of being part of a team working towards shared goals. I wouldn't have the opportunity to develop and use my talents – without that, what's the point? And I wouldn't feel as though I was earning my keep as a member of society.

**"I now have all of these things. I feel useful, rather than useless. I feel like I have options, rather than being stuck in a corner. I feel like things are possible if I can keep working.**

"The single most important aspect of going out to work is getting on the job ladder. By doing so, I've broken out of that old conundrum: how do you get any experience, if all experience requires experience? That may sound trifling, but as a person that happens to have a disability, who had been looking for work for over three years, I can tell you it's not. It's taken me from having no solid prospects to having loads.

"To cap it all, it's the kind of work and workplace that many

people would only dream of! One thing that's truly surprised me about working life is how accepting and nice people actually are. Life isn't really so dog-eat-dog, at least not in my industry. Soon after I started, I was hospitalised for a severe chest infection. As the ambulance took me to the hospital, I knew I'd not be in the office for a while, and I remember thinking 'that's it, they're not going to want to keep me after this'.

"To my surprise, they were not only incredibly sympathetic but also rather flexible about how I could work until I was feeling better. This flexibility has included the option to work from home at hours that suit me for at least the rest of the winter (see photo below).

**"The result of this is that I'm happier, healthier and more productive. I'm also better value for my company.**

"It shows I have a very smart employer, because they have treated me with such humanity and flexibility that I feel intense loyalty to the company. (Other industries take note!)



"So how do you get on the ladder if you're a young person with a disability? I'm going to be honest: I've found Access to Work infuriating to work with. Unless you're lucky, it's going to be very, very difficult. The good news is that it's all very, very worth it. Be resilient, be persistent, vent and swear in private if you need to, but just keep swimming.

**"Be fearless, don't let bureaucratic nonsense get you down, and remember that although it might not seem like it, there are some amazing employers out there who want to hire you.**

"Smart employers who understand the value of diversity know how sensible it is to seek actively and facilitate the hiring of those with disabilities. Everyone else will catch on one day.

"Life is good. Everything I'm doing is finally starting to pay off. I am just going to work even harder and be even nicer to make this all the most incredible adventure yet!"

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# MEDICOTECH



# Target Research

Welcome to the research pages of Target MD. You may or may not be aware of the changes we have planned to our quarterly magazine publications this year: in addition to one annual, comprehensive Target Research magazine, you'll also receive research updates in our lifestyle magazine, Target MD.

In this new format, we will continue bringing you a roundup of the latest research news from the UK and from around the world. We have divided these into 'updates on clinical trials', and 'scientific research articles'. We also introduce the brand new projects we fund for research into Duchenne muscular dystrophy, alongside our continuing research into other muscle-wasting conditions, and tell you about a recent study on perceptions of health-related quality of life. We hope you enjoy the research update in this new format.

Dr Özge Özkaya, Editor, Target Research



## Duchenne not a barrier to happiness, study suggests

A study on perceptions of health-related quality of life among people with Duchenne muscular dystrophy has found the majority to be happy with life, even in the later stages of the condition when health deteriorates.

Researchers in Newcastle, Sweden and the US conducted a study on the health-related quality of life (HRQOL) in 770 people with Duchenne muscular dystrophy and their caregivers, with the aim of examining how the perception of HRQOL changes at different stages of the condition.

They found that the vast majority of people with Duchenne muscular dystrophy (84 percent) were perceived as happy or somewhat happy and in excellent, very good or good health by their caregivers. This is

irrespective of whether they had lost the ability to walk or not, with affected individuals giving their own quality even higher rating.

The authors believe that the results may point to the progressive nature of the condition, which gives both people affected and their caregivers time to adapt to changing health. Improving standards of care and survival also mean that many caregivers' experiences today may be more positive than those they expected in the early days, after diagnosis.

Having grown up with Duchenne muscular dystrophy, those who took part in the study had different reference points for happiness and quality of life from those who had never experienced living with the condition, the researchers also suggest.

These findings are important, because they can help health professionals tailor the care given to people with Duchenne muscular dystrophy, in order to improve their quality of life, as well as to design new clinical trials.

Dr Marita Pohlschmidt, Director of Research at Muscular Dystrophy UK said: "The presence of a smaller group found to be very unhappy underlines the need for psychological care and support to be available to people of all ages living with Duchenne muscular dystrophy, as well as their families. It is also important to note that it is very difficult to measure HRQOL and these results should be taken with caution."

## Background

The study was sponsored by GlaxoSmithKline and supported by the Treat-NMD network. The results of the study were published in the journal *Developmental Medicine and Child Neurology*.

## About health-related quality of life (HRQOL)

The World Health Organisation (WHO) defines quality of life as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. HRQOL, on the other hand, refers to the individuals' perception of the impact of health and illness on physical, mental and social aspects of life.

## New research projects

In our last research grant round, we awarded funding for five new projects, a new clinical training fellowship and a new five-year lectureship position for research into Duchenne muscular dystrophy.

We invested around **£750,000** into the projects that will tackle Duchenne muscular dystrophy, using cutting-edge molecular biology techniques such as gene therapy and genome editing. This investment reflects our commitment to accelerating the pace of developing effective treatments for Duchenne muscular dystrophy and was made possible thanks to the support of UK families and other donors who support the Duchenne Research Breakthrough Fund (DRBF). The projects will take place in the laboratories of Professor Dame Kay Davies at the University of Oxford; Professor George Dickson at Royal Holloway University of London; Professor Francesco Muntoni at University College London (whose project is part-funded by the Duchenne Children's Trust); Professor Volker Straub at the University of Newcastle, and Dr Richard Piercy at the Royal Veterinary College.

Read more about the projects on our website at [www.muscular dystrophyuk.org/Duchenne-research-projects](http://www.muscular dystrophyuk.org/Duchenne-research-projects)

Together with the Chief Scientist Office in Scotland and Action Duchenne, we awarded a three-year clinical training fellowship in Scotland totalling £225,000. The fellowship, aimed at increasing research and clinical care capacity for Duchenne muscular dystrophy and addressing the lack of clinical trial capacity in Scotland, was awarded to Dr Shuko Joseph at the University of Glasgow. Dr Shuko will investigate bone health in boys with Duchenne muscular dystrophy.





**In partnership with Royal Holloway,** University of London, we invested £500,000 in research to develop new genetic therapies for Duchenne muscular dystrophy. The new five-year lectureship was awarded to Dr Linda Popplewell, who aims to develop a unique and comprehensive genetic therapy for Duchenne muscular dystrophy that will address the mutation in the dystrophin gene, reduce fibrosis and encourage muscle growth. With the fellowship, Dr Popplewell will be able to establish herself as an independent researcher.

**A new grant call was launched,** along with a new doctoral fellowship in the field of muscle-wasting conditions.

**We hosted a one-day workshop** to drive forward the development of treatments for nemaline myopathy, ahead of our new international grant call. This grant has been made possible thanks to a Family Fund, MAP Nemaline. The workshop brought together researchers and clinicians from all over the world to discuss strategic areas in the field.

**A call for a new doctoral fellowship** for research into muscle-wasting conditions, with joint-funding from the R&D Division of Health and Social Care Services (HSC) in Northern Ireland. The fellowship is intended to build expertise was launched in the field of muscle-wasting conditions.

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## Update on clinical trials

**PTC Therapeutics** recently announced the results of their phase III ACT DMD clinical trial, testing Translarna for the treatment of Duchenne muscular dystrophy caused by a nonsense mutation. The results showed that Translarna was able to slow the progression of the condition in a sub-group of participants who, at the beginning of the trial, were able to walk 300-400 metres in six minutes.

**SKIP-NMD**, a project funded by the European Union, reported on the progress of a clinical trial testing an exon-53-skipping drug. The trial was aimed at finding the most efficient dose of the drug called SRP-4053. An optimal dose has now been found and the second part of the trial to test the long-term benefits of the drug has started recruiting participants.

**A major investment of over £1.2 million** was announced at the end of 2015, to fund key roles at three neuromuscular Centres of Excellence. The commitment was driven by a collaboration between a number of Duchenne charities and Great Ormond Street Hospital charity to boost clinical trial capacity at UK muscle centres. Muscular Dystrophy UK's initial contribution is set at £361,000 over the coming two years.

**Ionis Pharmaceuticals** (previously known as Isis Pharmaceuticals) announced they would be initiating a follow-up study to evaluate the molecular patch IONIS-SMNRx for a potential treatment of spinal muscular atrophy (SMA). The study, called SHINE, is an open-label extension study for infants and children with SMA who have previously completed a phase III clinical trial evaluating the efficacy of SMNRx.

**Recruitment has been completed** for a phase I clinical trial called CALLISTO to test the new drug candidate omigapil in people with congenital muscular dystrophy. The aim of the trial is to test how omigapil is metabolised, how safe it is and to what degree its possible side-effects are tolerated by the body. The trial takes place in the US and will test the drug in 20 ambulatory and non-ambulatory participants aged five to 16 years, who have either Ullrich congenital muscular dystrophy or merosin-deficient muscular dystrophy.

**A new natural history study** in myotonic dystrophy type 1 in Newcastle and London has begun recruiting. The aim of the study, which will include 400 participants, is to understand as much as possible about the condition and how it affects people in different ways, to help in the development of new treatments in the future.

## Scientific research articles

**New research has been published** suggesting that the muscle-wasting in Duchenne muscular dystrophy is caused by the lack of dystrophin not only in muscle fibres but also in muscle stem cells that play a role in repairing damaged muscle tissue. The results are vital as they provide information about the cell types in which production of dystrophin protein needs to be restored for a potential treatment to be effective.

**New research by scientists** from the University of Aberdeen, University of Oxford, University College London and University of Edinburgh (including Professor Thomas Gillingwater, whose work is funded by Muscular Dystrophy UK and the SMA Trust) has shown that a decreased number of blood vessels leading to insufficient blood supply may contribute to the loss of motor neurons in SMA type 1. The results of this work will help us better understand the events leading to SMA and may have major implications for the development of possible future therapies.

**A new study at the University of Missouri, USA,** has shown that it is possible to transfer a small version of the dystrophin gene to all muscles in the body of dogs, including the heart and the diaphragm, using a harmless virus. If this success continues, researchers hope to see clinical trials using this approach in humans, in the coming years.

**A new study has shown** that blocking or removing a protein called P2RX7 in a mouse model of Duchenne muscular dystrophy has a measurable effect on many of the processes affecting the skeletal and cardiac muscles, inflammatory cells, brain and bones. These results mean that P2RX7 might be a good therapeutic target for Duchenne muscular dystrophy.

**In a series of exciting findings,** scientists from the University of Washington reported that a statin (simvastatin), a cholesterol-lowering drug already used by a large number of people, had unexpected and very positive effects on overall muscle health and function in a mouse model of Duchenne muscular dystrophy. These results suggest that statins could be a potential therapy for Duchenne muscular dystrophy and other

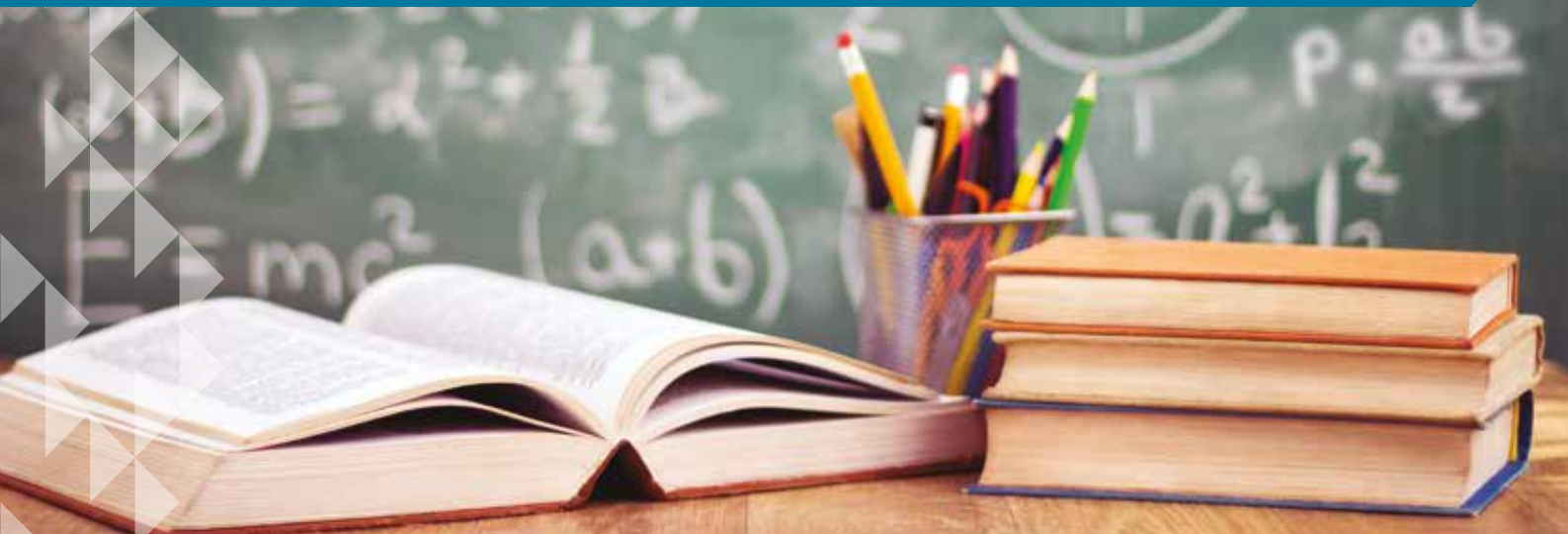
related muscle-wasting conditions. However, more research is needed before this approach can be moved into the clinic.

**Professor Shamima Rahman,** a Muscular Dystrophy UK-funded scientist, and her team recently published a scientific article in the journal, *Brain*. The article showed that a protein called STAT2, that normally regulates the body's immune response, was also crucial for the shape and function of mitochondria, the cells' energy factories. STAT2 protein, and the biological pathway it is involved in, may therefore represent a new potential therapeutic target for mitochondrial disease.

**In a scientific article explaining a laboratory procedure,** Dr Saverio Tedesco, a Muscular Dystrophy UK-funded scientist, and his colleagues described a new method of generating a cell line that can differentiate into muscle cells in just three weeks. In the future these cells could be directly delivered to the body via the blood stream and therefore could be used as a potential therapy for people affected by many types of muscle-wasting conditions.



# Getting the best school experience



**For every parent, careful planning and the right level of support can ensure their child's time at school enhances their range of experiences and quality of life. This then leads to opportunities for their child to enjoy activities and develop friendships and skills for the future.**

For parents of children with muscle-wasting conditions, getting that level of support can be quite challenging. Muscular Dystrophy UK is here to help parents get an Educational Health and Care Plan (EHCP) in place, or in Scotland a Co-ordinated Support Plan (a Statement of Special Educational Needs) and to help educational professionals understand the need for these plans.

Getting these plans in place is a long process and it is important that parents are aware of what is required. It is important they know they have the right to request such a plan, and they know who to contact within their local boroughs to start the process.

For parents facing these challenges, our care and information team can help you:

- ▶ choose the right school for your child's needs
- ▶ get the right level of support for your child's special educational needs (SEN)
- ▶ introduce adaptations in the school, and
- ▶ get support with moving into higher education.

In 2014, the old Special Educational Needs (SEN) Statements and Learning Disability Assessments were replaced with EHCPs. These aim for a better understanding of all aspects of a child's or young person's condition, to ensure they have a better quality of support. The SEN team at your local council can help you get the right plan for your child.

## Other types of support

Children with less complex needs who do not require an educational plan can also get support in school. You can discuss this with the school's Special Educational Needs Co-ordinator (SENCo).

You can get support such as:

- ▶ a special learning programme for your child
- ▶ extra help using a teacher or a learning support assistant
- ▶ working with your child in a small group
- ▶ supporting your child with physical or personal care difficulties, such as eating, getting around school safely, going to the toilet, or dressing.

**For support with higher education, read the Trailblazers' University challenge report at [www.muscular dystrophyuk.org/highereducation](http://www.muscular dystrophyuk.org/highereducation)**





## Discovering my inner strength

**Vivek Gohil (25) (pictured above) from Leicester has Duchenne muscular dystrophy. He shares his thoughts about what quality of life means to him, and how being involved with Trailblazers changed his perception of himself:**

“To me quality of life means allowing yourself the freedom to be happy. Once you have accepted all your positives and negatives, anything is possible. Maintaining the quality of life in your mind is important – your thoughts can change your worldview.

“I want to express the truth about how my Duchenne muscular dystrophy (DMD) has made me the man I am today. I’d also like to increase awareness that DMD can be a positive in life.

“It was a difficult road for me to initially accept my DMD. As a child/teenager it felt like I lost a huge part of myself – the loss of

walking seemed to change the trajectory of my life. I felt my life was over and I was worthless – this depression was more crippling to me than my DMD.

**“My Mum has always been very supportive and open to being truthful to all my questions, along with discipline when I became jealous of my sister doing what I could not.**

“We didn’t let bitterness or anger consume my family’s life or mine. It was not fair for me to be angry with able-bodied people; they can’t help being born without a disability as much as I can’t help being born with one.

“Between the ages of 13 and 15, I was bed-ridden due to the lack of a comfortable wheelchair. This period was tough but also strangely good for me. I discovered comic books and video games, I finally found an escape from the all-consuming condition. It opened me up to

imagination, which has now given me the ability to solve problems or understand my behaviour and others.

“Around this time, my parents got divorced. I ignored the problems with my condition and learnt to cope quickly, so that I could support my Mum and sister. Everybody has issues to deal with in life, be it physically, mentally or emotionally. I am not suggesting it is wrong to be upset about living with DMD, but I have discovered that it should not affect my self-worth or body image.

“The periods of being alone in my room forced me to look inwards to discover my inner strength. It also enabled me to stay calm and focused.

**“What helped me start accepting my DMD was during college, I realised that I have the same abilities as able-bodied people too.**



"To put things in context, I went to a special needs school before college. Initially, the school helped me to accept being a disabled person but towards the end, I lacked confidence and had a belief system that I was not as good as able-bodied people.

**"Joining Muscular Dystrophy UK and Trailblazers was**

**the reason that I found my confidence and worth.**

"I have been part of many campaigns: cinemas, transport, and airlines. The faith MDUK had in others and me pushed me to use my voice and fight for my rights.

"The reason I become an Advocacy Ambassador and

peer support volunteer for the charity was to honour my life experiences and realise that everything I've been through could help my peers cope or help improve the lives of other disabled people.

"I've finally found the secret; self-image is not what people think about you but how you see yourself. Changing your thinking can change your life.

"You can turn the worst into the best by thinking of hurdles as opportunities to test how well you can adapt. It is in the darkest time that your power is illuminated.

**"The man I've evolved into could not have happened without my condition. I can now finally say that it is a positive part of me and that I'm grateful for all my strength and abilities."**

## Join Trailblazers

**Trailblazers is a national network of more than 600 young disabled people, who work together to campaign on issues important to them.**

Part of Muscular Dystrophy UK, the network's main objective is to fight social injustices experienced by young disabled people. Members campaign to ensure equal access, everywhere in the UK. This often means meeting with decision-makers and MPs to have the voice of young disabled people heard.

There are lots of ways to get involved in Trailblazers, if you're aged 16 to 35. It is free to join, you can get involved in campaigns, make friends, and gain work experience opportunities.

Muscular Dystrophy UK is grateful to the City Bridge Trust, whose funding will enable work experience placements for young Londoners over the next three years.

Trailblazers' campaigns have covered issues such as access to transport, higher education, airline travel, sport, and assistive technology.

The reports are often quoted in Parliament and in the media, and Trailblazers are called on for media comment on a range of issues affecting young disabled people.

Muscular Dystrophy UK is extremely grateful to SimplyHealth for their support of the Trailblazers programme.

**If you'd like to find out about joining Trailblazers, here's how you can get in touch:**  
**020 7803 4846**  
**trailblazers@muscular dystrophyuk.org**  
**@MD\_Trailblazers**  
**www.facebook.com/mdtrailblazers**

# Happy holidays

**Martyn Sibley (pictured opposite) shares his experience of an accessible holiday in the Canary Islands:**

"Tenerife is situated in the Canary Islands. Some might say it is a tiny bit of land off of West Africa. For me it is a lot more! I've visited this wonderful island many times and simply love it.

"My first trip was with my family when I was eight. We returned many times during my teens. Plus I've been lucky enough to visit for work in recent years too. The reasons for my love of Tenerife are far reaching.

"To start with, my condition called spinal muscular atrophy (SMA) has specific health implications. In the winter time I struggle with colds, chest infections and the risk of pneumonia. This is because I don't move my body around much, the cold temperatures of winter weaken my immune system, a common cold becomes a cough, and my cough muscles are very weak. So the warmth and vitamin D from the sun have always been hugely beneficial.

"Another consequence of having my impairment is the certain access requirements. My 130kg wheelchair carries me everywhere and despite popular belief cannot be carried by people upstairs.

"There are many global places to escape to and avoid the

winter cold. Tenerife trumps most of these on access for me. It is known for its great wheelchair access at the airport, accommodation, transport, beaches and excursions. This is so vital for a happy holiday.

"In October last year, my soul mate Kasia, my mum, step-dad, two family friends and I went to the south of the island for an autumn boost of fun in the sun.

"The hotel we stayed had lifts and ramps, with the restaurant, sports hall, spa and swimming pool all fully accessible.

"The amazing family business that owns the hotel continues

to support disabled people visiting the island. The beach is also accessible.

"Kasia and I really wanted to get out and see more of the island. We took advantage of the accessible excursion up Mount Teide; the winding roads, steep slopes, and breathtaking views were so memorable. It was so smooth from an access perspective on the bus, and the others on the trip were fantastic company.

"I can't encourage you enough to get to Tenerife – I can't wait to return. Meet you there!

"Hasta luego! (See you later!) Martyn"



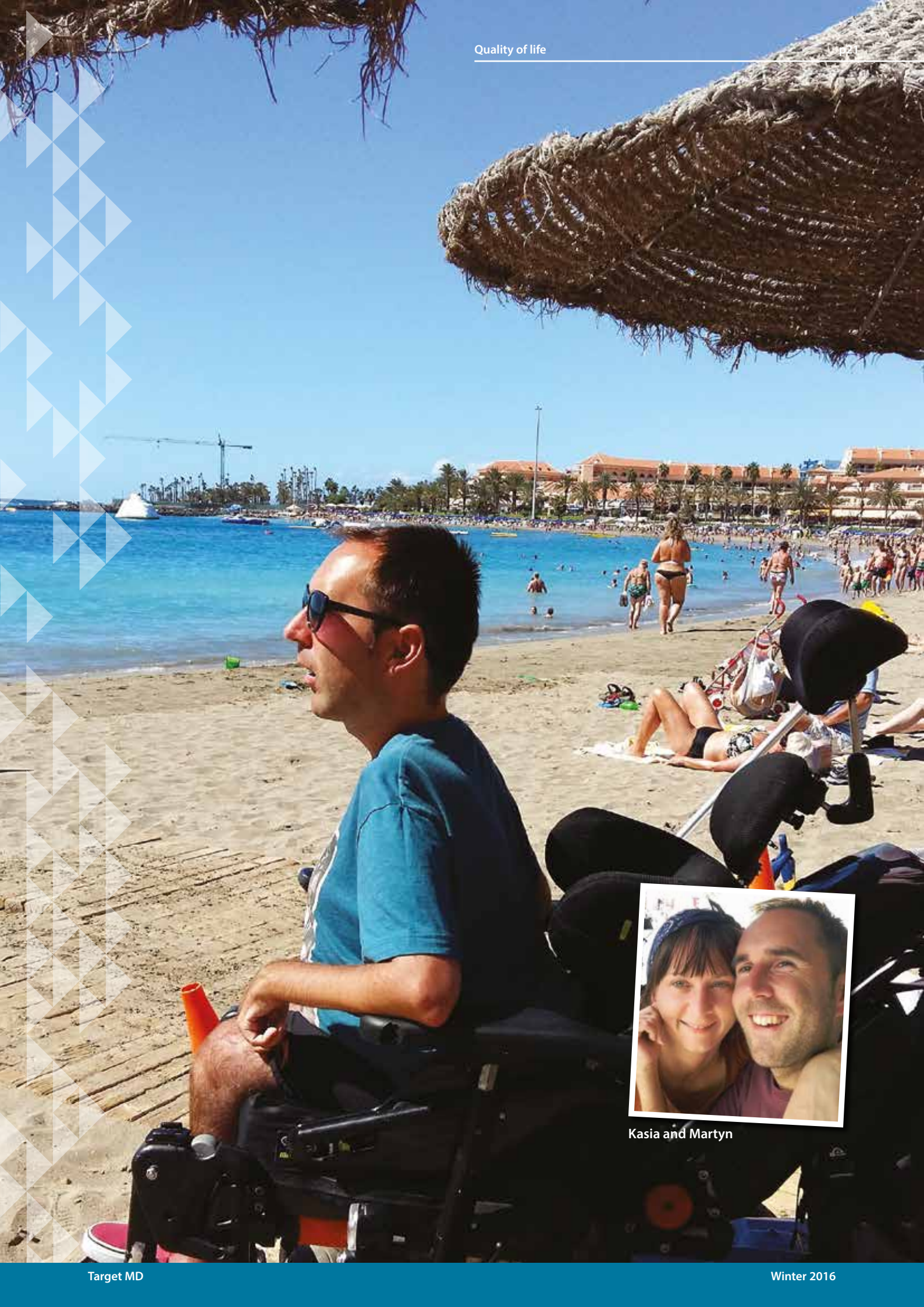
**If you're planning your next holiday, visit Disability Horizons' new travel site, *Accomable*, where you'll find information about accessible accommodation worldwide.**

Co-founders Martyn Sibley and Srin Madipalli met as children at an SMA Support UK Conference. They developed *Accomable* as a service to help people with mobility difficulties find accessible properties around the world. Through

work with tourist boards in the UK and abroad, and with their adventurous natures, they have both travelled all over the world and experienced some bumps along the road. They decided to list all accessible properties in one place, with detailed information about the property, the locality and services available.

[www.disabilityhorizons.com](http://www.disabilityhorizons.com)  
[www.accomable.com](http://www.accomable.com)





Kasia and Martyn

# Information and resources

Muscular Dystrophy UK works to ensure everyone living with a muscle-wasting condition has the specialist healthcare and support they need. We provide information and resources to ensure everyone has the right help at the right time, wherever they live.

## Improving care in an emergency

Imagine if, when you called an ambulance, the paramedics had information about your muscle-wasting condition before they got to you? That is likely to become a reality in London.

In a new project, Muscular Dystrophy UK is working with the London Ambulance Service to ensure people with muscle-wasting conditions get the exact emergency care they need.

Details of a person's key healthcare needs, including care plans and alert/symptom card information, can be added to electronic records linked to home and school addresses. If an ambulance were called, the paramedics would have that information immediately available helping them to react accordingly.

Muscular Dystrophy UK expects to begin rolling out the system in London within the next few months.

## Online training for GPs and physiotherapists

Since the new online training was introduced in 2015, more than 600 GPs and physiotherapists across the UK have signed up and completed the training modules.

## Fast forward – join the campaign

Together with families, Muscular Dystrophy UK continues to campaign to speed up access to potential treatments for muscle-wasting conditions.

We continue to press for a positive recommendation from NICE on Duchenne drug, Translarna. Keep an eye on our website for updates.

## Supporting families

As the first port of call for people recently diagnosed with a muscle-wasting condition, Muscular Dystrophy UK offers free information and support. Last year, the team responded to 2,892 emails and 480 social media requests for help. The team also helped 236 families get the benefits and equipment they were entitled to.

In line with requests for information, the charity has developed some new resources, specifically for families facing recent diagnoses. In addition to alert/symptoms cards for a range of muscle-wasting conditions, and care plans that can be customised for individual conditions, the resources include booklets on:

- ▶ *When your child has a muscle-wasting condition: A guide to talking with your child about their condition*
- ▶ *Research and clinical trials*
- ▶ *Financial and practical support: Find out what you're entitled to.*

**Call 0800 652 6352 (Freephone) or email [info@muscular dystrophyuk.org](mailto:info@muscular dystrophyuk.org) to order any of these or our other publications.**

## New Centres of Excellence

Following a national audit of neuromuscular centres, three centres have been newly-awarded Centre of Excellence status by Muscular Dystrophy UK. These are in addition to the seven Centres of Excellence that retain their status.

Centre of Excellence status recognises centres that provide specialist neuromuscular services and promote best practice locally and nationally.

The new Centres of Excellence are:

- ▶ Wessex Neurological Centre, Southampton General Hospital, Southampton (Adult Centre for Clinical Excellence)
- ▶ The Addenbrooke's Neuromuscular Service, Cambridge (Adult and Paediatric Centre for Clinical Excellence)
- ▶ Robert Jones and Agnes Hunt Orthopaedic NHS Trust, Oswestry (Adult and Paediatric Centre for Clinical Excellence).



# News and updates

## New Year honours list 2016

Our warmest congratulations go to Muscular Dystrophy UK President, Sue Barker (pictured right), on being awarded an Order of the British Empire (OBE) for her services to broadcasting and charity.



"We are delighted and want to congratulate our President Sue Barker on being awarded an OBE for her services to broadcasting and charity. Sue has been involved with our charity since 2004, and her constant commitment, compassion and motivation to support individuals and families living with muscle-wasting conditions, are invaluable," said Muscular Dystrophy UK Chief Executive, Robert Meadowcroft.

Our congratulations also go to Professor Deirdre Kelly, a Consultant Paediatric Hepatologist at Birmingham Children's Hospital and valued member of our Services Development Committee. Professor Kelly received a CBE for her outstanding work for services to children and young people with liver disease.

## New charity ambassador in Scotland

Muscular Dystrophy UK is delighted to welcome football pundit, former player and Scottish FA chief, Gordon Smith (pictured below with 11-year-old Robbie Martin from Lanark) as an official charity ambassador. A long-standing supporter of the charity, Gordon backs our fundraising events in Scotland, and has helped to raise thousands of pounds towards our work.

"I feel honoured to have become an Ambassador for Muscular Dystrophy UK. I hope my involvement will help raise awareness of the charity's work, and make a difference in fighting muscle-wasting conditions, which are affecting many lives today."

Join Gordon in Glasgow, where he will be hosting our annual Question of Support sports quiz and dinner on Friday 20 May 2016.

### Find out more at

[www.muscular dystrophyuk.org/events/question-of-support-dinner-quiz](http://www.muscular dystrophyuk.org/events/question-of-support-dinner-quiz)



Visit our website to keep up-to-date with the latest news: [www.muscular dystrophyuk.org/news](http://www.muscular dystrophyuk.org/news)



## Surbiton duo cycles for Dylan



Last August, Lucy Brown and Chris Wickens (pictured above) took on an epic 100-mile cycle challenge and raised an incredible £11,000 for Muscular Dystrophy UK. They did this all for their four-year-old nephew, Dylan.

“Three years ago, Dylan was diagnosed with Emery-Dreifuss muscular dystrophy. He was still just a baby, an adorable and squishy little baby. And it all seemed so horribly unfair that he would have to deal with such huge difficulties. Watching him cope with the daily physical challenges in such a heroic fashion motivated Chris and I to challenge ourselves and raise awareness and funds,” said Lucy.

The Surbiton couple decided to tackle the Prudential RideLondon-Surrey 100, which took them through London’s closed streets and Surrey’s stunning countryside.

“The ride was tough. No sugar coating. We trained, though in hindsight we should have probably done more – my thighs were very grateful to get off the bike!”

“I was overwhelmed as we rode the final stretch down the mall, just the two of us – so tired but

so proud that we’d made it. I remember Chris grabbing my hand and I welled up – I felt so emotional, remembering why we took on the challenge,” said Lucy.

“We wanted to raise as much money as possible for Muscular Dystrophy UK so they can continue supporting families like ours, and researching for treatments for conditions like Dylan’s.

“Lucy and I were blown away by the support of our friends and family and the total we raised. It was a great challenge and ride for us and we would love to take part again next year,” said Chris.

“The MDUK team was amazing – their clapping and whooping made us feel very important and loved!”

**Muscular Dystrophy UK would like to say a huge thank you to all our 32 #TeamOrange cyclists in the 2015 RideLondon, who together raised a fantastic £52,000 for the charity.**

**Join #TeamOrange in 2016 and cycle in RideLondon-Surrey 100 on 31 July 2016. To register, visit [www.muscular dystrophyuk.org/ridelondon](http://www.muscular dystrophyuk.org/ridelondon)**



# Make today count for my dad

**Megan James (19), from Edinburgh, is putting her nerves to one side when she leaps out of an aeroplane in March. She's doing this huge fundraiser for her dad.**

"My dad, Neil (pictured above, with me), has Duchenne muscular dystrophy. He was diagnosed with it as a child, and was given a life-expectancy of 25. He's now 45, and is the strongest person I know. He's my hero."

Megan, herself a carrier of Duchenne muscular dystrophy, had always wanted to fundraise for Muscular Dystrophy UK. She saw our 2016 Make Today Count event as the perfect opportunity, so she signed up to skydive.

"My mum and dad are both disabled, and they were told they could never have children. Muscular Dystrophy UK have supported them a lot over the years, and gave them helpful information that made their decision to have me a lot easier. We're all grateful to the charity for this amazing support.

"I also wanted to raise money so that if I ever decide to have children, there will be help and support for them. I want all children born with muscular dystrophy to have a happy and fulfilling life."

Megan's mum, Sheila, who has cerebral palsy, met Neil at a boarding school. They were together for 20 years, and have since separated.

"I've learnt a lot from my dad – he helps me put things in perspective, and never lets me get carried away with silly things. My dad has so much to deal with, and is always in a lot of pain, but he's always smiling and making jokes. I love spending time with him."

Megan works in a letting agency and lives with her boyfriend, in Edinburgh. She spends much of her spare time with her dad, her mum and her five-year-old half-brother.

**"My friends and family all think it's amazing that I'm going to skydive. They all want to come and watch me!"**

**Megan is one of nearly 200 skydivers leaping 10,000ft out of a plane to help raise vital funds for research into muscle-wasting conditions.**

Together they are aiming to raise £130,000 – that's enough money to fund nearly 3,000 hours of research.

Muscular Dystrophy UK wouldn't be able to continue the fight against muscle-wasting conditions without the support from generous people such as Megan and the rest of our **#Team100** skydivers – thank you so much for your support.

**You can help beat muscle-wasting conditions by joining #TeamOrange and doing a skydive. Sign up to Make Today Count in 2017.**

**Find out more at [www.muscular dystrophyuk.org/maketodaycount](http://www.muscular dystrophyuk.org/maketodaycount)**

**Megan's Justgiving page: [www.justgiving.com/megan-James2](http://www.justgiving.com/megan-James2)**



# Thanks for your support

## BGC Charity Day 2015



Every year on 9/11, global financial services company, BGC Partners, holds a global charity day. On this day, they distribute 100 percent of their global revenues to hundreds of charities in honour of the 658 friends and colleagues who lost their lives in the 2001 World Trade Center attacks.

In 2015, Muscular Dystrophy UK was delighted to be invited for the third time to take part in their London event. We were wonderfully represented by Sir Ben Kingsley (pictured above), Richard Wilson OBE and Sam Allardyce. We're also grateful to the Devenish, Sevenoaks and Foyle families who joined us on the day too. With events in New York, Tokyo, Sydney and London, BGC Charity Day has to date raised £83m for charities worldwide.

## Microscope Ball 2015

More than 650 guests came to our annual gala event with the property industry in London in October. The Studio 54-themed Microscope Ball at the Hilton Park Lane raised an amazing £113,000 towards our vital work.

Thank you to everyone who came along and generously supported our work in this way.

The Microscope Ball was set up 31 years ago by leading members of the property industry after a colleague's son was diagnosed with a muscle-wasting condition. Since its inception, it has raised in excess of £2m for the charity.

## Festive celebrations across the UK



Ten-year-old Tommy Lloyd (pictured above) took centre stage at the charity's Spirit of Christmas concert in Oxford in December. Along with celebrity readers, soloists and choir members, Tommy – who has limb girdle muscular dystrophy – helped make it a magical evening of festive celebration in the beautiful University Church of St Mary the Virgin in Oxford.

**"I feel honoured to be the person you've chosen to talk about and I really enjoyed lighting the candle," said Tommy.**

Among the high profile people who generously gave their time to support the charity in Oxford were Karen Lewis-Attenborough and The Hon. Michael Attenborough CBE. Karen Lewis-Attenborough was able to invite James Norton, Julie Peasgood, Oliver Milburn and Stephen Dixon to join us as readers in a star-studded evening. Michael Attenborough first became involved with Muscular Dystrophy UK in the late 1970s when his father – the late Lord Richard Attenborough CBE – was the charity's President.

**More than 700 supporters came along to our Spirit of Christmas concert series in Oxford, Gloucester, Henley and Hyndland, raising more than £21k to help beat muscle-wasting conditions.**



## Help us turn the Tyne orange

Be one of the more than 55,000 people to run the Great North Run on 11 September 2016. It is the world's biggest and most prestigious half-marathon. Join **#TeamOrange** and you'll help us turn the Tyne orange.

Entry will cost you just £29. You'll receive dedicated support and advice to help you reach a minimum fundraising target of £300. You'll also get into good shape – we'll send you great training tips every fortnight, starting a few months before your race.

## Move a Mile for Muscles 2016

Join us this summer for our fully inclusive Move a Mile for Muscles challenge. People across the UK will be scooting, walking, swimming and cycling a mile to help raise funds for our vital work. Join in between May and September, and move a mile however, wherever and whenever you want!

**Sign up for these and any of our other events at [www.muscular dystrophyuk.org/events](http://www.muscular dystrophyuk.org/events)**

## Town and Gown 10k – the anniversary year in Oxford

Congratulations and a massive thank you to everyone who ran Cambridge Town and Gown 10k last October! Record numbers took part, with over 1,500 sign-ups and more than £58,000 fundraised for Muscular Dystrophy UK.

**Looking forward to the spring, our 35th Oxford Town and Gown 10k will take place on Sunday 15 May. Enter the 10k or get the youngsters involved in the Junior 3k race at [www.townandgown10k.com/oxford](http://www.townandgown10k.com/oxford)**



## Honouring Huw

**Dr Huw Thomas, a retired research scientist and award-winning entrepreneur from Aberystwyth, passed away in September 2014.**

He became involved with the charity when he was diagnosed with limb girdle muscular dystrophy, and was a long-standing and generous supporter. He left a gift in his Will to Muscular Dystrophy UK.

Ann Hughes, who started the Aberystwyth Branch in 1975, first met Huw and his family in the early 1980s.

"Huw was a great supporter, a lovely character and was always a good laugh. He was highly intelligent and always willing and available to help. We all miss Huw very much.

"It is very typical of Huw and his generosity that he would want the charity and people with muscle-wasting conditions to benefit from a gift in his Will."

More than a quarter of our research projects are made possible by gifts in Wills to Muscular Dystrophy UK. If you'd like to consider leaving a gift in your Will to Muscular Dystrophy UK, you'll be creating the best tomorrow for everyone in the UK born with a muscle-wasting condition.

**Our legacy team is available to give you some helpful guidance. Leaving a gift in your Will does not have to be expensive or complicated. Please contact Cecile Laurent for a confidential chat on 020 7803 4834 or email [legacy@muscular dystrophyuk.org](mailto:legacy@muscular dystrophyuk.org)**



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