Muscular Dystrophy UK's lifestyle magazine

Issue 1 of 2015

Target MD

Just diagnosed: families share their stories

Updates on #Translarna

Fundraising successes for #TeamOrange

Muscular Dystrophy UK

Fighting muscle-wasting conditions

The Highest Quality Wheelchair Accessible Vehicles from Brotherwood®

Designed For Life.

5 YEAR CONVERSION WARRANTY

NEW CARETE
Ford Tourneo Connect

- Patented **"STORQ" Self Tensioning** Operational Restraint Quattro
- Quick, simple, easy loading operation
- Up to 59" internal headroom
- Low, flat, and level wipe-clean floor
- Wheelchair located next to rear seats
- Excellent outward visibility
- Four point wheelchair restraint
- Full cross & diagonal safety belt for wheelchair passenger
- Optional PAWRS Powers Assisted Wheelchair Restraint System
- 1 x Rear Passenger Seat included (x2 on Titanium models)

with **PAS2012-1:2012** Accreditation

Advance Payment £5,977

GOLD LION
Peugeot Partner Tepee

with **PAS2012-1:2012** Accreditation

Advance Payment £12,495

GOODLIFE
VW Caddy Life

with **PAS2012-1:2012** Accreditation

Advance Payment £3,847

At **Brotherwood**, we believe that a wheelchair accessible car should put the needs of the wheelchair user first. That's why since 1985 we have built the highest quality WAVS, that enable wheelchair users to travel comfortably, safely and inclusively: Next to the rear passengers, or up front, for a first class experience.

Motability

Home Demonstrations Nationwide

feefo
Service Rating:

To request a brochure pack or book your FREE, no-obligation home demonstration visit Brotherwood.com or call us on 0845 867 7307

BROTHERWOOD®

Manufacturer of the Best Wheelchair Accessible Cars

30 years 1985

Warranty T&Cs apply. 5 Year Warranty applies to retail orders only.

Muscular Dystrophy UK

Renewing our commitment to beat muscle-wasting conditions

You'll have seen that in late February, we changed our name to Muscular Dystrophy UK.

There are more than 70,000 people living with a muscle-wasting condition in the UK. These individuals, and their families, are at the very heart of the work we do every day.

Since our charity was established in 1959, we have seen some major progress in the quality and length of life for people living with muscle-wasting conditions. But we know this is not enough.

We need to accelerate the work we do to find treatments and cures, campaign for more specialist care and offer vital information and support to enable independence.

We have been listening to our supporters and have found that often people don't realise our work extends beyond campaigning. We invest in vital research and we support families through every stage of living with a muscle-wasting condition, from the very moment of diagnosis. It is important to us that everyone affected by a muscle-wasting condition knows they have our support and backing.

This hugely significant step to change our name reflects our long-term commitment and determination to beat muscle-wasting conditions, by drawing together all those in this country who share our vision and our goals.

Please visit our new website which reflects the changes in our brand **www.musculardystrophyuk.org**

We know that together we are stronger.

Thank you for your continued support.

Robert Meadowcroft
Chief Executive

Contents

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

Editor: Ruth Martin
Design: Toby Maslin
targetmd@musculardystrophyuk.org

Muscular Dystrophy UK
61A Great Suffolk Street
London SE1 0BU
020 7803 4800
info@musculardystrophyuk.org
www.musculardystrophyuk.org

Advertising enquiries: Richard Walters
richard.walters@cpl.co.uk
01223 477 428

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 bio-degradeable polybag.

On the cover
Pedro, Luca and Joanne Fernandes from Dorset. Read about their experience of a diagnosis of Duchenne muscular dystrophy on page 6.

Hello

Hello and welcome to the first edition of Target MD for 2015. It's also the first, new-look edition from Muscular Dystrophy UK – we hope you like the changes we've made after we asked what you thought last year!

It's been a busy time at the charity over the past few months, as we've been preparing for all that 2015 holds. Our new name brings with it a renewed commitment to our work to support families that you'll read about here, who are living with muscle-wasting conditions.

We are the first port of call for more than 4,000 families who receive a diagnosis of a muscle-wasting condition every year. Our care and support team, who answer our Freephone helpline from 8.30am to 6pm every day of the week, are there for anyone needing support from the day of diagnosis onwards. People who call our line tell us how helpful it is to have someone they can speak to who understands muscle-wasting conditions and can give them good advice and accurate information.

If you – or someone close to you – has recently been diagnosed with a muscle-wasting condition, please get in touch with our care and support team on 0800 652 6352.

Our team of fabulous supporters go to great lengths to fundraise to help keep our vital work going. Read about the excellent fundraising they do for us, and how you can get involved too.

Until the next edition, thank you for your support.

Ruth

Ruth Martin
Editor, Target MD
020 7803 4836
r.martin@musculardystrophyuk.org
@RuthWriter

About us

Muscular Dystrophy UK is the charity bringing individuals, families and professionals together to beat muscle-wasting conditions.

- We support high quality research to find effective treatments and cures; and lead the drive for faster access to emerging treatments for UK families.
- We ensure everyone has the specialist NHS care and support they need, with the right help at the right time, wherever they live.
- We provide a range of services and opportunities to help individuals and their families live as independently as possible.
- We know we can beat muscle-wasting conditions more quickly by working together and hope you will join us.

Join us online

Make sure you keep up-to-date by joining our social media networks.

www.facebook.com/musculardystrophyuk
Join the **20,000+ community** on our Facebook page.

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

www.pinterest.com/MD_UK
Follow our boards and pin our pictures on Pinterest.

www.youtube.com/c/musculardystrophyuk
Watch our videos on YouTube.

instagram.com/musculardystrophyuk
Share our pictures on instagram.

Media spotlights

@MDUK_News

This is what got people talking:

'Not a treatment but it saves lives': our Trustee Baroness Thomas challenges Minister on cough assist #RightToBreathe http://bit.ly/1F9lnSx

Did you know 1 in 3 people in need can't access a cough assist? Join #RightToBreathe to make this a thing of the past http://bit.ly/1Af4b9z

We have launched our new CMT symptoms card. Find out more about the card and how it will aid people with CMT here: http://bit.ly/1AH1nSE

Baroness Thomas calls on Clinical Commissioning Groups to provide cough assist machines where need identified @NHSEngland #RightToBreathe

In the media

In December NHS England delayed its decision to halt the assessment of the Duchenne muscular dystrophy drug, Translarna. More than 200 media outlets covered the story including *Good Morning Britain*, *ITV News*, *the Mail Online* and the *Huffington Post*, generating almost a million opportunities to see, hear or read.

After meeting the Prime Minister at No 10 Archie Hill was interviewed on *Good Morning Britain* about a surprise visit from his Arsenal hero, Jack Wilshere. There was more in the *Daily Mail* and *Daily Mirror* and *ITV London News*.

Trailblazers campaigned on issues relating to wheelchair user spaces on buses, and cinema access.ted bays on vehicles. The issues were covered by the *Daily Mail*, *Sky News*, *Metro*, *Daily Express*, *ITV National News*, *Daily Mirror* and *Yahoo News*.

Following approval of the mitochondrial transfer technique, Muscular Dystrophy UK was one of the most widely quoted voices on a headline news issue.

musculardystrophyuk

Our Facebook community have been talking about:

The #RightToBreathe campaign has made a big impact, after NHS bosses in Cornwall agreed to fund cough assist machines for people affected by muscle-wasting conditions.

PTC Therapeutics has announced today that it will make Translarna available to siblings of boys in certain clinical trials.

Kate Bushby, professor of Genetics at Newcastle University has won the 2015 EURORDIS Scientific Award for outstanding commitment and achievements in the field of neuromuscular disorders. Muscular Dystrophy UK has been funding the work of Prof Bushby for more than 20 years. http://bit.ly/1aJMNoS

We are excited to share that BBC One's Lifeline appeal will be presented by charity President, Sue Barker. The appeal will tell the stories of two people living with muscle-wasting conditions and show why funding is so vital.

Nine-year-old supporter Archie Hill and his brother Leyton had quite a surprise on Wednesday when their hero, Arsenal footballer Jack Wilshere, welcomed them home from school.

Archie Hill with mum Louisa, brother Leyton and Dave Anderson MP, meet David Cameron at No 10

Left abandoned at diagnosis

A snapshot survey of 700 people living with muscle-wasting conditions found that more than 75 percent received absolutely no emotional support at the time of diagnosis.

Some received the diagnosis over the phone or were advised to "search on Google" for more information.

Our '*Isolated and abandoned: The hidden impact of rare conditions*' survey found that more than 60 percent experienced feelings of isolation and only 15 percent were helped to connect with another family living with the condition.

"The evidence is clear. Too many families have been left abandoned to cope with a bombshell at diagnosis and no information about charities that can help with the feelings of isolation.

"We are calling for a joined up approach between the Government's rare disease strategy and the mental health and suicide strategies, to make sure that no-one falls through the emotional safety net" commented, Robert Meadowcroft, Chief Executive of Muscular Dystrophy UK.

Joanne Scott-Fernandes, whose son, Luca (5) was diagnosed with Duchenne muscular dystrophy, said: "Utterly devastated, we were left to spend long periods with no information and offered no emotional support. Instead we had to rely completely on family and friends, who were in the dark as much as us."

For more information call our Freephone Helpline on 0800 652 6352.

"We want to give Euan the opportunity to live life to the full."

Alex Ashurst and son Euan

Fundraising for Euan

At the end of April this year, Warren and Alex Ashurst are planning a bake sale. Not your average bake sale but one to mark the anniversary of their son's diagnosis with a severe muscle-wasting condition.

"There are always good days and bad days, but you learn very quickly that tomorrow is a new day."

The couple, who live in Alwoodley in north Leeds, learnt three years ago that their middle son, Euan, had Duchenne muscular dystrophy.

"We're holding a bake sale across a number of areas and offices on 30 April, the anniversary of Euan's diagnosis in 2012. We'd like to try and make an awful day a little bit better," said Warren.

"Euan's diagnosis came after an 18-month battle, during which time we tried to put our concerns across to medical experts. Although you try not to compare your children, we felt he wasn't progressing as he should, and felt he might need some physio work at least. The diagnosis came as a major shock," he said.

Warren, a sports reporter, and Alex, a radiographer, both felt numb, helpless and in a state of shock when they heard the diagnosis.

"Nothing can prepare you for hearing this type of news and we often still find it hard to come to terms with. But we were helped in a big way by the specialist care advisor in our area [Sue Manning], and especially by a poem she gave us called 'Welcome to Holland'.

"Unfortunately Euan struggles developmentally as well as physically, so he has struggled a bit at school. He really enjoys going to school, though, and has learnt an awful lot in the first two years. And, for the first time, he is making friends. He sometimes gets frustrated that he can't do what some of the other boys can do, and he's becoming more aware of this. But he often just gets on with things as best as he can," said Warren.

"Nothing can prepare you for hearing this type of news and we often still find it hard to come to terms with."

Euan has just turned six and is into computer games, technology, baking and has recently started horse riding. His parents describe him as 'a determined, bubbly and endearing little boy, who with his lovable nature has the ability to get his own way'!

His older brother, Luke is eight and is into sport, computer games and music. A 'confident but sensitive and caring boy, Luke is also very talkative and friendly'. Their youngest son, Rory, turns two in March. He is 'boisterous, very active and smiley and loves following his older brothers around'.

"a determined, bubbly and endearing little boy, who with his lovable nature has the ability to get his own way"

As is often the case with a new diagnosis, Warren and Alex have very different coping mechanisms. Warren says he deals with it very much on an individual basis, although he does often talk things through with Alex, whom he describes as a 'massive help to me'.

"I sometimes throw myself into things to take my mind off it, be it work, sponsorship events, or organising things."

Alex, on the other hand, has found it a real help to talk to other parents of boys with Duchenne muscular dystrophy but also finds it hard to open up too much.

"We tend to try and put on a brave face," said Alex.

"...make the most of the good days with your children"

If they were to advise parents facing a similar diagnosis, they would encourage them to take one day at a time.

"There are always good days and bad days, but you learn very quickly that tomorrow is a new day. Allow yourselves time to grieve and take time out when you need to. Try and make the most of the good days with your children," said Alex.

"Not long after Euan's diagnosis, our neuromuscular care advisor, Sue, along with Euan's specialist, made us aware of the charity. The charity has given us important information and supported us in a big way with charity events and fundraisers. Sara Wilcox (Regional Development Manager) in particular has kept in regular contact with us, and we've found that really helpful," said Warren.

In February 2014, Warren and Alex set up Euan's Gift Family Fund. They plan to split the money two ways.

Please contact us on 0845 872 9058 or volunteerfundraising@musculardystrophyuk.org to find out more about setting up a Family Fund.

"We plan to raise funds for Euan, to give him and his two brothers the gift of happy memories. We want to give Euan the opportunity to live life to the full and make sure he gets the best care possible. And we'd also like to fundraise for the vital support services Muscular Dystrophy UK offers to other families living with muscle-wasting conditions.

"Through the charity's support of regional care advisors across the UK, families like ours are able to come to terms with the massive shock of a diagnosis of Duchenne muscular dystrophy and what they are facing. And then there is the practical support they offer families living with and caring for someone with a severe muscle-wasting condition," said Warren.

Warren and Alex have galvanised a community of support around their fundraising events and have found these to be helpful in ways they hadn't anticipated.

"It has made us realise we aren't on our own, and friends and family will go out of their way to help Euan and his brothers. The support has been incredible and, at times, overwhelming – particularly as neither of us is good at asking for help. The events also help us cope with issues and achieve goals we didn't think possible," Warren said.

Making a difficult anniversary a little bit better is just one goal they hadn't thought possible.

Muscular Dystrophy UK is ensuring everyone has the specialist NHS care and support they need, no matter where they live. By bringing families together to campaign with us, we've secured more than £4m worth of investment in specialist healthcare and statutory services across the UK. In the last five years, we've achieved an increase in the number of NHS care advisors and specialist nurses across the UK from 13 to 45.

Setting up a family fund like Euan's Gift Family Fund is a great way to help us beat muscle-wasting conditions.

(l to r) Rory, Luke and Euan

Your independence, our motivation

The Mobility Roadshow

25th - 27th June 2015, Donington Park

Free admission & parking

In partnership with DAILY EXPRESS

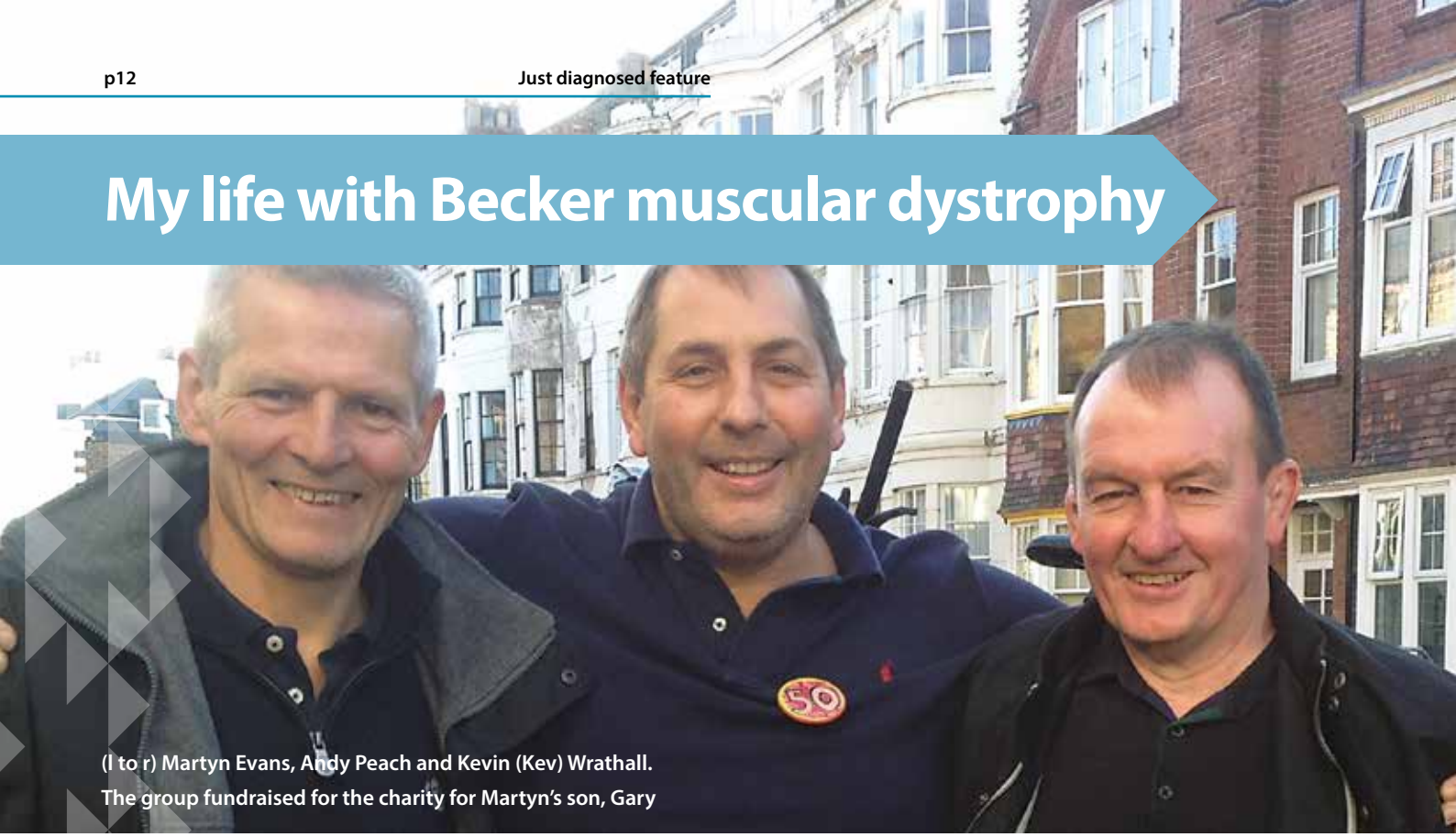
The Mobility Roadshow®
the future of mobility

test-drives · conversions · adaptations
scooters · wheelchairs · innovation & more

TV's Dr Hilary Jones opens the show

www.mobilityroadshow.co.uk 01332 810007

My life with Becker muscular dystrophy



(l to r) Martyn Evans, Andy Peach and Kevin (Kev) Wrathall. The group fundraised for the charity for Martyn's son, Gary

For Gary Evans, his 2006 skiing holiday was not going according to plan. He kept falling over on his right knee, and then had a really bad crash on it. When he got back home, his consultant told him the growing weakness in his leg was down to ligament damage.

Gary (33), who lives in Burton-upon-Trent, had a series of X-rays and MRI scans over the years. However, in mid-2014 when he felt his upper body strength deteriorating, Gary knew it was something more than a lack of fitness and a knee problem. He did some online research and diagnosed himself with a thyroid problem.

"I visited my GP to get my self-diagnosis confirmed. He gave me a blood test, and my creatine kinase (CK) levels were through the roof. I was given an urgent referral to a neurologist, who – on 19 September 2014 – diagnosed me with Becker muscular dystrophy.

Gary had never heard of muscular dystrophy. His neurologist wrote the condition name on a piece of paper and told him to go and research it.

"That was a tough weekend.

"My initial reaction was to focus on the bad stuff. Everyone around was trying to keep me positive and all I could focus on was the bad."

"My mum and aunty, dad and brothers and I were trying to find out what we could. My initial reaction was to focus on the bad stuff. Everyone around was trying to keep me positive and all I could focus on was the bad.

"I found lots of websites explaining muscular dystrophy but I didn't find a lot of helpful information. Fortunately I came across the Muscular Dystrophy UK website fairly quickly. That was the only place where the information was consolidated, and tangible. It's a really good source of information."

Less than a month after his diagnosis, Gary and his family found themselves at the Muscular Dystrophy UK's national conference in Coventry.

"We had seen the conference advertised on the website, and decided to buy tickets and go along. It was a real eye-opener for us all.

"I was petrified going; I felt a bit of a fraud because I can still walk and I was quite worried about what I'd hear. I got a lot of information during that day and met a whole world of people out there that I would never otherwise have encountered. It was great how welcome people made us feel and how nice everyone was.

"We met a few people from the charity – including our regional care advisor Jane O'Connor, who has been fantastic. The charity is a wonderful family and everyone has been great."

Gary, who is the eldest of three brothers, comes from a close-knit family.

"My family has been brilliant. My dad took it upon himself to do a 170-mile bike ride over three days. He joined two friends to take on the Way-of-the-Roses cycle challenge and to fundraise for the charity. The response was amazing and he raised £4.7k in three weeks. Some of the messages on his JustGiving page were very heart-warming and heartfelt."

"The best advice I'd give to someone newly-diagnosed with Becker muscular dystrophy – which is what I got – is to reach out and talk to other people who have the same condition."

Gary's dad's fundraising challenge gave him an outlet to tell people about his diagnosis.

"I was so nervous about telling people at work and telling my friends. I didn't want people to look at me or treat me differently. By asking people to support my dad, I had a great opportunity to tell them what was happening. I realised it wasn't something I should be hiding from. It took me eight hours after writing the email to press 'send'.

"The reactions were interesting. Some people wrote back straight away, saying how sorry they were. Some people didn't respond at all. I guess that's what I wanted – not to be treated differently.

"The best advice I'd give to someone newly-diagnosed with Becker muscular dystrophy – which is what I got – is to reach out and talk to other people who have the same condition. I'm an independent person and have been quite hesitant to do that. However, the only really tangible advice I've been given is from people who know exactly what I am going through, and what it means. So that has been really helpful," he said.

"At the moment I want to do everything I can for myself. I don't want to focus on what I can't do."

Gary loves watching sport, particularly rugby.

"I used to play rugby until I was about 14, and played very badly. Now I know why," he said.

He also loves to travel and enjoys exploring new places and meeting different people. His job as European Marketing Manager for an automotive consultancy takes him all across Europe.

"At the moment I want to do everything I can for myself. I don't want to focus on what I can't do. I'm going headfirst and joining up and signing up for everything I can," said Gary, who's offered to become part of an advisory group for a Becker muscular dystrophy fundraising appeal.

"I hope I can add value to the group – I'd like to feel part of achieving something for the group. It will also put me in contact with other people in similar situations.

"I didn't want people to look at me or treat me differently."

"If I can do anything to raise awareness of Becker muscular dystrophy – my GP doesn't know much about it, for example – with people who weren't aware of it before, then I have achieved something. I am looking forward to being involved," he said.

Muscular Dystrophy UK provides a range of services and opportunities to help people live as independently as possible. We are a first port of call for 4,000 individuals and families newly diagnosed each year. We offer a personal support system for people at their point of need, with a specialist helpline and free information. Last year we responded to more than 25,000 requests for help. If you, like Gary, have recently been diagnosed with a muscle-wasting condition, do get in touch with us. You can call us on **0800 652 6352** Monday to Friday between 8.30am and 6pm or **info@musculardystrophyuk.org** any time.

Find out more about Becker muscular dystrophy at www.musculardystrophyuk.org/becker

Music gives me hope

Eighteen-year-old musician, Jason Weaver from Cheshire, dreams of the day he can break into the international music scene. A tough gig for any budding singer/songwriter. Even tougher when local venues aren't accessible to wheelchair users.

Jason, a history student at Worcester University, was diagnosed with Duchenne muscular dystrophy at the age of eight. He recently had a gig in Brighton, but would like to wait until he can get to bigger, more accessible venues before gigging again. He also feels putting his music online offers him better exposure.

"While I don't like the fact that many venues aren't accessible – especially locally – I don't think it will stop me in the long run. I hope I'm not proved wrong," he said.

"I'll try gigging again when I have music I can release. For now, YouTube is my best option to get known and to spread my message. Fortunately a few YouTubers (tarynsouthern and inthefrow) have taken an interest in my music and said they'd like to use it some time in the future."

Music has always been a form of escape for Jason. He loves the feeling of being somewhere else.

"My singing changed when I started using my wheelchair. I worked a way round it so I could perform to my fullest"

"Music gives me hope that things will get better. Or knowing that things could be worse," he said.

"I've always had music around me, from a very young age. My dad used to play Bad Company, AC/DC, Def Leppard – who wouldn't want to be a rock god? It was my – and every young lad's – dream!

"And then my music taste got progressively diverse. I have an aunty who lives in Missouri and she got me into the blues," said Jason, who counts Howlin' Wolf and BB King among his early blues icons.

With huge inspiration from folk musicians around the world, Jason now describes his style of music as Americana – his all time favourites being Joni Mitchell and John Martyn.

"My singing changed when I started using my wheelchair. I worked a way round it so I could perform to my fullest, and now I find it easier to gig sitting down. My hand gets really sore after playing the guitar for a while, though, so I put my hand in cold water to relieve the pain," he said.

It was in December 2005 that Jason was diagnosed with Duchenne muscular dystrophy. He said it was just a surprise to him – a child with not a care in the world.

"I wasn't that aware of why I was having tests, getting orthotics and having physio all the time. I just thought that was what happened to every other child. Then I went to Oswestry Hospital – the Robert Jones and Agnes Hunt Orthopaedic Hospital – and was diagnosed with Duchenne muscular dystrophy.

"My parents took it hard, as they would. I used to get apologies from them that it was somehow their fault. I hated that. While I'd like to think I take the brunt of my condition and deal with it myself, my parents have supported me through this remarkably.

"You'll gain more drive and determination."

"It is, of course, as much of an adjustment for them as it is for me. But I'm proud to have had their support. I experienced awful bullying as a child and used to get beaten up a lot for being 'disabled'. I could always rely on a safe, caring home – something many children don't have.

"Swings and roundabouts," Jason said.

"What would I say to a young person just diagnosed with Duchenne muscular dystrophy? Cherish the people around you – friends and family in particular. One day you'll rely on them heavily, and you'll need happiness.

"More importantly, don't think your disability defines you because it doesn't. You're the same person inside; you may even grow in character as a result – like I have. Nobody can define you but yourself.

"Go out and inspire millions of people. We all have the ability to do it. You aren't disabled, you're differently abled. Show it. Show people what you're made of!"

"I've met some amazing lads with muscular dystrophy, and they don't let it stop them. I can't say it'll be easy. I'm still adjusting to being disabled, and having to deal with a different future from a lot of people I know. But you'll grow as a person. You'll gain more drive and determination," he said.

Jason has only recently personally become involved with the charity, and has enjoyed being part of a support network. Knowing there is a community willing to share their experiences and help him cope with his disability not only in the music world, but in general, has been helpful.

His final piece of advice for someone newly-diagnosed with a muscle-wasting condition seems to be his own rallying cry.

"Go out and inspire millions of people. We all have the ability to do it. You aren't disabled, you're differently abled. Show it. Show people what you're made of!"

He aims to do just that.

"I hope to go to the United States soon to write music for other people and, I hope, climb the ladder of success. Mostly, I don't want my disability to be a hindrance or a reason why people listen to me. I am a musician. I just happen to have a disability."

If you'd like to work with Jason, or find out more about his unfolding career in music, do follow him on Twitter **@jdweavermusic** or listen to his music at **soundcloud.com/weaver12345**

Muscular Dystrophy UK brings people together to beat muscle-wasting conditions. We provide services and opportunities to help people live as independently as possible. Trailblazers, our network of 600 young disabled people, campaign for change on issues that affect them, including access to live music. If you've been denied access to a live music gig, or would like to find out more about the work of the Trailblazers, please get in touch at **trailblazers@musculardystrophyuk.org** or **020 7803 4800**.

Find out more about Duchenne muscular dystrophy at www.musculardystrophyuk.org/duchenne

The new Avantgarde^3

Living ahead!

31 year old Nina is a model, mother, wife and rugby player. She lives her dreams and enjoys life to the full. When posing before the camera Nina emits passion, beauty and radiance that even her wheelchair cannot distract – quite the reverse!

'I would like to make a difference and hope my actions inspire others with a similar disability, to have the courage to live their dreams'. Following a car accident that changed her life leaving her a quadriplegic, with the assistance and support of family and friends Nina energetically fought her way to regain her old (new) life back. 'Most important is a healthy self being and feeling of value, whether disabled or not. I have learned to live with change and have become extremely disciplined' states Nina.

'Obviously my family and modeling career keep me extremely busy, however, during 2008 I commenced a new hobby and actively and enthusiastically play wheelchair rugby defense for the Maple Panthers. Rugby is like playing chess, only more complicated since the figures move considerably faster!'

Ottobock
0845 600 7664 · www.ottobock.co.uk

provider Paralympic Games

Official Prosthetic, Orthotic and Wheelchair Technical Service Provider of the 2012 Paralympic Games

Muscle SmART

It all started with an observation from a young person attending a session with a clinical psychologist five years ago. Having a diagnosis of mini-core myopathy and living in a semi-rural part of the West Midlands meant that opportunities to meet and interact with other young people with similar conditions were few and far between (not including the waiting room phenomena at clinic out-patients).

What we heard from families and observed in clinic was that talking about the emotional aspects of having a neuromuscular condition could often feel quite difficult and at times took second place to thinking about getting through the practicalities of day-to-day life. This was the catalyst behind the idea of a group for children and young people for Sue (who was new to the Neuromuscular Care Advisor role at Birmingham Heartlands Hospital at that time) and Harvey (the clinical psychologist in the team).

Although the group was for the young people, at the end of the session the work was shared with the parents.

Thus the group was started and held during the various school holidays. It did not have the most enticing or catchy of names to begin with until the idea of the 'Muscle SmArt' group was devised by group members two years later. We had noticed that the young people often found it hard to talk about the difficulties and worries they were experiencing. However, using art as a way of expressing views about a particular topic appeared to free up the young people's thoughts and feelings.

For example, in one session we discussed how we would show to others the things that we do not like that happen to us. It was interesting to see that often the young people focused on other areas of their lives (such as school) before considering aspects of their condition or healthcare that they did not like (such as going to have MRI scans).

We have consistently been amazed by the creativity in the group to draw, make models, write, cut-and-paste and stick things together, as well as their ideas

for the topics of the groups. We've also observed the support they gave to each other in sharing ideas or helping to put things together. Having one main topic for the group helped the group feel contained rather than the optimistic two to three topics per group we had originally planned.

We quickly learned that playing the simplest of games was the greatest way of encouraging the team element of the groups and allowed everyone to interact (from the quietest members to those who were extremely confident in getting across their views). This was especially important as there were often different young people who would attend each time, in addition to the regulars. One of the mainstays of the Muscle SmArt group was the 'I went to shop and bought a...' game, though it was challenging for us as group leaders trying to remember the long list of things!

Although the group was for the young people, at the end of the session the work was shared with the parents. We hoped that it helped families think together about some of the other feelings that can arise from having a muscle-related condition.

The Muscle SmART group is a therapeutic thinking group aiming to provide a safe space for children and young people with a neuromuscular diagnosis, using art and creative materials to talk and express themes arising that are important to them and their lives.

Dr Harvey Tagger, Clinical Psychologist
(Birmingham Children's Hospital NHS Foundation Trust)
Sue Gallagher, Neuromuscular Care Advisor
(Heart of England NHS Foundation Trust)

If you would like to know more about the group, please contact Sue Gallagher at Birmingham Heartlands Hospital on 0121 424 0689 or susan.gallagher@heartofengland.nhs.uk

A night hike to remember

On a cold Saturday evening in early December, 'Team Tangerine' took on the first Mournes Night Hike to the summit of Slieve Donard to raise funds for the charity.

The team of seven took seven hours to complete the challenge in freezing temperatures and 60mph winds. Despite the extreme weather conditions, the group all made it up and down the highest peak in Northern Ireland.

Thanks to Demelza Stuart (Advocacy and Information Officer for Northern Ireland), Jonny Stuart, Brenda Campbell, Tara Torrens, Claire Dick, Naomi Orr and Cathryn Gibson (Regional Development Manager for Northern Ireland). They not only completed the first local challenge for Northern Ireland, but also together raised £1,500 for Muscular Dystrophy UK.

"This hike was a real challenge against the elements but it was a great experience with a huge sense of achievement at the end. I'm very happy to have supported the charity!" Brenda Campbell

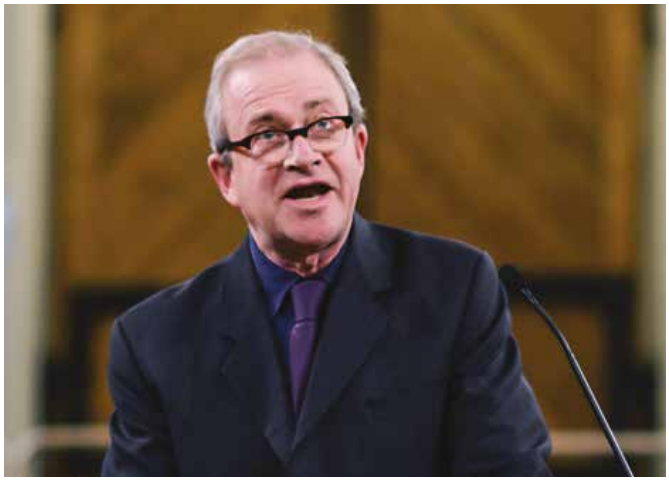
The Spirit of Christmas

December 2014 saw six Spirit of Christmas concerts take place across the country – from Hyndland to Henley. All the concerts were a huge success.

This year's Oxford Spirit of Christmas concert moved from Christ Church Cathedral to a new venue: the Sheldonian Theatre. There was loads of festive cheer, with fantastic musical performances from The Dragon School and soloist Elizabeth Dury. Celebrity readers at the event included Harry Enfield (pictured right), Dominic West and Karen Lewis, and a brilliant time was had by all.

Gloucester Cathedral saw around 100 guests through their doors. Choirs from Innsworth Junior School, the Cotswold School and Shurdington C of E Primary School, performed at the Gloucester concert, while the Hyndland Cathedral concert was hosted by Glasgow soap star, Tom Urie.

We'd like to say a huge thank you to all the volunteers and committees who helped organise these fantastic festive events. And, of course, to those who attended and helped us raise around £26,500. We hope you all enjoyed the evenings.



If you'd like to help organise a Spirit of Christmas concert in 2015 please do let us know. Get in touch with Louisa on l.mclellan@musculardystrophyuk.org or 020 7803 4816

Every day is a new day

Soon after Lesley (pictured above with Ashley) and Les Wegg's son Ashley (7) was diagnosed with Duchenne muscular dystrophy, Lesley threw herself into fundraising for research.

Lesley and Les have an older daughter, Melissa (11), and the family lives in Driffield in East Yorkshire. Les is an aircraft designer, while Lesley has worked for Lloyds Bank for the past 29 years.

There had been difficulties with Ashley's birth, and Lesley and Les put his delayed milestones down to that. When he was four years old, and his school teachers mentioned he had an unusual way of getting up and sitting down, Lesley and Les started to pay more attention. Ashley had various assessments with health professionals, including an orthopaedic surgeon who examined Ashley's hips. He was then referred to a paediatrician, who sent him for a blood test.

"When the blood test results came back, the paediatrician said she thought Ashley had Duchenne muscular dystrophy. She wanted to do some genetic testing before confirming the diagnosis. She gave us a factsheet, which I read and put out of my mind – I thought she just had to be wrong. When she called us in June to confirm it was Duchenne muscular dystrophy, I can't even put into words how shocked we were.

"We had never even heard of the condition, we have no family history of muscular dystrophy and had no idea there were so many different conditions," said Lesley.

"I thought she just had to be wrong."

"Our care advisor (Tracey Adjei) came to see us within weeks of the diagnosis. She brought with her one of the charity's Advocacy Ambassadors, Tracey Franklin, and I've kept in touch with her. It's good to chat to someone who knows about the condition, and to hear how she has dealt with it for such a long time. Things have progressed over the years since her son Jack, who is now 18, was diagnosed with Duchenne muscular dystrophy. There seems to be more support and research

into the condition has moved on so much.

"A few weeks after the diagnosis, I came to the decision that I could either bury my head under the pillow for the rest of my life, or I could do something. I feel we are really lucky to have Ashley and he is very lucky to have us. His quality of life is really good.

"There are some good days and some not so good days, but it helps to think every day is a new day."

"So after doing a lot of research into the condition, I decided I would focus on what I could do to make a difference to Ashley. I realised I could raise money for research into treatments for Duchenne muscular dystrophy in the hope that the money raised will help not only Ashley but also lots of other boys with the condition.

"Lloyds Bank is very supportive of work in the community. So I started with my own team and looked for volunteers to do a zipslide event in October in North Wales. I thought we might recruit five or ten people, but we ended up being oversubscribed and had to turn people away. We'll be doing another zipslide event in April.

"We got the Hull City Legends to play 'Ashley United' in a pay-to-play football event. People who had grown up with Hull City football team were really happy to have the chance to play against their heroes, and the Hull City Legends signed T-shirts for the Ashley United members as mementoes."

This was followed by a 'Hull's Got Talent' event with local star, Leroy Vickers, in November. Lesley has a few events lined up for 2015, including '10 up at 10,000ft' for the charity's Make Today Count event in March and a toga party at their golf club in the summer.

When Lesley met the two Traceys and told them she wanted to do some fundraising, they put her in touch with the charity's regional development team. Lesley has found their support really helpful.

"It gives me peace of mind knowing if we ever need anything, we know where to go."

Lesley has also valued the distraction of organising events, and has been overwhelmed at the response social media has generated.

"Through Facebook, I've had people speaking to me whom I've not heard from in 25 years. The support from friends – and not just my closest friends – has been so surprising and it has really helped the fundraising take off for us.

"After one of my posts on Facebook, a friend of a friend asked me to get in touch with someone she knew. It turned out to be my best friend from junior school. She and I were not only born on the same day, but we also lived on the same street, were in the same class at school and had the same friends until I moved out of the area as a teenager and we lost touch. It turns out her son also has Duchenne muscular dystrophy. He is 14.

"We arranged to meet up and meet each other's families. I was sad to think we'd lost touch, but it's brilliant to be back in touch with her. Our daughters are the same age, and their friendship will also help them both in the future.

"It gives me peace of mind knowing if we ever need anything, we know where to go."

"Ashley is a really friendly little boy. He brings a smile to everyone's face and has a great sense of humour. He doesn't have a care in the world. He's a fan of Lego, Star Wars, and the movie Home Alone, and he wants to be an inventor when he grows up. Because Les is an aircraft designer, Ashley also loves planes and understanding how they actually work."

"My mantra is 'one day at a time'. There are some good days and some not so good days, but it helps to think every day is a new day."

Muscular Dystrophy UK invests in high quality research to find effective treatments and cures as quickly as possible. Using a robust international peer review process, we've invested more than £55m in high quality research. We've laid the foundations for the first potential treatments for Duchenne and Becker muscular dystrophy, which are now being taken forward into clinical trials.

If you'd like to find out more about the research we fund, please visit: www.musculardystrophyuk.org/research

High fashion in Sydney

"I was so proud I had achieved something I never thought I'd be able to. But I guess that's what great about being in a wheelchair in this modern world. If you try hard enough, there is nearly always a way."

Laura Richter (21) from Huddersfield recently returned from a work placement in Australia. Not only had she completed 13 weeks as a studio assistant, but she also managed to squeeze in a skydive while she was in Sydney.

Diagnosed at the age of four with the same condition her father has – facioscapulohumeral muscular dystrophy (FSH) – Laura is a student of Fashion Design with Marketing and Production at the University of Huddersfield. The four-year degree course requires her to take a year out to gain experience in the industry.

Laura likes to travel and find different places in the world she can access in her wheelchair. Looking for placements, however, proved to be more difficult than Laura anticipated. She was about to call it a day when she applied to the small couture bridal company, which was in Sydney.

"I was offered a placement at the bridal company for nine months. That would have made up a pass for the placement year of my degree. Although my disability can be a drive for my determination, it can also sometimes be a hindrance.

"Imagining how someone in my position was going to pull off this kind of trip was difficult. It seemed impossible. I've been described as having a 'stubborn nature', so I was determined to do it," said Laura.

"I wanted to do something exciting while I was out in the bright Australian sunshine, so decided to skydive."

"I discovered however that if I took the placement for nine months, it would cost me my Motability adapted car, along with my DLA (disability living allowance). I could then only re-apply for DLA six months after returning from Sydney. I decided just to go for the time that was allowed – 13 weeks – without losing any benefits."

Laura found accessible accommodation in a brand new accessible studio at the Australian Catholic University, only 11 minutes away from her placement.

Laura travelled to and from work by taxi (booked through a wheelchair accessible taxi company), and at other times travelled by train or bus.

"My boss, Souraya, was extremely pleasant and never had any problem with me being in a wheelchair. Her father-in-law built a little ramp for

the step up to the bathroom at work, and Souraya got me a lower table I could work from in the studio. I had access to everything I needed in the work environment, so I could just focus on and enjoy the creative work I was doing," said Laura.

"I think it's important to anyone living with a muscle-wasting condition to make use of the services and support available."

"I wanted to do something exciting while I was out in the bright Australian sunshine, so decided to skydive. I found a company that made it possible for me, and the views were so beautiful it almost didn't look real! The team was very encouraging and helpful, it was really fun.

"I decided not to tell my parents back in the UK until after I'd done it and it was too late to worry!

Back home in Huddersfield, Laura has started another placement as a vintage specialist at Oxfam.

"I wasted a long time fighting against using my wheelchair when I shouldn't have. I think it's important to anyone living with a muscle-wasting condition to make use of the services and support available. That way you can live your life as normally as possible without missing out on anything."

Laura is part of our Trailblazers, a network of 600 young disabled people who campaign for change and provide guidance on issues that affect them. As a charity, we are committed to providing services and opportunities to help disabled people live as independently as possible.

If you'd like to find out about becoming a Trailblazer, please contact us on 020 7803 4800 or trailblazers@musculardystrophyuk.org

Speaking out in West Yorkshire

The Yorkshire Neuromuscular Awaaz Forum was set up in August 2014 by two West Yorkshire mums of boys with Duchenne muscular dystrophy.

One of the mums, Anisa Kothia from Dewsbury, talks about why she feels this group is so important to families from South Asian backgrounds.

'Awaaz' comes from the Hindi/Urdu word that means to 'speak out'.

"I set up the Neuromuscular Awaaz Forum with Nazma Chowdhury from Bradford. Leeds General Infirmary and Muscular Dystrophy UK offered their support too.

"We started the group because we wanted to reach out and support South Asian families to get the best health services available. We also wanted to ensure a better quality of life for our children.

"Living with Duchenne muscular dystrophy – or any muscle-wasting condition or disability – can be a rollercoaster of emotions. Add language and cultural barriers to that, and it becomes really difficult.

"As parents of a seven-year-old boy who has Duchenne muscular dystrophy, we were devastated at the news of his diagnosis. We also felt isolated and frustrated, and didn't know which way to turn.

"Searching for information, I recognised there was a major gap in the system for families facing language and cultural barriers. The Awaaz Forum has opened up a new window of hope for me."

Nazma Chowdhury (left) and Anisa Kothia

If you would like to be involved with our Yorkshire Neuromuscular Awaaz Forum or would like more information, please contact Bobby Ancil on 07920 188970 or b.ancil@musculardystrophyuk.org

Sharing your experiences

"As an Advocacy Ambassador you are there to assist others going through periods of change and offer advice and support according to your experience. Everyone's experiences are different and as an Ambassador, you get to see different people at various stages of their journey and hopefully offer some support along the way."

Ian Robinson from Hertfordshire has been an Advocacy Ambassador for a year. He has been supporting people in his local community, using his own experience of living with the rare condition – vacuolar myopathy.

In this voluntary role, Ian goes to local Muscle Group meetings to connect with people from his area. It was at one of these meetings that he was put in touch with Adrian, who wanted support and encouragement to manage his muscle-wasting condition.

"My wife met Ian at a Muscle Group meeting. I'm always a bit stubborn when asking for help or support but after contacting Ian I immediately felt at ease.

"I've recently had to stop driving so am quite restricted on getting out and about. It was nice to speak to someone who understood what it is like to live with a muscle-wasting condition. And just chatting and putting the world to right over a cup of tea was a fantastic tonic for my confidence," said Adrian.

"Ian is very relaxed and happy to share his experiences and advice on daily life. Just by chatting and listening, I learned I wasn't on my own. There is support out there. Ian has been encouraging me to get out and about and enjoy as best as I can.

"He shares lots of tips and information, keeps in regular contact, is always supportive and I thank him for this. The Ambassador network is definitely a fantastic source of support."

Ian says his main approach is always to be himself.

"Use the advice that you feel will help and discard any that won't. Life's challenging enough without making it more complicated."

Our Advocacy Ambassadors can give advice and intervene on your behalf if you're struggling to get the services, care or equipment you're entitled to. They really understand what it's like to live with a muscle-wasting condition because they're doing that themselves.

Ian is pictured above (right) with fellow Advocacy Ambassador, Martin Hywood

Our Advocacy Ambassadors project has been made possible thanks to the Big Lottery Fund.

If you would like to speak to an Ambassador, or to find out how they can support you contact Maddy on 020 7803 4845 or ambassadors@musculardystrophyuk.org

Improving wheelchair services

Tanvi Vyas-Brady (pictured above), a leading light of Muscular Dystrophy UK's Trailblazers network, has been appointed to a new national group to lead NHS England's work to improve wheelchair services.

The National Wheelchair Leadership Alliance had its inaugural meeting at the end of January in the House of Lords. Set up by NHS England and chaired by Baroness Tanni Grey-Thompson, the task group aims to 'transform the quality and effectiveness of services for people who use wheelchairs'.

"I felt rather privileged to be representing families and young people from Muscular Dystrophy UK. The group is made up of people from across England who have a wealth of experience of dealing with wheelchairs, either first hand or throughout their careers.

"I've been involved in the charity's activities for just over five years. I've learned how bittersweet, crucial, rewarding, and challenging it is to obtain the funding for the right wheelchair.

"Suitable equipment makes a huge difference to getting into work, school or university or seeing family and friends. For those of us with progressive conditions, this should never be underestimated. Time is of the essence," Tanvi said.

"I am very keen to present to Baroness Grey-Thompson the experiences of people with muscle-wasting conditions who use wheelchair services. Please do share your opinions and evidence and together we will be a louder, clearer voice."

Our Bridging the Gap team will now work closely with Tanvi and the National Wheelchair Leadership Alliance to ensure the needs of wheelchair users with muscle-wasting conditions are fully represented. With evidence from our wheelchair services reports, and your stories, we'll push hard to ensure commissioners and wheelchair providers improve their services for people with muscle-wasting conditions.

If you'd like to share your story of wheelchair access, contact Rebecca Johnson on r.johnson@musculardystrophyuk.org

www.medicotech.co.uk

ADVANCED TECHNOLOGY TO KEEP YOU ON THE MOVE

THERA TRAINER

Hire Plan Available

TOGO 502	TIGO530	TIGO 504	TIGO 534	TIGO 506	TIGO 508	TIGO 510

Choose the right exercise bike to suit both your needs and budget from our range of THERA-Trainers

Interactive gaming software

Attachments for weak hands

Regular exercise at home is encouraged to help maintain and improve muscle tone, improve circulation and flexibility, decrease fluid retention and increase stamina levels - all vital for anyone with limited mobility

FOR A FREE NO-OBLIGATION DEMONSTRATION IN YOUR OWN HOME OR REQUEST A BROCHURE CALL US ON

01908 - 564100

Email us at: info@medicotech.co.uk

CYCLING	BALANCING	GAIT TRAINING
		

MEDICOTECH

Updates

Scholarship for disabled Masters' students

Academically excellent graduate students with disabilities can apply for a new graduate scholarship to fund their Masters' studies at the University of Oxford.

A generous £75,000 donation will establish the Oxford Wadham Graduate Scholarship for Disabled Students. The scheme, which will enable disabled students to study a taught postgraduate course at Wadham College, is thought to be the first such funding opportunity for disabled students at Oxford.

The scholarship has been hailed as a hugely positive step by Wadham graduate student and disability campaigner, Marie Tidball, who helped to secure the funding.

The scholarship recognises the additional burdens that many Masters' students with disabilities face when contemplating further education, often unable to do paid holiday work to earn money to fund their education.

"Many disabled students use holiday time to have surgery, treatments and follow-up medical appointments which they do not have time for during term time. They may take longer to complete the necessary studies and have to use more of their vacation in order to do this," explained Marie.

"I really want to get outstanding students with disabilities to apply to Oxford and to have a strong voice in this vibrant academic community. This scholarship is part of the celebration of a group of people who bring invaluable new perspectives to academia, the work place and our public life," said Marie, who spearheaded the Oxford 'Let's get disability on the list!' campaign. She also added that the cumulative impact of cuts to services for disabled people since 2010 could further hinder opportunities for bright, disabled students to progress into higher education.

"This donation and scholarship mean that the brightest disabled students will have a greater opportunity to come through and excel not only in the academic environment, but in their chosen profession. Wadham College is delighted to play its part in this," said Ken Macdonald QC, Warden of Wadham College.

It is hoped that this anonymous donation of £75,000 over three years will attract further donations to expand and continue this scholarship scheme. Donations will be matched by the University of Oxford Graduate Scholarship Matched Fund.

"From Darwin on there has been a long, distinguished tradition of housebound scholars. This donation is intended to ensure that in the future the full academic participation of scholars with disabilities is maximised." (Anonymous donor.)

Applications for the first scholarship will need to be submitted by the closing date of the relevant subject and application details can be found on the college website. **www.wadham.ox.ac.uk**
Wadham College, University of Oxford

North Star Adult Network

Muscular Dystrophy UK is part of a newly-launched national clinical alliance to improve the care of adults living with Duchenne muscular dystrophy.

The North Star Adult Network is made up of neuromuscular expert consultants, allied health professionals, people with Duchenne muscular dystrophy and Muscular Dystrophy UK.

Dr Ros Quinlivan, a consultant at the Centre for Neuromuscular Diseases at the National Hospital for Neurology and Neurosurgery chaired the network launch. She said:

"It was great to launch the new North Star Adult Network and be able to bring together so many colleagues from across the UK with an interest in the care of adults with neuromuscular conditions. The group will now be working towards the development of a North Star database of adults with Duchenne muscular dystrophy, which we hope will help to see improvements to the care available."

Bobby Ancil, Muscular Dystrophy UK Neuromuscular Outreach Manager, said:

"This new network will hopefully have a major impact on the sharing of expert knowledge and best practice in the treatment of adults with Duchenne muscular dystrophy."

New posts secured in Northern Ireland

Families in Northern Ireland living with muscle-wasting conditions recently learned that funding had been secured for five new specialist roles.

Along with local families, Muscular Dystrophy UK has been pressing for improvements to neuromuscular services in Northern Ireland. The *McCollum Report* revealed that Northern Ireland lagged far behind the rest of the UK in many areas of care.

As a result of this pressure, Northern Ireland Health Minister Jim Wells MLA announced in mid-February that funding had been allocated for an adult neuromuscular nurse specialist and four neurological care advisor posts.

It is hoped these roles will be in place by Spring 2015.

Rare disease drug funding a step closer in Northern Ireland

Thanks to pressure from our Fast Forward initiative, the Northern Ireland government is now a step closer to establishing secure funding for rare disease drugs.

According to Health Minister Jim Wells MLA, the Northern Ireland Government was going to consult on whether or not it should introduce a ring-fenced fund for rare diseases. Muscular Dystrophy UK will be having our say at the forthcoming consultation.

Our Fast Forward campaign has been pressing for a ring-fenced fund for rare disease drugs. We are very pleased the Northern Ireland Government has now moved a step closer to introducing one.

Families in Northern Ireland today learned the good news that funding has been secured for five new specialist roles, including a much needed specialist post supporting adults.

For more information on our work in Northern Ireland, please contact Jonathan Kingsley on 020 7803 4839 or j.kingsley@musculardystrophyuk.org

New clinical trial for Duchenne muscular dystrophy

Summit Therapeutics has announced that a new phase 1b clinical trial was approved by UK regulators. The trial aims to test the compound SMT C1100 in boys with Duchenne muscular dystrophy when they are on a particular diet.

Summit announced that the first participant has been enrolled and dosed for the trial. The trial will enrol a total of 12 boys aged between five and 13 years. They will be divided into three groups and each group will receive a different dose of the compound.

If this trial is successful, a phase 2 open label trial will be initiated. It will evaluate the safety and longer-term effects of SMT C1100 on muscle health and function.

If you'd like to find out more about this clinical trial or any other research news, please get in touch with research@musculardystrophyuk.org

New online course on muscle-wasting conditions for GPs

Muscular Dystrophy UK and the Royal College of General Practitioners have created the first-ever online course for GPs on the presentation and management of muscle-wasting conditions in primary care. The hour-long training module has been developed by a group of clinical experts, people with muscle-wasting conditions, our Bridging the Gap team and GPs. With important information in an easy-to-use format, the course is designed to help GPs understand their role in the management of muscle-wasting conditions.

If you'd like to find out more, or promote the course to your local GP practice, please contact Bobby Ancil on 07920188970 or b.ancil@musculardystrophyuk.org

New alert cards launched

Our Bridging the Gap project recently launched some alert cards for people living with muscle-wasting conditions. The Duchenne muscular dystrophy alert card and the Charcot-Marie-Tooth (CMT) disease symptoms card will give families the security of knowing they can easily inform emergency health care professionals of the vital and specific issues that affect people living with these conditions. The cards are conveniently shaped to fit inside a wallet and outline key recommendations and precautions that a non-specialist clinician would need to know during a time of worsening health. The Bridging the Gap team is now developing similar cards for other muscle-wasting conditions, which will be launched soon.

Please contact us on 0800 652 6352 to order a card or to find out more.

#Translarna campaign

As our campaign to secure fast access to Translarna ramps up, we met senior officials from NHS England recently at a meeting led by James Palmer, Clinical Director of Specialised Services.

Jules Geary and Louisa and Gary Hill joined us and put their concerns directly to NHS Directors. Jules is mum of budding DJ, seven-year-old Jagger, and Louisa and Gary are mum and dad to Leyton and Archie (pictured right at 10 Downing Street, it was Archie who wrote to David Cameron).

We are now looking to gather details of families living in England whose children could benefit from Translarna and are at risk of losing the ability to walk within the next few months. This is because, when pressed on the risk of boys losing their ability to walk while the NHS administrative wheels were turning, Mr Palmer at NHS England agreed to look at exceptional cases such as these. He also agreed to look at exceptional cases where someone with Duchenne muscular dystrophy, who would be eligible for Translarna, was also affected by another very severe condition.

We hope this could result in a positive outcome, but ultimately this decision lies in the hands of NHS England.

If you think your child may be in this exceptional category, please get in touch.

NHS England under the spotlight

At the meeting, NHS England confirmed it intended to have a decision on whether or not to approve Translarna for all eligible children by June 2015. This is earlier than families first feared, however an interim solution is urgently needed before then.

NHS England is consulting on how they assess new treatments. The outcome will be crucial for any future drugs for Duchenne muscular dystrophy. If you'd like to join us please respond to the consultation and make your voices heard.

PM's pledge to Archie

After pledging to help Archie Hill, Mr Cameron wrote to the Hill family to say the Government and the Health Minister, George Freeman, were committed to 'trying to broker an agreement'.

With the MPs campaigning on Translarna, we're upping the pressure on Mr Freeman. We're pushing for him to meet with families to explain the next steps and see what can be done before June.

For more information on any of the issues raised here, please contact Peter Sutton on p.sutton@musculardystrophyuk.org or call him on 020 7803 4838

Make Today Count

"It was a bit daunting when I just fell out of the plane. But once we levelled off, it was really great!"

Steph Knight

Huge congratulations to all our skydivers who jumped 10,000ft over the last weekend of February. Thank you to our 154 brave #TeamOrange members who together raised more than £54,500 towards our groundbreaking research.

"It was a bit daunting when I just fell out of the plane. But once we levelled off, it was really great!"

Steph Knight from Horsham has always wanted to skydive. She also wanted to do a special challenge in 2015 to mark her fiftieth year. So when the mum of two sons with Duchenne muscular dystrophy got an email from the charity inviting her to skydive, it was just the prompt she needed. She applied straight away.

"My sons inspired me to sign up for the skydive. I wanted to do it for the challenge, but also to raise funds for research into this devastating condition. We as a family have benefited from so much that the charity has done for us since the boys were small too, so it was also a way of saying thank you.

"As the day drew nearer, I thought 'I've actually got to do this'! My older son Jack (21) came with me to Hinton on the day, with my mum, husband and daughter. But Ben (17) was too nervous for me so he stayed away! He congratulated me afterwards, though!

"All of my family and friends have been really supportive. I had hoped to raise £1k for the charity, but it looks likely to be more than double that," said Steph.

Make Today Count is one of Muscular Dystrophy UK's unique events. In 2016 it will be back, and bigger and better than ever before. As it's a leap year, consider leaping out of a plane at 10,000ft and raising funds for research into muscle-wasting conditions.

If you feel inspired or would like to take on an exciting challenge like Steph did, please contact us on 0845 872 9058 or volunteerfundraising@musculardystrophyuk.org

London Marathon 2015

We would like to welcome over 100 runners to #TeamOrange in the Virgin Money London Marathon this year.

We are looking for own place runners, who secured their place in the London Marathon official ballot to join our team.

We are also looking for volunteers to join #TeamOrange and cheer on our runners and help at our post-race reception.

If you'd like to be involved or to find out more, please contact Jess on j.galvin@musculardystrophyuk.org

Oxford Town and Gown 10k Sunday 10 May 2015

Sign up to run the Muscular Dystrophy UK Oxford Town and Gown 10k.

You will be joining 4,000 runners of all abilities in the 34th run and together you'll help us turn Oxford orange on Sunday 10 May 2015.

Voted one of the best road races in the UK, the Oxford Town and Gown 10k gives entrants the unique opportunity to run through the closed streets of Oxford city centre, passing historic sites and ending in the beautiful University Parks.

The route is flat and scenic, which makes this event perfect for everyone, including those who want to take to the streets in fancy dress, beginners who have signed up to their first race as well as the more experienced runners who want to get their personal best. We also have a Junior 3k race, which is suitable for children aged 9 to 15.

For more information and to register for the Town and Gown 10k or for the Junior 3k event, please visit www.townandgown10k.com

Exciting #TeamOrange events in 2015 include:

Scuba dive with sharks Saturday 25 April

London bungee jump Sunday 26 April

Virgin London Marathon Sunday 26 April 2015

Milton Keynes Marathon and Half Marathon Monday 4 May

Belfast Marathon Monday 4 May

Great Manchester Run Sunday 10 May

Muscular Dystrophy UK Town and Gown 10k Oxford, Sunday 10 May

Shark dive encounter North Queensferry, Saturday 16 May

London Superhero Run Sunday 17 May

Bupa London 10k Monday 25 May

Question of Support Dinner and Quiz Glasgow, Friday 29 May

Edinburgh Marathon Festival Saturday 30 and Sunday 31 May

Two Castles Run, Warwick Sunday 14 June

Icelandic Lava Trek Wednesday 15 July

Prudential Ride London-Surrey 100 Sunday 2 August

Muderalla, Kettering Monday 31 August

Birmingham Fun Run Sunday 6 September

WOLF Run, Royal Leamington Monday 7 September

Great North Run Sunday 13 September

Royal Parks Foundation Half Marathon Sunday 11 October

Himalayas Trek Saturday 17 October

Whole Hog, Ipswich Sunday 18 October

Great South Run Sunday 25 October

Muscular Dystrophy UK Town and Gown 10k Cambridge, Sunday 25 October

To find out more contact us on 0845 872 9058 or volunteerfundraising@musculardystrophyuk.org

Lewis Reed

DIFFERENT BY DESIGN®

LEWIS REED EXCLUSIVE

WHEELCHAIR ACCESSIBLE VEHICLES

Outstanding for style comfort and quality, Lewis Reed provide practical, flexible and highly accommodating vehicles.

For more information call **FREE** now on **0800 247 1001***
Or visit **www.lewisreedgroup.co.uk**

*Calls from UK landlines are free of charge, calls from mobile networks may incur additional charges, please check with your telephone provider for details

Naidex NATIONAL
NEC BIRMINGHAM
28TH - 30TH APRIL 2015

Motability · Flexi-seat seating system · Torspring · Mercedes-Benz · SEAT · ŠKODA · VCA · ACS REGISTRARS ISO 9001 · UpFront · MAVLA