Muscular Dystrophy UK's lifestyle magazine

Issue 1 – 2018

Target MD

Claire and her fight for Ryan

Stories of our amazing supporters

Target Research: news and updates

Muscular Dystrophy UK

Fighting muscle-wasting conditions

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

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On the cover
Claire Chidzey and her four-year-old son, Ryan. (Read more on p6.)

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Disclaimer

Hello

Hello and welcome to our first *Target MD* of 2018. We've shared stories from a range of amazing people making every day count.

Some of the stories include Rebecca talking about how she won't let her disability stand in the way of raising an amazing young daughter, and Daniel sharing his experience of being an extra in a popular *BBC TV* series. Chloe talks for the first time about her love/hate relationship with her ventilator; Cath shares her passion and enthusiasm for Powerchair football and Alexandra talks about what it means for her son, Declan, to be able to drive.

You'll also read about how Claire learnt of her son's diagnosis of Duchenne, and how her family has chosen to fundraise for research.

Woven through these stories are updates on our campaigns and the care and support we offer people living with muscle-wasting conditions, as well as news of your incredible support at some of our recent fundraising events.

We can't thank you enough for the huge difference you make in the fight against muscle-wasting conditions.

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

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

I'd love to hear from you.

Ruth

Ruth Martin
Editor, *Target MD*

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About us

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

Helpline

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

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

Thank you for your ongoing support

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

Join us – we can do this, together.

Please contact our Fundraising Team to find out about all the ways you can get involved.

Call 0300 012 0172 or email fundraising@musculardystrophyuk.org

Join us online

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

musculardystrophyuk.org/talkmd
Join this friendly online community.

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

www.facebook.com/musculardystrophyuk
Join the **27,000+ community** on our Facebook page.

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Share pictures with us on Instagram.

www.youtube.com/user/MuscularDystrophy
Watch our latest videos.

Muscular Dystrophy UK
Fighting muscle-wasting conditions

Run the Great North Run!

Sunday 9 September 2018

Join #TeamOrange!

Lace up your trainers and turn the Tyne orange in the biggest, most prestigious half-marathon in the world.

By running for us, you'll be helping to beat muscle-wasting conditions.

Registration fee: £29

We ask you to pledge: £300

Get your place today – for just £29

Call: 0300 012 0172

Email: volunteerfundraising@musculardystrophyuk.org

www.musculardystrophyuk.org/GNR18

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From the CEO's desk

It's very encouraging to be looking at progress in research and improved care. It's been said we are seeing a wave of genetic treatments and this is certainly evident in neuromuscular conditions as many potential treatments are now in trials with some positive results emerging.

We're working closely with families to secure long-term access to Spinraza as the first licensed drug treatment for SMA and also gearing up to battle for access to Exondys 51 for eligible boys with Duchenne. This follows the successful campaign we led with families almost two years ago with NICE and the SMC in Scotland to gain access to Translarna.

It's vital that the regulators and indeed the NHS listen to the families and allow their children access to the treatments. Where an effective new drug has a high price then the NHS has to negotiate an agreement that satisfies all parties and allows the patient fast access to what can be a life-saving treatment. That's when we call for a Managed Access Agreement (MAA) to be in place, which gives people access to the treatments while researchers gather further data and evidence over several years.

Thanks to your support, we've been able to step up our research commitments, with close to £7m committed in the last 18 months alone. While on the one hand we're building clinical trial capacity at several centres, we also know from parents how confusing it can be to hear about the different trials available and to understand more about them. That's why we've launched our Clinical Trials Information Service, which Dr Sofia Nnorom leads. If you have any questions about clinical trials – or any science-related questions at all – Sofia can help you.

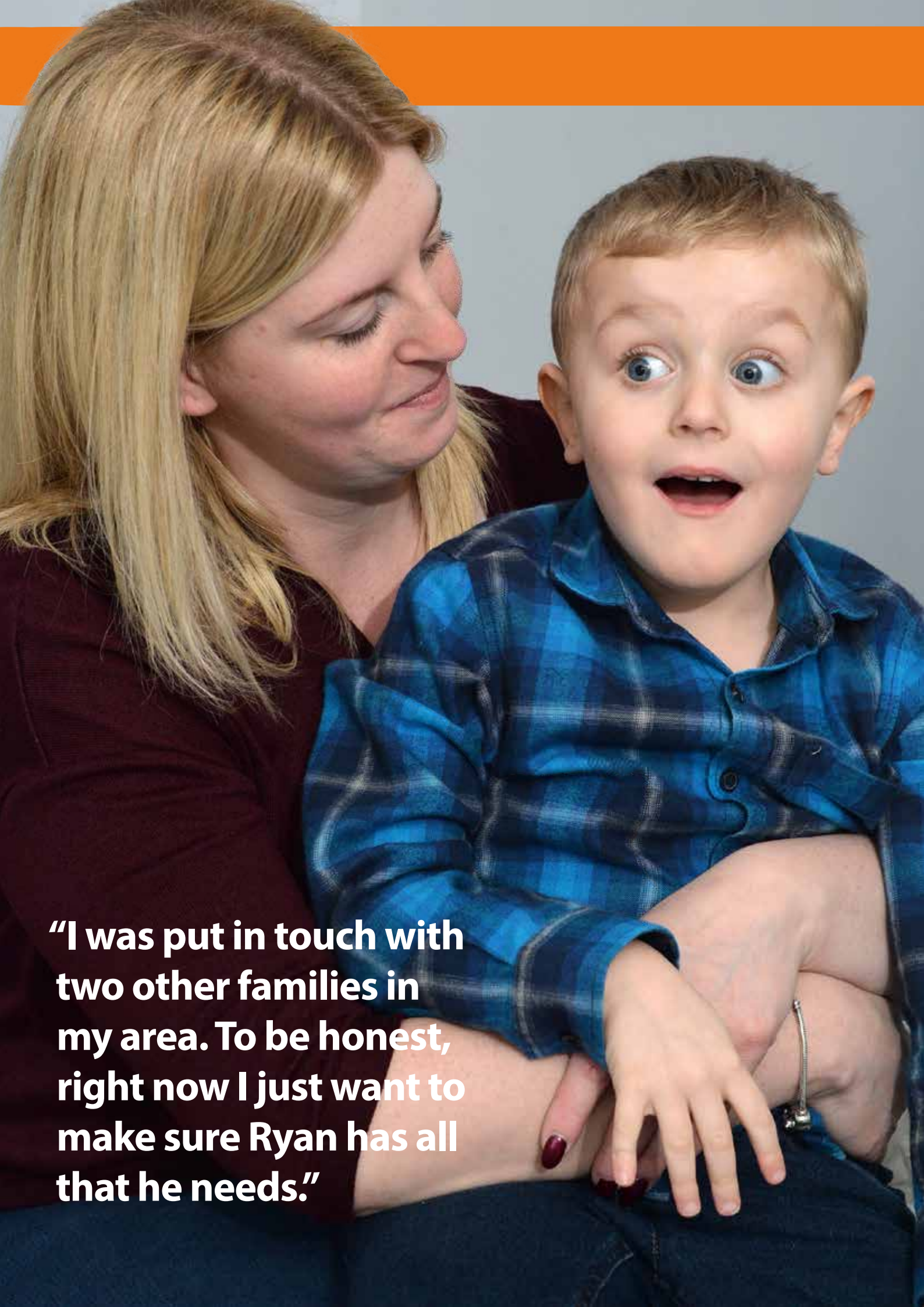
As you'll read in the pages ahead, our focus is not only on developing research but also on improving access to specialist care and support and the right to enjoy a full, independent life.

We've just launched a UK-wide consultation into our new three-year strategy. We've identified four new areas, from better access to emotional and psychological support, to improved access to sport and leisure activities and the technology to improve communication and control as well as the Fast Track to Treatments.

Do get in touch with Nic Bungay, Director, at n.bungay@musculardystrophyuk.org if you'd like to have your say in our plans and the next steps. Nic would welcome your ideas and we'd value your involvement.

Many thanks for your support, working together we're making faster progress in the fight to beat muscular dystrophy.

Robert Meadowcroft, CEO


"I was put in touch with two other families in my area. To be honest, right now I just want to make sure Ryan has all that he needs."

"When Ryan was diagnosed with Duchenne muscular dystrophy, it felt like my heart broke.

"After the consultant told us the news, she said he'd need a wheelchair and wouldn't live past his 20s. It felt like my hopes and dreams had gone too.

"But the consultant told us to look after Ryan and make memories with him. She also gave us a lot of hope. She said boys of Ryan's age could live longer with the condition.

"Research has come a long way, and there are trials and things that would make a difference to boys like him.

"Now we're raising awareness and as much money as we can for research so that one day they will find a treatment. I'm hopeful this will be in time for Ryan but we still want to end this condition and slow down its progression."

Claire Chidzey lives in Gainford, near Darlington, with her husband Cieran and their three children. Four-year-old Ryan is their middle child, Abigail is 13 and little Harry is two.

The signs

"When Ryan went to pre-school, a teacher noticed he had an unusual way of getting up from the floor. We now know this is the Gowers' sign*. He would also trip over often and then need to hold on to something to pull himself back up."

The teacher suggested Claire take him to the GP for an assessment. The GP didn't see any problems at the initial assessment or at the follow-up assessment three months later.

After a second person at school commented on how Ryan moved, Claire asked their GP for a referral to a paediatric consultant. They got an appointment in January 2017.

The diagnosis

The consultant watched Ryan get up off the floor, and straight away asked for blood tests to check his CK levels**. She said it was nothing to worry about but called the following day to give Claire the results.

"She asked if I was with someone. I was with my mum, and we both listened in. The consultant told me Ryan's CK levels were 25,000 when they should have been in the 100s. She wanted to see us the following Monday, and told me not to do any Googling over the weekend.

"Of course I Googled 'high CK levels'. I saw it could mean Ryan had a muscle-wasting condition. I found some YouTube clips of boys with Duchenne and saw how they got up off the floor. It was the same way Ryan did.

"At that moment, in my head, I'd decided Ryan had Duchenne. I made myself so poorly with worry."

Ryan, Claire, Harry and Abigail
© Roger Moody / MDUK

*Gowers' sign is a medical sign that indicates weakness of the lower limb muscles. Patients use their hands and arms to 'walk' up their own body from a squatting position.
**Creatine kinase (CK) is a type of protein found in muscle. Some forms of muscular dystrophy are associated with high levels of CK in a blood test because, when muscles are damaged by disease or injury, the CK leaks into the bloodstream.

The following Monday, the genetic team at Newcastle confirmed that Ryan had Duchenne. And that was when the family's world changed.

Getting support

Soon after getting Ryan's diagnosis, Claire searched on the Internet to see where families like hers could get support. She found Muscular Dystrophy UK's website.

"I called the helpline and had a good chat with the Info and Advocacy Officer, who was a huge support. She sent me a lot of information about the condition, gave me advice about what to think about for school and what Ryan was entitled to.

"I was put in touch with two other families in my area. To be honest, right now I just want to make sure Ryan has all that he needs."

Our Ryan

"Ryan is a character. He's just lovely. He is happy, full of life, cheeky, and can hold his own! He gets on well with his siblings, and is good at school. He's just a normal little four-year-old boy.

"He and his two friends at school are known as 'the three amigos'. He knows he doesn't run as fast as the other children at school do, but he takes part in everything and always has a smile on his face.

"We want to give Ryan a good life and make sure he is happy and never frightened about his condition.

"We tried so hard for him; he's our first boy. We're making memories with him, and we'll fight for everything he needs."

Duchenne muscular dystrophy is a genetic condition that causes muscles to weaken and waste over time, leading to increasing and severe disability. Usually affecting only boys, the condition weakens not only the muscles used for movement, but the heart and breathing muscles too.
If you'd like to speak to someone about your condition, our helpline team is here for you on 0800 652 6352 or info@musculardystrophyuk.org

Our Fight for Ryan – a Family Fund

"We wanted to do some fundraising for research into Duchenne, and decided on a target of £5k. My brother-in-law said we should reach for the stars, and raise £50k!

"In the first week, we'd raised £6k. MDUK's regional development team told us we could direct all funds raised into Duchenne research. They helped us set up our Family Fund, Our Fight for Ryan and in under a year our fundraising isn't far off £30k," said Claire.

They have held a coffee morning, a children's disco, a family fun day, a black tie ball, raffles, and a Christmas brass band event. They have more events planned for 2018.

"My sister and brother-in-law and a couple of friends are doing a skydive for us in March. Everybody has been so supportive."

You can find out more about Our Fight for Ryan here: www.musculardystrophyuk.org/our-fight-for-ryan

If you'd like to set up your own Family Fund (see p33), get in touch with your local Regional Development Manager or visit www.musculardystrophyuk.org/family-funds

MATCH-CHANGING GOALS

The lure of Powerchair football

"My favourite thing about playing Powerchair football is that I can take part in it on my own. During the game, I'm in control of everything and can do whatever I need to. In almost every other aspect of my life, that's not the case.

"In everyday life, I can't run. But when I play Powerchair football I can move really fast!"

Cath McNicol (pictured) lives in Middlesbrough and plays Powerchair football competitively for her local club. She found the sport about 10 years ago and got hooked – now spending most of her time training, coaching or competing.

"Nothing can beat the feeling of euphoria you get from scoring a goal, or being part of a match-changing goal!

"It's only in sport that you can get that feeling. It makes your heart race, makes you feel like you're part of a team. There's nothing quite like it.

"I can remember the exact moment I was first part of scoring a match-changing goal. Our team always came second and we were playing the leaders, Aspire. A pass across the top of the box and a wait for what seemed like an eternity; I tapped the ball through a ball-sized gap between the keeper and the post, and that took us into the lead just before half time.

"Unfortunately, we conceded in the second half and the game ended in a 2-2 draw! A few years later we went on to win the national premiership for the first time – one of my highlights. Another was making the European Champions League final in Paris!

"I think the sport is more competitive than people realise. There's always a buzz about who's transferring to which team, who has the best chance of winning, who has the best squad to play. People will travel great distances to find a better coach, or play in a better team. Some clubs even have trials for their teams."

Born with spinal muscular atrophy (SMA) Type 2, Cath tried a range of sports at school. She couldn't find any competitive sports for disabled people, or any she could play without assistance.

"I don't think enough people know about Powerchair football. Apart from playing, it's a fun and exciting sport to watch at all levels – you can get completely engrossed in it. We train in a public sports centre and there's often a sea of people watching us from the viewing area at the top. Our game is fast, you can pass the ball and dribble, just the same as in the able-bodied sport.

"Powerchair football is completely inclusive. Anyone, male or female, of any age and with any kind of disability can play. At our club, we have a 70-year-old who trains with his niece, and our youngest player is a five-year-old.

"If you like sport, or socialising, or you're a 'dirty wheels' kind of person, I'd really encourage you to find out more about this amazing sport."

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

The goal of good health and wellbeing
Muscular Dystrophy UK has partnered with The WFA in England and the Scottish Powerchair Football Association to sponsor the three main national leagues in the UK: the MDUK Premiership and Championship in England and the MDUK Premiership in Scotland.

Spinal muscular atrophy (SMA)
SMA is a rare inherited neuromuscular condition that affects the lower motor neurons in the spinal cord. There are different types of SMA, which vary in severity. Most require complex medical support.
If you'd like to speak to someone about your condition, our helpline team is here for you on 0800 652 6352 or info@musculardystrophyuk.org

Daniel Baker (pictured) features in the new BBC One primetime drama *Requiem*, which launched in January.

The psychological thriller series, filmed and set in Wales, follows a young woman as she unravels her identity and hunts for truth in a remote community.

The BBC production team contacted MDUK, as they wanted to cast someone with Duchenne muscular dystrophy in the role.

Daniel (43) was successful in getting the role. He appears in scenes with Brendan Coyle, best known as *Downton Abbey's* John Bates.

Daniel shares his story:

DANIEL AND PRI

Being an extra

I've never acted and am not particularly social. But I remember from the time I first watched *The X-Files* I always wanted to be an extra in a scene, to be part of that magic. I'd never pursued it though as I thought it wouldn't be practical, and who would want me?

It turns out there is a show that does. I was surprised to one afternoon receive a Facebook message from MDUK saying that a production company were looking for an adult with Duchenne to be an extra in a new show.

It was certainly something I was interested in, but I was concerned I may be too old as there aren't that many people my age with Duchenne.

But someone from the production company rang and had a long chat with my mother (I was unfortunately out, but she's very chatty!).

The audition

Age was a slight concern so I needed to send some recent pictures, but a producer emailed me back the next day and seemed happy with how I looked. It's always nice to be told you look younger than you are! I'm sure most people have to go through a more rigorous process of auditioning and other things, but this was not a talking role so that made everything easier.

Daniel and Lydia Wilson

Other than the fact I was personally looking forward to doing this, there was also an element of wanting to show disability on television and raise awareness of Duchenne.

I think this is starting to get better but in the past often a non-disabled actor would have got a part like this.

Setting up the filming took many back and forth emails. The fantastic team on the programme needed to check in on make-up, hair, costumes, production

METIME DRAMA

and transport. Everything was extremely thorough, checking what I'd need and listening to my advice regarding the hiring of equipment. They were all also very friendly, patient and helpful, which was great for a first experience of the industry.

Daniel and Brendan Coyle

I even had contact with Brendan Coyle, who would be with me on the day. He was an amazing and kind man who helped me feel right at home.

On the set

The day of filming was exhilarating but long. Me, my mother and PA were greeted at the filming set by some of the production team and we were shown to the green room, specially set up with a fridge to keep my drink nice and cold.

There was no star on the door, but you can't have everything!

We had visits from all the different teams throughout the day. Filming was running late but I'd expected that. It gave me more time to prepare and chat with Brendan too.

The set looked brilliant. It was pretty much perfect for what was needed.

When filming came around, I spoke with the director Mahalia Belo, who was very soft spoken, patient and willing to listen. Not at all what I'd expected a director to be like!

The filming itself went smoothly; I had no concept of time while it was going on so couldn't tell you how long it took.

I was just enjoying the experience and trying to do what was asked of me. I was checked on regularly and they sent my PA in between takes to see if I needed anything. I definitely felt part of the team.

The friendly crew

I really enjoyed my first experience of filming. I wasn't nervous and I think I managed to take everything in my stride; I just hope my calmness didn't make anyone feel I wasn't happy or liking it.

I loved talking to everyone and I think part of the reason I was so calm was the friendliness of the crew and how well they did their jobs.

I don't know if I'll ever have the chance to do something like this again but I would love to.

I think I may have been bitten by the bug! I also hope to keep in touch with some of the crew who were so helpful and nice to me.

Requiem aired on BBC One from 2 February. The whole series is now available on BBC iPlayer.

Do you have a story to share? Please get in touch with Ruth at targetmd@musculardystrophyuk.org We'd love to hear from you.

ACCEPTING DISABILITY AND BECOMING A DISABLED PARENT

by Rebecca Brown

Being a parent is never easy, let alone if you have a disability to contend with as well. But that hasn't stopped Rebecca Brown (pictured). She has had cardiomyopathy and kidney failure, and just after giving birth, she was diagnosed with muscular dystrophy. It wasn't easy, but she's incredibly proud of how her daughter, Penelope has developed, in part, because of her disability.

I would describe myself as a mum, wife, an advocacy officer and, lastly, disabled.

The first experience I had of what it is like to be disabled was at the age of 15 when I was diagnosed with cardiomyopathy. This is essentially where the heart muscle becomes stretched, thickened or stiff, and so struggles to pump blood around the body.

A few months of being breathless, exhausted and unable to do anything for myself really taught me a lot about life and I grew up very quickly. Thankfully, I was amazingly lucky to receive a successful heart transplant in time, which saved my life.

Nine years later, after again becoming extremely unwell and unbelievably fatigued, I was told my kidney was failing. I was very fortunate, once again, to have a kidney transplant swiftly – this time from my mother – after only being on dialysis for a few months. After about a year I recovered my health and returned to university and working part-time.

Living life to the full

These early experiences meant I was determined to make the most out of life. I met my now husband, Jeremy, on a night out and we just got on really well. We got engaged in 2010 and planned to get married the following year.

He was understanding and supportive of the fact that having children was unlikely to be straightforward for me.

Deciding to become a parent

Because of my heart and kidney problems, when it came time to start our family, we took advice from the medics involved in my care. Although we knew it was going to be risky, we were determined to proceed.

There are very few women who have successfully had a baby after two transplants. Those who have, are put on different medications and face a variety of other problems. I was told there was a risk of pre-eclampsia, early labour, heart or kidney rejection, heart failure and infection.

I was very closely monitored and I think I gave everyone, including the doctors involved, several grey hairs with worry!

It was in no way easy, and there were several ups and downs throughout my pregnancy. Also, towards the end of my pregnancy, I had become tired and had a couple of falls, but didn't think anything of it at the time. I had no idea that I might have muscular dystrophy.

I managed to cope and get to 37 weeks. I had a healthy baby girl who was a good weight. It was time to enjoy being a mum.

If being a new mum wasn't busy enough, I had also taken my dream job as a healthcare assistant, which I would be starting after my maternity leave, and enrolled to start my nurses training the following year.

Discovering I had muscular dystrophy

I had started to notice I couldn't get up off the floor after playing with my daughter without having to lean on a chair. I also seemed to be falling easily. So I went to the GP, thinking it would be because of being tired with a new baby and needing to get some physio to strengthen up again.

However, after seeing several doctors and having many investigations, I was diagnosed with muscular dystrophy. I was devastated but determined to create a good life for my family.

Being a disabled parent

I can walk, so don't use a wheelchair, but I have weakness in my hips and upper arms. This massively affected how much I could look after my child.

As my daughter grew, it became more obvious that I couldn't lift her, or carry her upstairs for a nap. It meant I had to take someone with me if we went out.

I also had to change my career as I was struggling with the physical demands of nursing. But, I was very fortunate to still have contact with and support patients when I started my new job in 2016.

It's been frustrating and, on occasions, upsetting. I couldn't run or play with my daughter in the park, so I went through a period of grieving. I felt that I had let my baby down by not being 'normal'.

I decided that I needed to start being creative – like so many other disabled people I have met – so she napped on a mattress in the lounge instead of upstairs. I cuddled her sat down and other people carried her for me up and down the stairs. We did it our way.

I realised, I am her normal. She doesn't know the 'right' way to do things.

She was a baby and simply wanted me there with my love and attention. Once I realised this, I stopped being so hard on myself!

Being who she is because of my disability

I won't deny that it's been hard at times. Particularly when she was a toddler and would run off or want to play, but I couldn't keep up. However, any parent will tell you toddlers are difficult!

She is now six and is an empathetic and very independent little girl. I believe this is, in part, because of my disability. I still find it hard to accept my disability and to tell people about it, but she is fantastic about it. It's normal to her. I am so amazingly proud of how she just accepts things.

This summer we were out with friends at a local park and one of the little boys wanted me to push him on the swing while his mum was feeding his baby brother.

My daughter just ran over and said, "I will push you, my mum has bad legs". It was just a beautiful moment.

She has, in turn, made me more accepting of my limitations. She also makes me challenge my expectations of what I can do and achieve by thinking differently. I used to be unwilling to ask for help, but this has changed because of her. We all need some support sometimes, whoever we are. My daughter has made me realise that.

To all the disabled parents out there, keep doing it your way, you are amazingly adaptive and resilient, and so are your children.

Published in Disability Horizons: www.disabilityhorizons.com

Whether you've recently been diagnosed, or have been waiting for a diagnosis for some time, our helpline team is here for you. They are available to speak to you about any aspect of living with a muscle-wasting condition. Call them on 0800 652 6352 or info@musculardystrophyuk.org

Jeremy, Rebecca and Penelope

PROMOTING INDEPENDENCE

Assistive technology
Anyone with a muscle-wasting condition can apply to the Joseph Patrick Trust (JPT) for a grant towards the cost of assistive technology. Assistive technology has been defined as any product or service that maintains or improves the ability of individuals with disabilities or limited mobility to communicate, learn and live independent, fulfilling and productive lives.

Through powered wheelchairs that provide access to the outside world, computer technology that provides a gateway to the online world, and communication aids that quite literally provide a voice, assistive technology has the power to transform the lives of disabled people.

The JPT focuses on communication aids that help people who are losing muscle strength in their fingers, hands and arms not only to communicate online, but also to use their communication devices.

The JPT awards grants towards the cost of specialist equipment and assistive technology, so that people with muscle-wasting conditions can live as independently as possible.

Find out more at www.musculardystrophyuk.org/jpt

With no family connection to muscular dystrophy, David Jackson (pictured) and his wife Ann have dedicated more than half a century to supporting people living with muscle-wasting conditions. Thanks to hearing Lord Attenborough speak at an event, they've been involved with the charity since 1965.

Over the years, David has served MDUK as a Trustee and a Chair of the finance committee. In 2009, he was awarded an MBE for services to the charity. He retired from the JPT Grants Panel in February 2018 after serving an impressive 32 years. On David's watch, the charity's grant-giving arm has awarded well over £6m worth of grants, supporting close to 10,000 people to live independently.

"After being sincerely committed to the charity for the past 52 years, I feel the time has now come for me to retire as Chair of the JPT Grants Panel. It's time for a younger person to take over with new and fresh ideas.

"I consider myself extremely fortunate to have had a professional, supportive JPT panel. They have been of great benefit to the charity and the people we support.

"I've also been privileged to witness the development of assistive technology. Thanks to the generosity of our supporters, JPT is able to award grants towards the cost of technology such as communication aids and computer controls.

"What has meant so much to me is seeing how the JPT has helped improve the independence and quality of life of so many people with muscle-wasting conditions. The panel receives many heart-warming letters, talking about the difference the grants and equipment have made."

David and Ann will continue to fundraise for the charity through the Brentwood Branch, where David is Chair and Ann Secretary.

Target Research

Welcome to the research pages of *Target MD*

I'm delighted to share with you some of top research news stories from over the last few months. There have been some exciting announcements about clinical trials taking place in the UK and the rest of the world. Many of these are testing gene therapies for different muscle-wasting conditions, which reflects the rapid pace of progress in the gene therapy field currently. Researchers are constantly learning from each other, so advances in gene therapy for one condition can be greatly beneficial for other conditions.

I've also provided updates on some MDUK-funded research, including our latest research partnership with Cure CMD. We hope that this will be the start of a fruitful collaboration that will help to develop treatments for types of congenital muscular dystrophy (CMD).

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

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

Progress in MDUK-funded research

New study on the role of SMN protein

Professor Tom Gillingwater and colleagues at Edinburgh University have discovered a new role for the SMN protein, which is reduced in people with spinal muscular atrophy (SMA). They found that SMN regulates the production of proteins inside cells (a process called translation). This new study, which has come out of a grant funded jointly with The SMA Trust, improves our understanding of SMA. That's key to developing future treatments.

Research partnership with Cure CMD

We're excited to announce a new funding partnership with US-based charity, Cure CMD. This will drive research into LMNA congenital muscular dystrophy, a very rare muscle-wasting condition that starts within the first few months of a child's life. We have invited researchers around the world to apply for PhD studentships and research project grants.

These applications will be peer-reviewed and assessed by our Medical Research Committee and Lay Research Panel. This is our standard process to ensure we fund the best quality science that is relevant to people with muscle-wasting conditions.

Pain affects quality of life in FSHD

A new study has found that people in the UK living with facioscapulohumeral muscular dystrophy (FSHD) frequently experience pain, which greatly affects their quality of life. The data was collected using the UK FSHD Patient Registry, which is funded by Muscular Dystrophy UK. Out of 339 survey respondents, about 86 percent reported experiencing some degree of pain. This was mainly localised in the shoulders and lower back. These findings highlight the importance of pain management and will help to improve the care of people with FSHD.

Myotonic dystrophy registry studies

Two research studies using the UK Myotonic Dystrophy Patient Registry – which is jointly supported by Muscular Dystrophy UK and the Myotonic Dystrophy Support Group – have been published in scientific journals.

The first study summarises clinical and genetic information from over 500 people living with myotonic dystrophy type 1. Most commonly reported symptoms included fatigue and myotonia, and those reporting myotonia seemed more likely to experience fatigue. A heart condition was reported in almost half of the group.

The second study describes the prevalence of tumours among 220 registry participants. There is a link between myotonic dystrophy and some types of cancer, however more research is needed to fully understand this. As always, it's important to remain vigilant and seek medical advice if you notice any new signs or symptoms.

Clinical trial updates

Summit report on PhaseOUT DMD trial

Summit Therapeutics has released preliminary results from its ongoing phase 2 trial, called PhaseOut DMD. The trial is testing a utrophin modulator called ezutromid in boys who have Duchenne and are aged between five and 10. The preliminary data shows that most boys had reduced muscle damage after being treated with the drug for 24 weeks. As a long-standing funder of utrophin modulation research, we're delighted with this news, although it's important to remember that we don't yet know if utrophin modulation will be able to improve muscle function. We'll keep you updated on progress.

International SMA gene therapy trials

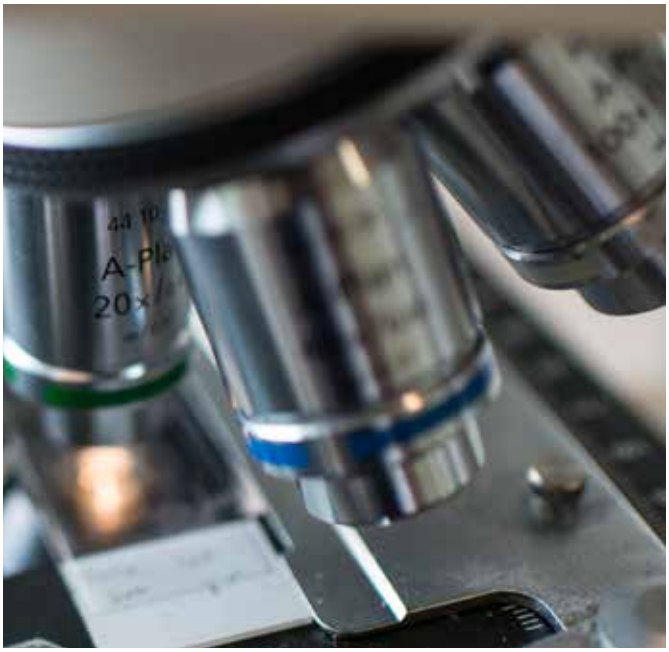
Gene therapy company, AveXis, has announced three new trials for children with SMA. These will assess the safety and efficacy of AVXS-101, which uses a harmless adeno-associated virus (AAV) to deliver a healthy copy of the SMN1 gene into the body. AveXis hasn't announced yet where the trials will be held, but one of them will be based in Europe.

IBM trial to take place in London

A trial is scheduled to begin soon to test the safety and efficacy of arimoclomal in people with inclusion body myositis (IBM). Arimoclomal is an experimental drug that enhances cells' ability to refold proteins. This could help to clear the toxic protein clumps in muscles affected by IBM. A company called Orphazyme has assumed sponsorship of the arimoclomal trial, which will take place at University College London (UCL). We expect UCL will begin recruitment soon – keep an eye on our website for updates.

Myotubular myopathy gene therapy

Audentes Therapeutics is currently developing a gene therapy called AT132 for X-linked myotubular myopathy (XLMTM). AT132 uses a harmless adeno-associated virus (AAV) to deliver a healthy copy of the MTM1 gene into the body. Audentes has received the green light from the Medicines and Healthcare Products Agency (MHRA), to begin a clinical trial in the UK. The phase 1/2 trial – called ASPIRO – will assess the safety and efficacy of AT132 in children who have XLMTM and are younger than five years old.



Results from FSHD drug trial

A drug that could build muscle mass in people with FSHD has had positive early results from its phase 2 trial. Acceleron Pharmaceuticals has been testing ACE-083, a drug that stops a family of proteins from reducing muscle growth. So far, the trial has shown that the drug increased the size of the muscles that it was injected into. No serious side-effects have been reported.

While these results are promising, they are based on a small number of patients (23 in total). We also don't yet know what effect ACE-083 has on muscle strength and function. This will be investigated in the next stage of the study, which is due to start later this year.

LGMD gene therapies

Myonexus Therapeutics has secured $2.5 million to move limb girdle muscular dystrophy (LGMD) gene therapies into the clinic. This seed funding will enable Myonexus to initiate a phase 1/2a clinical trial testing MYO-101, a gene therapy for LGMD type 2E (LGMD2E).

The company's pipeline also includes MYO-102, a LGMD2D gene therapy that is currently being tested in a phase 1/2a clinical trial, and MYO-201, a LGMD2B gene therapy currently in phase 1. Myonexus is also developing gene therapies for LGMD2C and LGMD2L, though these are not yet in clinic trials and are currently undergoing preclinical testing.

To find out more about research or clinical trials, do get in touch with us at research@musculardystrophyuk.org or call us on 020 7803 4813

FIGHTING FOR SPINRAZA

Spinal muscular atrophy (SMA) is a rare inherited condition that leads to the loss of the ability to walk, move, breathe and swallow.

Spinraza, developed by pharmaceutical company Biogen, is the first and only treatment for people with SMA. It was approved by the European Medicines Agency in June 2017.

Clinical trials showed significant improvement in children's motor function. This could allow them to achieve or maintain physical milestones that they'd never reach without treatment, and to survive longer than expected considering the typical course of the condition.

So effective was Spinraza in clinical trial that Biogen agreed to provide the drug to all children with Type 1 SMA (showing symptoms before six months of age) through an expanded access programme. But the scheme provides the treatment for only a small number of children who could benefit from Spinraza. It's not sustainable as a long-term solution.

Discussions are taking place to put a Managed Access Agreement in place to give more people with SMA access to the life-changing treatment. At the same time, further data and evidence will be gathered over several years. This is positive news for families like Ayden's.

Ayden's story

Aliya (pictured with three-year-old Ayden) and Khalil Anjarwalla live in Highgate, North London. Aliya and Khalil first noticed something was wrong with their son Ayden when he was 11 months old. Up until then, he'd been able to stand while holding on to the coffee table, but suddenly he no longer could – his legs buckled beneath him, unable to support his weight.

After his paediatrician referred him for further tests, Ayden was diagnosed with SMA Type 2. This was just two weeks after his first birthday. Weeks of hospital visits and doctors' appointments followed, and Aliya and Khalil clung to the hope that the diagnosis was a mistake. They hoped the doctors had it wrong. The symptoms, however, became too stark to ignore and Ayden's strength rapidly deteriorated.

To begin with, any hope the family had of regaining any routine or sense of normality seemed impossible. Over time, this has changed.

A typical day for the family involves getting Ayden up and dressed, followed by 45 minutes of exercises and stretches. After this, Ayden uses a cough assist machine to help clear his chest, then Aliya and Khalil put his orthotics* on him and place him in his standing frame for breakfast.

During the day Aliya and Khalil try to take him swimming to help loosen any tightness in his joints and strengthen his muscles. At dinner, Ayden is back in his standing frame, then bath time, more stretches, a story and, finally, bed.

Aliya and Khalil are incredibly proud of everything Ayden achieves each day. While life can be challenging at times for the family, Ayden's parents are hopeful that one day, researchers will find a treatment or cure for SMA.

"SMA is a devastating condition that turns lives upside down. Spinraza may not be a cure, but it could buy many families more time to spend with their loved ones. We would move heaven and earth to secure a better future for Ayden.

"Knowing there is a treatment out there that could make life easier for our little boy has given us renewed hope. NICE has the power to bring this important breakthrough treatment to the families who really need it. If NICE squanders this opportunity, families, like ours, will be made to pay the heaviest price."

The prospect of access to Spinraza is welcome news for many families affected by SMA. But they still face an anxious wait while NICE considers Spinraza for long-term delivery on the NHS.

We know every day counts for everyone living with muscle-wasting conditions and that's why we are working with other SMA charities to fight for access to Spinraza.

So far the charity has held a major event at Westminster to ensure politicians understand the issues, lobbied the officials who are working on the assessment and got the story in media including the *BBC Ten O'Clock News* and the *Daily Mail*.

To find out more about the campaign and how you can get involved, get in touch with Clare at c.lucas@musculardystrophyuk.org or visit www.musculardystrophyuk.org/fast-track

*Orthotics, such as shoe inserts, foot beds or arch supports, are placed on the foot or in the shoe to improve foot function.

CARE IN EMERGENCY:
Carrie's story

"Every time I've called for an ambulance or been admitted to hospital, I've had to relay every detail of my disability and how it affects me. There seems to be a large gap in the most basic knowledge of muscular dystrophy.

"I can't complain about the care and conscientiousness shown towards me by paramedics, nurses and doctors. However, I'm concerned about being in a position where I'm unable to answer their questions about my condition."

Carrie Aimes (pictured) is a Trailblazer and a disability campaigner. She lives in Worcestershire and has Ullrich congenital muscular dystrophy.

"Having Ullrich congenital muscular dystrophy means I have contractures in my joints, a severe 'S' shaped scoliosis, and respiratory decline. I now use an electric wheelchair to get around.

Medics don't know my condition

"I've endured several bouts of acute pneumonia, a collapsed lung and pleurisy, so ambulances, A&E and hospital wards are all too familiar to me. Mostly, my treatment is thorough and adequate, if a little clueless at times! Whenever muscular dystrophy is mentioned, though, medics immediately assume it's Duchenne, which can be incredibly frustrating.

"People with my condition, and many other conditions, should never be given supplementary oxygen because we retain carbon dioxide. It's preferable to support breathing with non-invasive ventilation such as a Bi-pap machine.

"When healthcare professionals don't know this, the outcome can be life-threatening. Equally, the fact that I need the support of a carer while I'm an inpatient

has to be explained again and again. There seems to be a complete lack of awareness."

Ambulance action

MDUK's Ambulance Action campaign aims to address these issues so that Carrie, and others like her, can get the best quality emergency care. We're working with ambulance trusts across the UK to ensure that all ambulance services have 'flagging' systems in place. These will alert paramedics, when they get the emergency call, to the fact that they're attending to someone with a neuromuscular condition. They will then have access to individualised care plans before they arrive on the scene.

Alert cards

The charity has also developed alert cards for a range of muscle-wasting conditions. These cards, which can fit in your wallet, outline the vital and specific issues healthcare professionals need to look out for in times of emergency. **Find out more or order yours at** www.musculardystrophyuk.org/alert-cards

To join this campaign or share your experience of emergency care, get in touch with David at d.stephenson@musculardystrophyuk.org

Ullrich congenital muscular dystrophy
is caused by the lack of a vital protein that acts as a scaffold supporting muscle cells. It is one of the most common forms of congenital muscular dystrophy.
If you'd like to speak to someone about your condition, our helpline team is here for you on 0800 652 6352 or info@musculardystrophyuk.org

#VentAboutTheVent

Chloe Ball-Hopkins (pictured) is a Trailblazer, Paralympic hopeful and GB para archer, and a BBC Bristol sports reporter. A dedicated MDUK supporter, Chloe has taken on some amazing challenges and campaigns over the years, and has represented the charity at events and in the media. Here she shares a side of her life that she doesn't often share, and offers some insights many readers may find familiar.

I will spare you the full story because that will take all day: at the age of four, I was diagnosed with a rare form of muscular dystrophy – called nemaline myopathy.

The way I have the condition is different to others with the same diagnosis though, so every day is an adventure to say the least.

I work, and recently a nasty virus worked its way around the newsroom and I knew it was me next. I got a cold and was managing pretty well, considering, and recent tests showed my lungs were clear and working at 98/99 percent in terms of oxygen levels.

Now if you were to get a virus, you'd rest up a few days with some cold and flu and then get back to it. Well, it doesn't work like that for someone like me. In 2012, on the Monday I had a cold and by the Friday I was fighting for my life. A scary thought.

So right now, what began as a cold has become a virus. Luckily it isn't affecting my breathing (yet) so preventative measures are put into place in a heartbeat.

I have ointment on my chest as well as some mixed with hot water in the room. I am sniffing Olbas oil and using cocoa butter on my nose to try and stop it getting sore from blowing it so much. Hot showers are also good for trying to clear your airways. All of these are things you could do when unwell but using a cough assist and ventilator?

I first started using a ventilator way back in 2008 and I have to admit it's one element of my condition I've always hated and rebelled against. The first vent nurse I had had the patience of a saint! In 2012 when I was unwell I had to use the vent more to get my lungs working again, but since 2013 the vent now only comes out if I am unwell to keep my lungs going to prevent anything going on to my chest.

The cough assist is a similar concept. I cannot make myself cough, and if I do have a cough when unwell, it's pretty useless. The cough assist helps keep everything moving so nothing can settle on my chest.

This is an element of my condition that I'm not a fan of and have always tried to keep hidden. I realised today, that actually these machines help keep me alive and well, so I really should appreciate it instead of hiding it (from myself and the world).

I bet I'm not the only one in this position either. As a 21-year-old who is fairly independent, I don't want to believe there is something I can't do. But every now and then I have to realise that actually my lungs can't do it. So sitting with a mask on for a couple of days isn't the end of the world … but not using it could be!

If you're reading this and you're the same as I was, please stop and think. Yes it's "not cool" but it is saving yourself, so let it! Don't be stubborn. Just sit down for a while and get yourself well again!

Join MDUK's 'Right to breathe' campaign to improve the provision of vital respiratory equipment. To find out more, get in touch with Jonathan at j.kingsley@musculardystrophyuk.org or visit bit.ly/mduk-righttobreathe

Nemaline myopathy

Nemaline, or rod, myopathies are a group of conditions which fall under the umbrella of congenital myopathies. They are characterised by rod-like structures in the muscle cells, and clinical features such as muscle weakness, breathing problems, and feeding problems.
If you'd like to speak to someone about your condition, our helpline team is here for you on 0800 652 6352 or info@musculardystrophyuk.org

DECLAN'S DRIVING DREAM COMES TRUE

A teenager with Duchenne muscular dystrophy has fulfilled a life-long dream by passing his driving test.

Declan Spencer (pictured with his mum, Alexandra), from Leicester, has been "obsessed" with cars from a young age. After being diagnosed with Duchenne at the age of eight, he'd given up on his dream of being able to drive.

Four years ago he was told that another young man with Duchenne had passed his driving test. After taking lessons in an adapted Motability vehicle that he could control using just his hands, Declan passed his first driving test.

"He just wants to lead a normal life. He's always been obsessed with cars, ever since he was young. He's part of a car club, spends hours every day on YouTube watching car videos, and he's been twice to watch *Top Gear* being filmed. His life revolves around cars," says mum, Alexandra.

"From the moment he opens his eyes in the morning, Declan needs help to do everything. He can't move his arms or legs, so I dress him and use a hoist to get him out of bed. He needs medication, and uses a ventilator and cough assist. This is all before he's even left the bedroom.

"When he was 10, he found out he wouldn't be able to walk. We were at Great Ormond Street Hospital. He'd only been diagnosed 18 months earlier, and he asked me, 'Does this mean that I won't be able to walk?'

"I'd told myself I would never lie to him, so I told him that it did. And then he said, 'Does that mean that I'll never drive?' I had to tell him it did. The journey back from London that day was awful. We were both so upset."

Declan walked for the last time almost exactly a year later. Both he and his mum had assumed he'd never

be able to drive a car. But when he was 15, they were told by another family that it was possible.

"He's had so many obstacles on the way to passing his test. I was told he wouldn't make it through the night three years ago, when he had pneumonia that turned into sepsis and liver failure. It came on when we were on holiday and Declan had to be airlifted off the cruise ship.

"But despite all the setbacks, he passed his driving test first time. For him, being able to get into the van and drive is better than being able to play football.

"Everyone has said they feel safer driving with him than with most people, and obviously he's used to having spatial awareness because of his wheelchair."

Alexandra said that Declan's next ambition was to travel to Germany to drive his van around the famous Nürburgring Formula 1 Grand Prix track.

"I'm lucky because it's just me and Declan. I don't have any other children to consider, so my life has become about giving him the best life possible. If I've got the funds to do it, then we're going to do it."

If you'd like to find out more about driving and adapted vehicles, our helpline team can put you on the right track.
They are here for you on 0800 652 6352
or info@musculardystrophyuk.org

LIVING LIFE TO THE FULLEST
by the Co-Researcher Collective

Living life to the fullest… a simple statement, but what does it mean? And what does it mean for the lives and futures of young disabled people with life-limiting and life-threatening impairments?

This is a question being asked within our project, Living Life to the Fullest, a partnership research project of the University of Sheffield and leading disability and arts organisations, DMD Pathfinders, Purple Patch Arts, and the Good Things Foundation, as well as other supporters, like the brilliant MDUK Trailblazers.

The aim of the project is to use the arts to understand the lives, hopes, desires and contributions of this unique group of young disabled people. In today's culture, most people don't often think of young disabled people – or young people in general – as making vital and important contributions to their families, schools, wider communities and civil society.

Living Life to the Fullest recognises that disability experiences are valuable, that disability can enable important connections in life and, most of all, young disabled people have valuable skills, knowledge and talents to offer the world.

The project seeks to capture this spirit to make visible the lives of young disabled people, their aspirations, needs and rights – to wider society, disability communities, the professionals and families who support them, and within the health, education and care policy that governs their lives.

Want to get involved?
Living Life to the Fullest runs from April 2017-March 2020. Currently we are looking for young disabled people and their families to participate in the following ways:

- online interviews (via Facebook Messenger, Skype and/or email) and/or telephone interviews
- an Art Retreat Workshop, run by Purple Patch Arts.

If you have any questions or want to know more about the research, do get in touch with us at k.liddiard@sheffield.ac.uk

www.livinglifetothefullest.org

Living Life to the Fullest is funded by the Economic and Social Science Research Council (ESRC)

The Co-Researcher Collective co-leads the project. This group of young disabled people is taking ownership of the project, working with academics, researchers, and partners, and shaping the process and outcomes.

HERE FOR YOU in Northern Ireland

Receiving a diagnosis of a muscle-wasting condition can be devastating, and can often leave you feeling isolated. At a time like this, it's important to know MDUK is here for you, working with your clinicians to ensure you receive the best health and social care and advice. Our new Here For You: Clinic Support Team will do just that.

As part of this project we have recruited a team of advocacy officers to work with clinical teams in London, Oxford, Newcastle, Wales, Northern Ireland and Scotland. The team is drawn from a range of therapy and social work backgrounds to enhance the support we are able to offer.

Demelza Stuart (pictured), Information and Advocacy Officer, is part of the team and is based in Northern Ireland. She works at muscle clinics in Belfast City Hospital and will do home visits too. The team's role is to help you get the benefits, housing or specialist equipment you're entitled to, and to live well with your muscle-wasting condition.

A qualified Occupational Therapist (OT), Demelza also offers specialist support UK-wide to anyone who needs it. She sits on the All Party Group for Muscular Dystrophy in the Northern Ireland Assembly, and runs the Northern Ireland Muscle Group, bringing together families and individuals.

"I've found that people living with muscle-wasting conditions often feel isolated, and some healthcare professionals may not understand these rare conditions. Part of my role is to bridge that gap – offering practical support to families and helping professionals to understand what it means to live with a muscle-wasting condition."

Q and A with Demelza

Where and when do you work in clinic?

I go to the twice-monthly muscle clinic at Belfast City Hospital outpatients department. The adult clinic runs all day, and the paediatric clinic just in the afternoon. I'm lucky to work with such a supportive team, and to be a fully integrated member of it. I sit in during consultant appointments so I can meet patients and find out what support they need. I may also meet people in the waiting area, where I explain my role and the support I can offer. I also attend the new weekly clinics, led by nurses and physios, offering review appointments to adults.

How would you support families after they've just received a diagnosis?

I'm not usually present when a family receives a new diagnosis, but I may meet them fairly soon after this. I'll let them know how MDUK can support them, tell them about our information and explain how I can support them throughout their journey. Many families will want to meet others who are going through similar experiences so I'll invite them to local events or link them up with others.

What kind of information do people need the most at this point?

A diagnosis is often devastating, and many people need emotional support. I listen to their story, and answer any questions they may have about navigating the healthcare system. Beginning to build a relationship with them at this point can help so they'll know where to go if they come across difficulties in the future.

How would you support an adult coming into the clinic for an annual review?

I usually introduce myself, tell them about my role and give them my contact details. If they talk about any support needs, we'll discuss them in more detail. This usually requires a follow-up appointment, away from clinic. I'll visit people at home when needed, or ring them.

What kind of information do people need the most at this point?

Many people will already know us, but may need help with specific advocacy issues. For example, many adults have to move from Disability Living Allowance (DLA) to Personal Independence Payments (PIP) and this is a difficult process. I can help them to complete forms, and write supporting letters.

What is the most difficult part of your job?
It can be challenging and, of course, there are limits to what we can help with. It's still shocking to hear about the difficulties many people still experience, so I'm glad to be part of the All Party Group on Muscular Dystrophy. We'll keep up the pressure until there is better support for people living with muscle-wasting conditions.

And the best?
I enjoy working with a great clinical team and supporting and helping people deal with a huge variety of issues. It is fantastic when someone tells you that the support you have given has made a real difference.

To get in touch with or find out more about MDUK's team of Information and Advocacy Officers here for you in clinics UK-wide, visit www.musculardystrophyuk.org/clinic-support-team

Sharon (pictured right, with Demelza), who has myotonic dystrophy, needed support with PIP. Demelza wrote a supporting letter which helped Sharon successfully get both the care and mobility components.

"Without Demelza's help, I wouldn't be getting PIP. I need it to pay for a home help, as I really struggle with so many day-to-day tasks. It was also great having Demelza there at my clinic appointment – it's fantastic that she can be a point of contact for me."

DISABILITY AND EMPLOYMENT

Trailblazers, MDUK's network of young disabled people, is determined to knock down the barriers preventing young disabled people from finding and staying in work. That's why they've set up a Working Group on Disability and Employment, led by Trailblazers Employability Officer, Emma Vogelmann (pictured).

"By identifying attitudes and preconceptions of employers on disability, and learning from the experiences of young disabled people, we want to change the landscape for disabled people in employment," said Emma.

The Group, which is made up of employees and employers, will gather evidence and work with MPs and decision-makers to shape future policy.

"It was great to be present at the first Working Group on Disability and Employment and to be able to hear and share stories with people who've had similar experiences. Bridging the disability employment gap will most certainly require concerted/collaborative action involving a number of organisations and policy makers. But I think disabled people and disability organisations have a crucial role to play and the working group does a fantastic job in facilitating this." Conrad Tokarczyk, Group member

© Chris O'Donovan / MDUK

If you're an employee or an employer and would like to get involved in this campaign, please get in touch with Emma on e.vogelmann@musculardystrophyuk.org

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FUNDRAISING UPDATES

Pedal, Paddle, Peak

In July last year, 14 teams came from all over the UK to join in our second Pedal, Paddle, Peak event in the beautiful Lake District. Fifty-four people took on the challenging course and families and companies raised a grand total of £38,000. A huge thank you and congratulations to everyone who took part, and to Team Oarsome Foursome who set an astonishing course record of six hours and 10 minutes.

Cambridge Town and Gown

Thank you to all the runners who braved the windy conditions last October to run in our sixth Cambridge Town and Gown 10k. Over 1,800 runners turned the streets of Cambridge orange and helped to raise over £70,000 to beat muscle-wasting conditions. That makes 2017 the biggest-ever Cambridge Town and Gown! Thanks to everyone involved.

The 2018 Cambridge Town and Gown takes place on Sunday 21 October. Book your place at www.townandgown10k.com/cambridge

Prudential RideLondon-Surrey 100

Well done to our wonderful #TeamOrange cyclists who saddled up and took on 100 miles through the streets of London and Surrey countryside last July. Months of training and our booming Kingston cheer squad helped everyone to cross the finish line. Together, our riders raised a brilliant £16,877 to help in the fight against muscle-wasting conditions. A huge thank you for all your hard work and fundraising efforts.

Fancy joining #TeamOrange for the 2018 event on Sunday 29 July? Book today - entries are going fast. www.musculardystrophyuk.org/ridelondon

Q Trust – Giffords Circus

The Q Trust held another successful event in 2017, this time hosted by the magical Giffords Circus. The incredible show played to a packed big top, full of Q Trust friends and family, who raised £38,000 towards the new research centre in Oxford. A huge thank you to the committee and those who attended. The Q Trust was set up in 2001 in memory of Quentin Crewe. Since then, family, friends and supporters have worked tirelessly to create awareness of muscle-wasting conditions and have raised more than £2million.

Microscope Ball

Our 34th Microscope Ball brought the glitz and glamour of roaring 20s Monaco to London last autumn. The event raised a staggering £369,000 – a record total for the event. Our wonderful host, World Cup-winner Will Greenwood, and auctioneer Duncan Moir did a brilliant job encouraging the audience to dig deep on the night. The Microscope Ball Chairman, David Morris, paid tribute to the late Sam Sananes, who served as Chairman of the Microscope Ball for four years. Sam's legacy, breaking down barriers to participation in sport, was honoured through a pledge dedicated to growing Powerchair football in the UK. Thank you to all those in the commercial property industry who supported the event, particularly the Sananes family and the Microscope Ball Committee.

Charity Shoot Day

Our first Charity Shoot Day took place last year at the prestigious Royal Berkshire Shooting School. Eight teams honed their marksmanship skills in a bid to win the award for Top Gun and Top Team. The day was a great success: some excellent shooting in the glorious sunshine, a delicious lunch, wonderful auction lots and £12,500 raised for the charity.

Move a Mile for Muscles

In 2017, hundreds of supporters took on Move a Mile for Muscles events across the UK, with the theme of moving a million miles together! People grabbed this challenge with gusto and scooted, swam, cycled, wheeled, and walked to raise over £58,000.

This year, there are a number of Move a Mile for Muscles events taking place across the UK:

Wednesday 28 March
– Newcastle
Saturday 2 June
– Snuff Mills in Bristol
Sunday 2 September
– Mote Park in Maidstone
Sunday 2 December
– Longford Park in Manchester
Saturday 15 September
– Castle Semple Loch

To find out about other events, or how to organise your own Move a Mile event, get in touch with us at volunteerfundraising@musculardystrophyuk.org

Make Today Count

In 2017, an impressive 211 daredevil fundraisers jumped out of planes for MDUK and raised over £136,000. Thank you to you all – the money you raised will fund around 30 months of groundbreaking research.

In 2018, there are more than 12 skydiving sites and indoor skydiving sites UK-wide where supporters will be jumping out of a planes with or without parachutes! Over 100 skydivers are hoping to beat last year's fundraising total.

Go Orange for a Day 2018

More than 40,000 people joined #TeamOrange in February to make it 2018's brightest day of the year! Our fun and colourful Go Orange for a Day saw hundreds of schools and companies donning orange for the day to help beat muscle-wasting conditions. The funds are still coming in, but it looks likely you've raised a whopping £40k.

Next year we are turning the UK orange on Friday 1 February 2019. Save the date, or get in touch to find out more at go.orange@musculardystrophyuk.org

NEW FAMILY FUNDS

A Family Fund is a great way to fundraise for MDUK, as a family or group. If you've considered setting up your own charity to have control over what your money funds, a Family Fund is a fantastic alternative for you.

We take care of the admin, Charity Commission paperwork, accounts and the agreed associated costs, on your behalf. That leaves you to concentrate on fundraising.

If you'd like to set up a Family Fund to support a particular condition or a specific area of our work, come and talk to us. You can direct your funds to planned projects, research or the broader areas of activity that most interest you – and you'll have the final say.

There are now 75 MDUK Family Funds, and these are the newest ones:

- Luke's Army
- Alex's A-Team
- Leo's Pride
- Moving Muscles for Marcus
- A Cure for George
- Elliot's Fighting Fund
- Giving 4 Gabe
- Our Fight for Ryan
- Project GO, Scotland
- Muscle in with Somhairle

Find out more at
www.musculardystrophyuk.org/family-funds

SHARE YOUR FUNDRAISING IDEAS

Our fundraisers tell us that traditional bake sales work a treat, but there are plenty of options to get creative too!

Get in line for some dance fun

Ask your local line dance club to hold a fundraising event, like the Renegades Line Dance Club (pictured) did recently for anyone who fancies some line dancing fun.

Boss in a Breakout

Get one or a group of your company's managers in a room with their mobile phones and list of contacts. The challenge is for them to phone and pledge money to MDUK, and they can't leave until they've reached their target.

Going for gold

A little bit of friendly competition is a great way to get people involved in your event! From Office Olympics to Poker Nights, these fun events can really bring in the pounds.

Photo © Brian Jackson/Fotolia

Give a gig

Do you know someone in a band? Ask them to put on a gig for you and donate the proceeds to your fundraising.

Photo © DWP/Fotolia

A day to remember

Hold your own seasonal event. Make it as big or small as you'd like. Organise an Easter egg hunt, or host a Halloween party.

Or why not try a champagne hoop toss, a duck race, or a blind date with a book? Send in your tried-and-tested ideas to inspire others!

To find out more, get in touch with us on volunteerfundraising@musculardystrophyuk.org or on our fundraising helpline: 0300 012 0172

MDUK CONFERENCES 2018

National Conference 2018
13 October in London

Scottish Conference 2018
3 November in Glasgow

Save the dates for these opportunities to meet others and hear all the latest news and updates. Email us at infodays@musculardystrophyuk.org and we'll let you know when registration goes live.

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