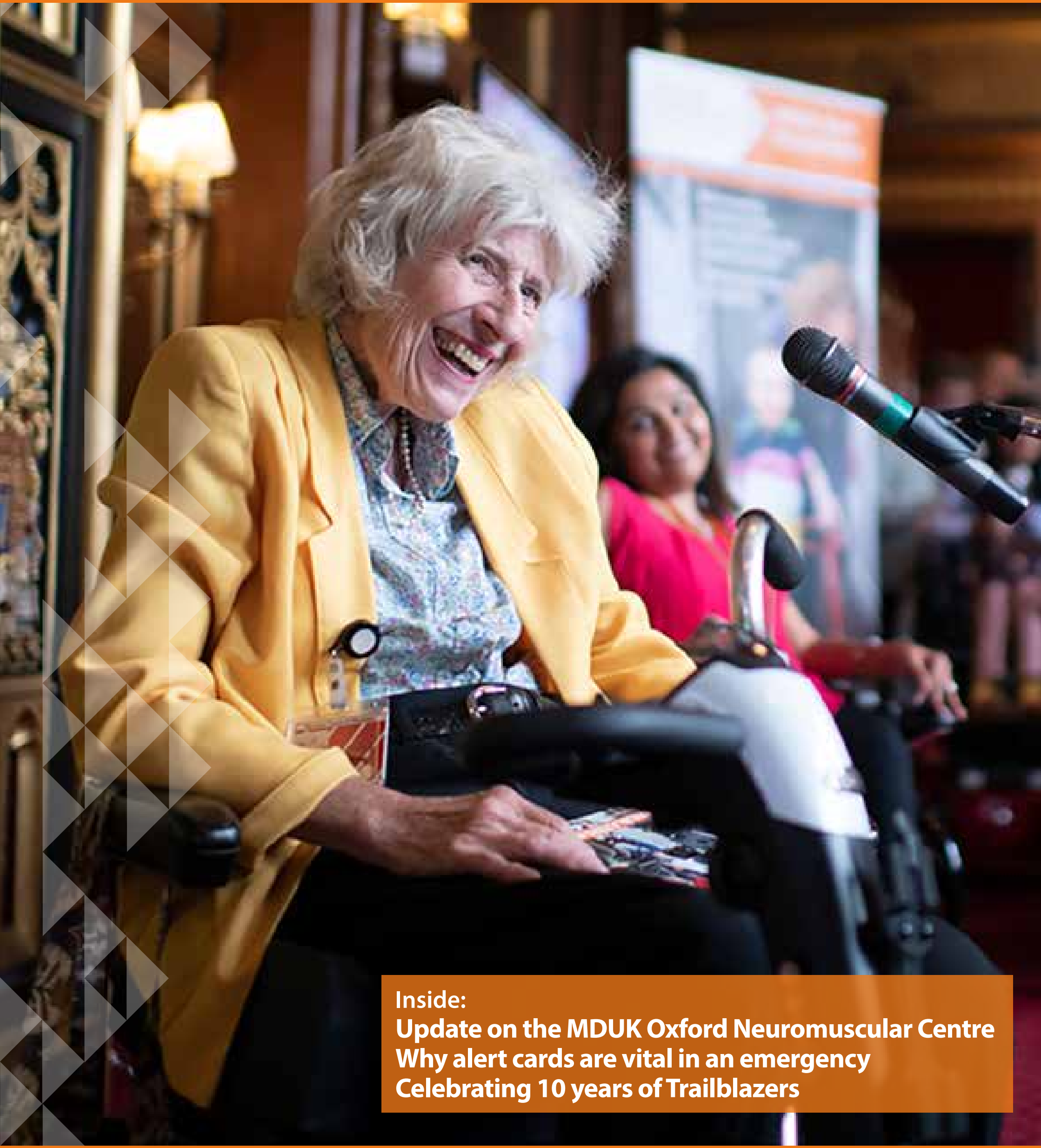
Muscular Dystrophy UK
Fighting muscle-wasting conditions

Campaign

The newsletter for our supporters



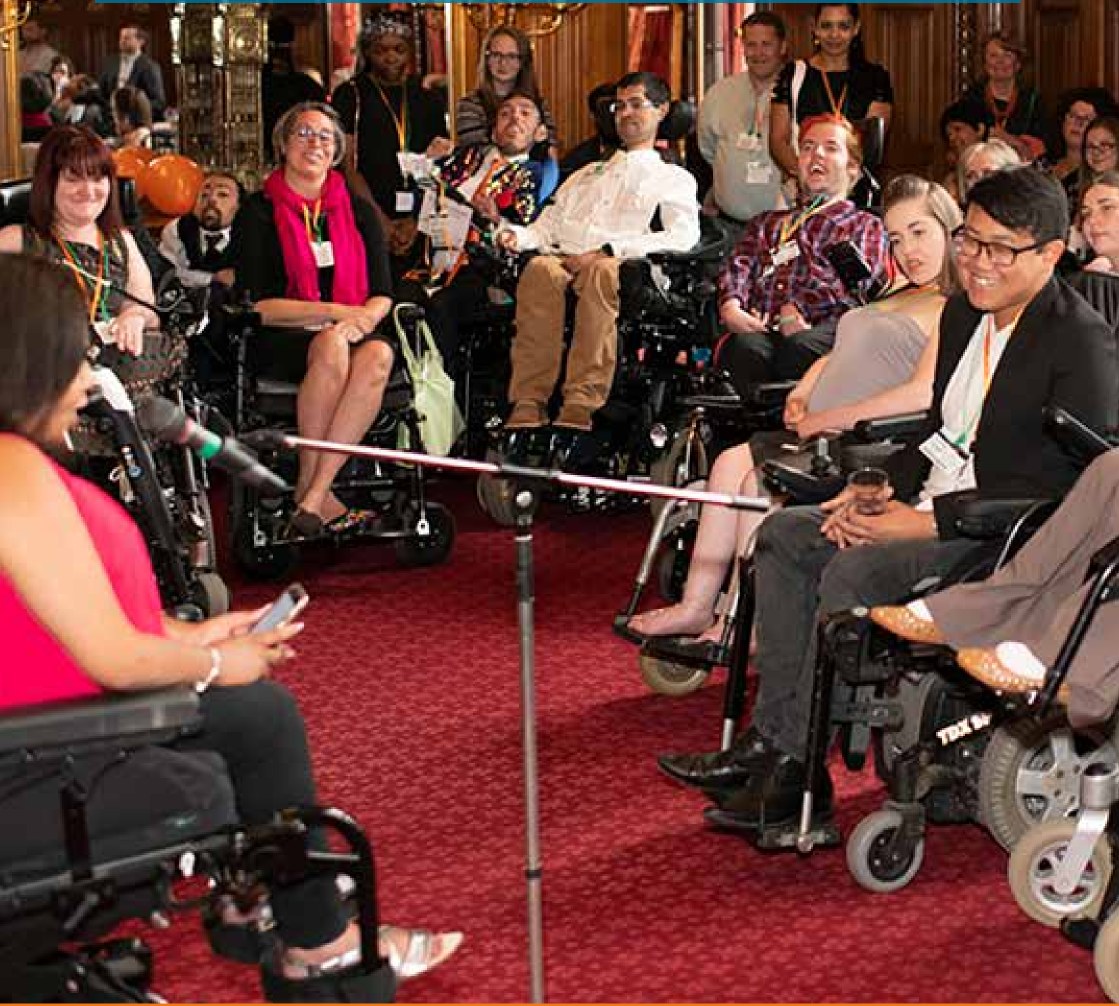
Inside:
Update on the MDUK Oxford Neuromuscular Centre
Why alert cards are vital in an emergency
Celebrating 10 years of Trailblazers

Autumn 2018

It's been 10 years since the start of Trailblazers – Muscular Dystrophy UK's 800-strong national network of young disabled people and their supporters. Since 2008, the group has campaigned tirelessly to remove the social barriers that prevent young disabled people from living full and independent lives.

To mark this special day, there was a reception at the Speaker's House, Houses of Parliament. About 40 Trailblazers as well as Peers, MDUK trustees and other disability organisations were invited to celebrate the Trailblazers' achievements.

Read about the Trailblazers' latest campaigning work on pages 12-13



Welcome

Welcome to this autumn edition of *Campaign*, featuring updates and news of exciting developments from Muscular Dystrophy UK.

Inside, you'll see how your support is helping to make sure people living with muscle-wasting conditions receive the right care in an emergency as well as how our alert cards are proving vital for people with these conditions.

You'll also read about the development of artificial 'mini muscles', and how they could speed up testing potential treatments for muscle-wasting conditions.

I hope you enjoy reading *Campaign* and seeing the very real difference your support makes to so many lives. Thank you for all you do.

Sue Barker

Sue Barker OBE
President, Muscular Dystrophy UK

PS It's never too early to get ready for Christmas, do take a look at the MDUK online shop where you'll find our lovely range of Christmas cards and gifts – there's something to suit everyone.
www.musculardystrophyuk.org/shop

Our vision

A world with effective treatments and cures for all muscle-wasting conditions and no limits in life for individuals and families affected.

Campaign newsletter for supporters of Muscular Dystrophy UK, written and designed entirely in-house.

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DMN/1809

On the cover: Baroness Celia Thomas, trustee of MDUK and who lives with Pompe disease

Join us online

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

www.facebook.com/musculardystrophyuk
Join the **25,000+ community** on our Facebook page.

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

YouTube
www.youtube.com/user/MuscularDystrophy
Watch our videos on YouTube.

instagram.com/musculardystrophyuk
Share our pictures on Instagram.

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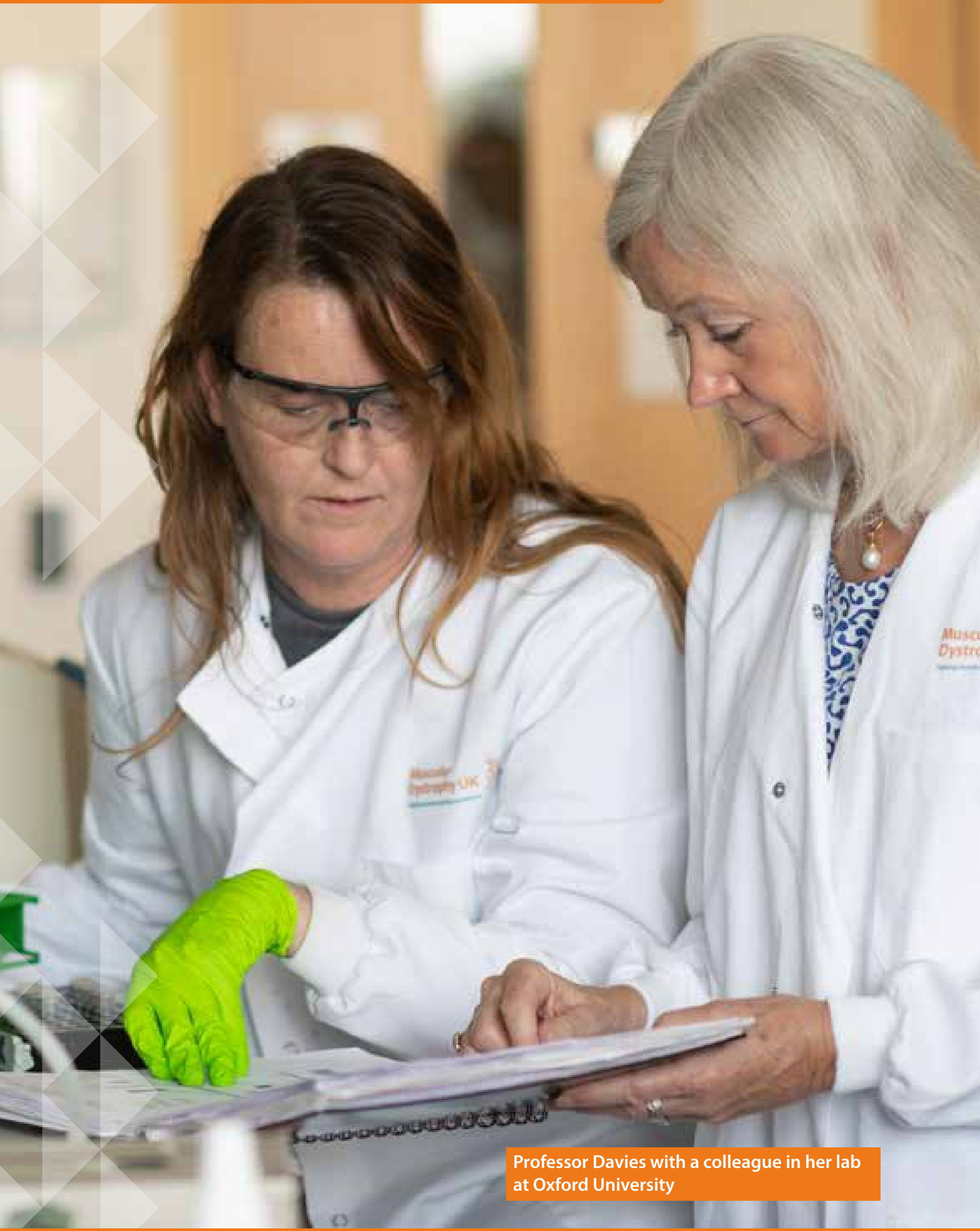
Oxford Centre update



Professor Davies with a colleague in her lab at Oxford University

An enormous thank you to all our supporters who gave so generously to support the new MDUK Oxford Neuromuscular Centre. In response to Professor Dame Kay Davies' letter in January, 1,150 of you wonderful supporters kindly donated, raising just over £47k. Thanks to your support, we can help ensure people with muscle-wasting conditions will have sufficient opportunities to participate in any suitable clinical trials that arise in order to develop effective treatments for these conditions. And your kindness will go twice as far, because thanks to one of our key donors, all gifts to this appeal were matched. Your gifts will have double the impact!

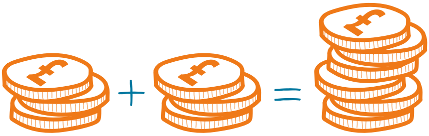
Since Professor Davies wrote to you, recruitment has started for a Chair of Paediatrics who will bring the necessary knowledge and experience to drive translational research and lead clinical trials at Oxford.

The MDUK Oxford Neuromuscular Centre will link with the existing centres in London and Newcastle, and will boost clinical trial capacity. This means more opportunities to test potential drug therapies for muscle-wasting conditions as they emerge.

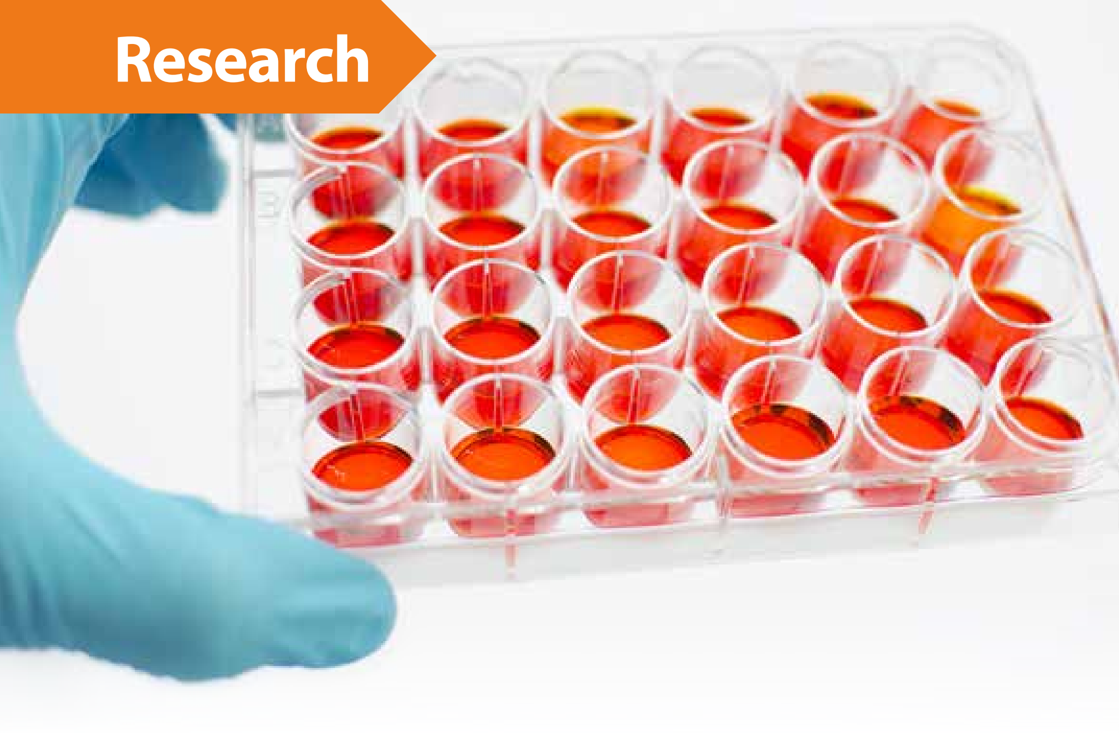
We fund a broad range of projects in our drive towards treatments and cures for muscle-wasting conditions and we'll soon be announcing 10 new research projects that came through our rigorous review process. These projects reflect a commitment of over £1.2 million into six muscle-wasting conditions. More information about each of the projects will be released very soon - so watch this space!

And we're delighted to let you know that if you didn't get a chance to donate to the MDUK Oxford Neuromuscular Centre and have your GIFT DOUBLED, there is still time! If you'd like to make a donation, simply visit

▶ **www.musculardystrophyuk.org/Times2**



Remember – your donation will be matched pound for pound. Don't miss the opportunity for your gift to have DOUBLE the impact.



Artificial 'mini-muscles' developed

Researchers have developed artificial 'mini-muscles' that could speed up testing potential treatments for muscle-wasting conditions.

Dr Francesco Saverio Tedesco - who receives some of his funding from MDUK - and his team at University College London (UCL) took cells from people with Duchenne, limb girdle and congenital muscular dystrophies and turned them into a form of stem cell. Stem cells are special as they can be developed into any other type of human cell, and in this project, scientists used them to build tiny muscles with nerves and blood vessels, much like a real muscle. They found that using this technique, they could effectively model the muscles of people with conditions like muscular dystrophies.

The process can generate a near-unlimited supply of cells to create model muscles, which could be used to make it easier to test treatments.

"Our work shows that we can make patient-specific mini-muscles in the lab and those artificial muscles show distinctive features of some forms of severe muscle diseases," said Dr Tedesco.

“Our findings are expected to facilitate development of therapies for incurable forms of muscular dystrophy by providing a novel way to test treatments in a personalised fashion and on multiple cell types at the same time. They could also help in developing artificial muscles for tissue replacement.”

The next step in the project is for scientists to track how well the ‘mini-muscles’ respond to treatment.

Understanding falls in myotonic dystrophy

A new study has found that middle-aged people with myotonic dystrophy have a higher risk of falling than healthy people aged over 65.

Falls are a concern for people with muscle-wasting conditions as they can cause fractures that reduce mobility. This can lead to further weakening of muscles and potentially losing the ability to walk. Some people also develop a fear of falling, which may make them less active.

The study of falls and fractures was based on data from the UK Myotonic Dystrophy Patient Registry, which is funded by MDUK and the Myotonic Dystrophy Support Group, as well as data from registries in Germany and the Netherlands. The survey found that 70 percent of participants had a fall in the last year and 17 percent had falls that resulted in a fracture. The most common causes for falling were weakness in the legs and impaired balance.

It is hoped that the findings will encourage healthcare professionals to record patients’ falls history, provide advice on fall prevention, and refer patients to special falls clinics if needed.

Dr Cecilia Jimenez Moreno was the first author of the study.

“As a physiotherapist, I am aware that we are increasingly recommending a more active lifestyle for patients with myotonic dystrophy. However, we must not underestimate these patients’ risk levels to fall and should adjust our advice accordingly to ensure that patients feel safe while moving more.”

To find out more about the important research you’re helping MDUK to fund, visit

- ▶ **www.musculardystrophyuk.org/research**

Ways to plan for an emergency

New 'ambulance flagging' systems launched

The West Midlands and Northern Ireland are the latest regions to adopt vital 'ambulance flagging' systems for people with muscle-wasting conditions.

It means that if someone listed on the system calls 999 or 111, their details will be flagged to paramedics and first responders as priority cases and they will get access to the relevant emergency care plans. They can then fully consider what they'll need to provide the best care before even getting to the patient.

MDUK has been working with ambulance services to introduce the ambulance-flagging systems around the UK region by region. This is after many of our supporters found that in emergencies they had to explain complex information about their conditions or were even at risk of receiving the wrong treatment.

If you have a muscle-wasting condition and want to find out whether your emergency care information can be flagged to your ambulance service's system, please discuss this with your healthcare professionals. Or for more information, get in touch with Neuromuscular Outreach Officer, David Stephenson at d.stephenson@musculardystrophyuk.org or 020 7803 4826

Why alert cards are vital in an emergency

We have now distributed over 12,000 alert cards to people living with muscle-wasting conditions and their family members, so they can easily inform paramedics of care issues during an emergency.

The alert cards, which can fit in your wallet, were developed with the help of specialist health professionals. There are cards available for 16 different conditions, and they highlight the key issues healthcare teams need to be aware of during emergencies.

Michaela Hollywood, Trailblazers Campaigns Officer who has spinal muscular atrophy (SMA), wouldn't be without one of these alert cards.

"Having access to my alert card means that I do not need to repeat important medical information. I have often been asked by medical staff why I should not have oxygen, how to spell my condition and to explain what it is.

"My alert card takes the pressure off me so that I can focus on staying calm and getting better."

To order your alert card or to find out more, email info@musculardystrophyuk.org

Better neuromuscular care means fewer A&E admissions

Thanks to a series of improvements introduced by the NHS and initiatives by MDUK, emergency hospital admissions for people with muscle-wasting conditions in London and the South East have been dramatically reduced over the last five years and the readmission rate halved.

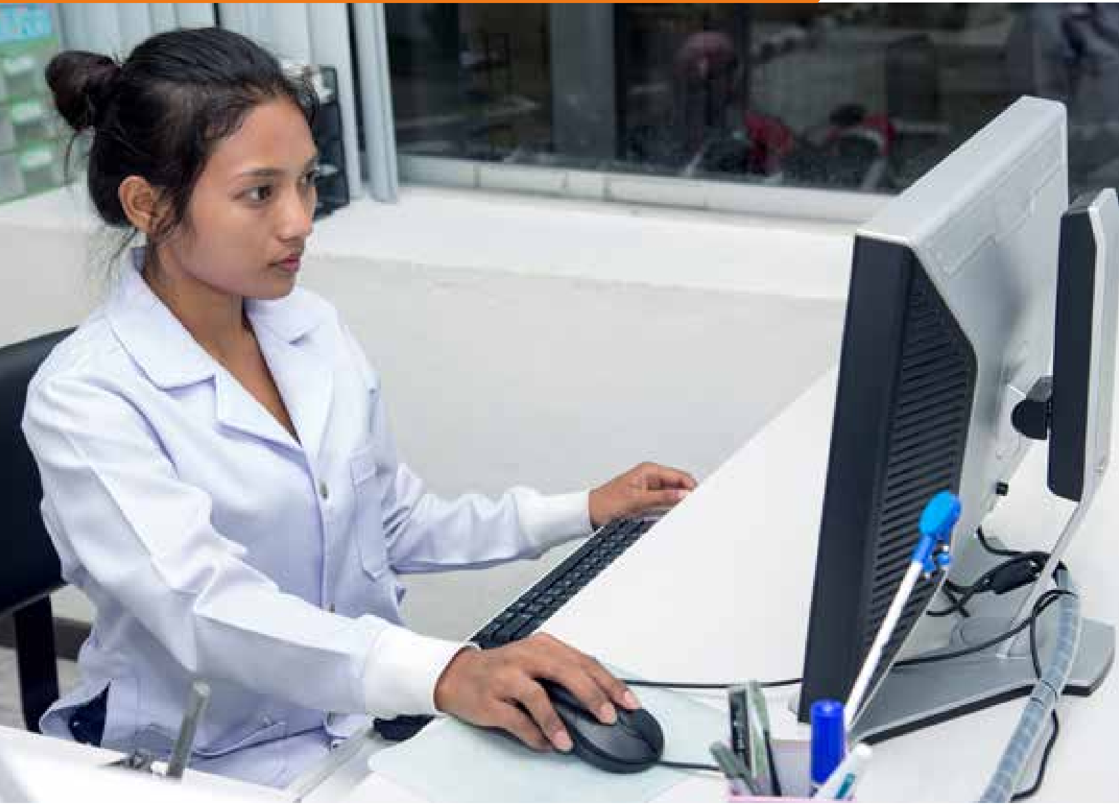
An audit, which followed up on a report from 2012, showed that best practice in neuromuscular care could prevent further acute hospital admissions.

However, there remains room for improvement, with one-third of emergency admissions still being potentially preventable. We'll continue to push for best practice healthcare including having access to care advisors, specialist training and better service provision in all regions.

MDUK Chair Professor Michael Hanna led the team who carried out the audit, and we promoted the results to NHS commissioners and MPs at a special parliamentary event.

To find out more about the work MDUK is doing to improve specialist healthcare, visit www.musculardystrophyuk.org/care-and-support

MDUK expands range of e-learning modules



Working with neuromuscular specialists and people living with muscle-wasting conditions, Muscular Dystrophy UK has expanded its range of e-learning modules for health professionals.

Because muscle-wasting conditions are so rare, health professionals may know little about the impact of these conditions on individuals and families. These e-learning modules have been designed to equip health and social care professionals who work with individuals and families with muscle-wasting conditions with a greater understanding of the conditions. Nurses, occupational therapists and staff working in wheelchair services are among those who will benefit from these new tailored courses.

After completing this online training (which includes a short test), participants will have more knowledge on treating a person with a muscle-wasting condition as well as where to go if patients need more specialised support.

These modules aimed at allied health professionals are part of a wider range of training courses provided by MDUK that are already supporting health professionals in this way.

Over 4,500 community health professionals, such as physiotherapists and GPs, have used resources provided by MDUK to learn about how best to support people with muscle-wasting conditions.

More than 1,000 GPs have taken our GP eLearning module, which provides general practitioners with support around the diagnosis and practical management of patients living with muscle-wasting conditions. We're excited to expand this range of online learning resources to help ensure people with these conditions get best-practice care.

Dr Lucy Martin, a GP at Eve Hill Medical Practice who has completed the GP e-learning module said:

> **"I have taken the Muscular Dystrophy UK online eLearning module [for GPs] myself and confidently recommend it to colleagues across the area I practice in. The resource is a great tool that can easily be referred back to as a prompt. It is quick, user friendly and full of information relevant to GPs. It really does bridge the gap between community and specialist healthcare provision in a way which will surely benefit all neuromuscular patients."**

Over 1,000 GPs have taken our GP eLearning module

Over 4,500 community health professionals have used MDUK's resources

- **If you'd like to let your GP or health care professional know about these online learning services, please contact Neuromuscular Outreach Officer, David Stephenson at d.stephenson@musculardystrophyuk.org or on 020 7803 4826**

Trailblazers' latest campaigning work

First Trailblazers employability weekend

Employment rates for disabled people are far lower than for other groups. Through Trailblazers, MDUK is working hard to make sure people with muscle-wasting conditions get the right support to build confidence and find work.

At a recent weekend event, Trailblazers brought together a panel of experts to help a group of young disabled people tackle employment issues.

There were sessions on networking, CVs and career development, from experts at Amnesty International, HSBC and employment experts PUSH.

> **"Interviews were my biggest fear and now I feel so confident. I am so glad I came to this workshop."**
> Employability weekend participant

Councils still failing on wheelchair taxi law

The Equality Act has applied since last April to taxi drivers, meaning they could be fined up to £1,000 if they refuse to transport wheelchair users or attempt to charge them extra. However, the rules only apply if a local council has created a 'Section 167' list of local drivers, and two thirds of councils have yet to do so. This is despite a government-recommended deadline of October 2017.

MDUK has publicised research from disability activist Doug Paulley on the issue, prompting some councils to complete the lists and raising awareness of the little-known rules. The work we have done has led to these rules being enforced for the first time under the law.

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

New adaptive gaming controller launched

Microsoft has launched a new adaptive controller for gamers with limited mobility.

MDUK welcomed the news, having worked with Microsoft to launch the new controller and to highlight the issues facing disabled gamers.

Playing video games can be an important social interaction for gamers young and old with muscle-wasting conditions who cannot participate in other leisure activities. Trailblazers' *Changing the Game* report into disabled gaming found that one in three respondents couldn't play video games because of their disability. Adaptive controllers were among the report's recommendations.

The controller, which was tested by people with muscle-wasting conditions at our London office, will be made available later this year and will be priced at the same level as standard controllers.

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

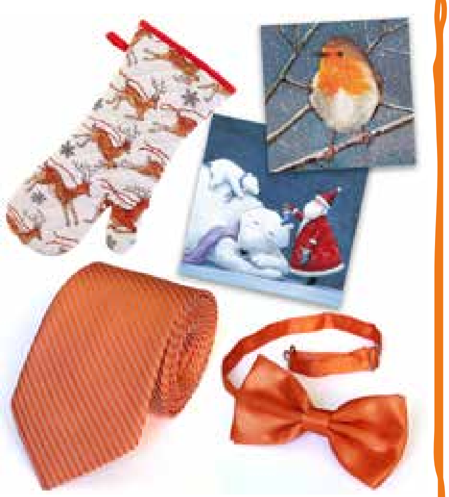
- **To stay up to date with the latest Trailblazers news, visit www.musculardystrophyuk.org/trailblazers**

Ways to get involved

Shop and show your support

Wonderful new items have arrived at the MDUK shop – including our lovely range of Christmas cards and stunning new orange ties, which are the perfect way for a gentleman to show his support in style. Whether you're looking for the perfect Christmas gift or treating yourself to something special, you're bound to find it in the MDUK shop.

- **You can view the range and purchase online at: www.musculardystrophyuk.org/shop**



Congratulations to our Spring Raffle winners!

1st prize: £3,000
Mrs Martin, Ramsgate

2nd prize: £250
Mr Amm, London

3rd prize: £50
Mr Davidson, Hexham

Our Christmas Raffle will open in October. If you'd like to receive raffle tickets in the post to buy or sell to family and friends, please contact us on **0300 012 0172** or **raffle@musculardystrophyuk.org**

Unleash your inner star baker this October and take part in Bake a Difference!

To sign up to 'Bake a Difference or for more information, please visit:

www.musculardystrophyuk.org/bake-a-difference

go orange for a day!

Join #TeamOrange on 1 February 2019 and Go Orange for the day for MDUK!

It promises to be an orange day to remember so make sure you don't miss out on the fun! Signing up your school, club or workplace couldn't be simpler – and it's totally free to take part. All we ask in return is a small donation to help beat muscle-wasting conditions.

Why not combine the day with some extra fundraising events? You could hold a bake sale, lunchtime quiz or an office sweepstake. And don't forget to check out the MDUK online shop where you'll find everything you need to Go Orange for the day!

If you'd like to join in or find out more, please contact the fundraising hotline on 0300 012 0172 or email go.orange@musculardystrophyuk.org

Cambridge Town and Gown

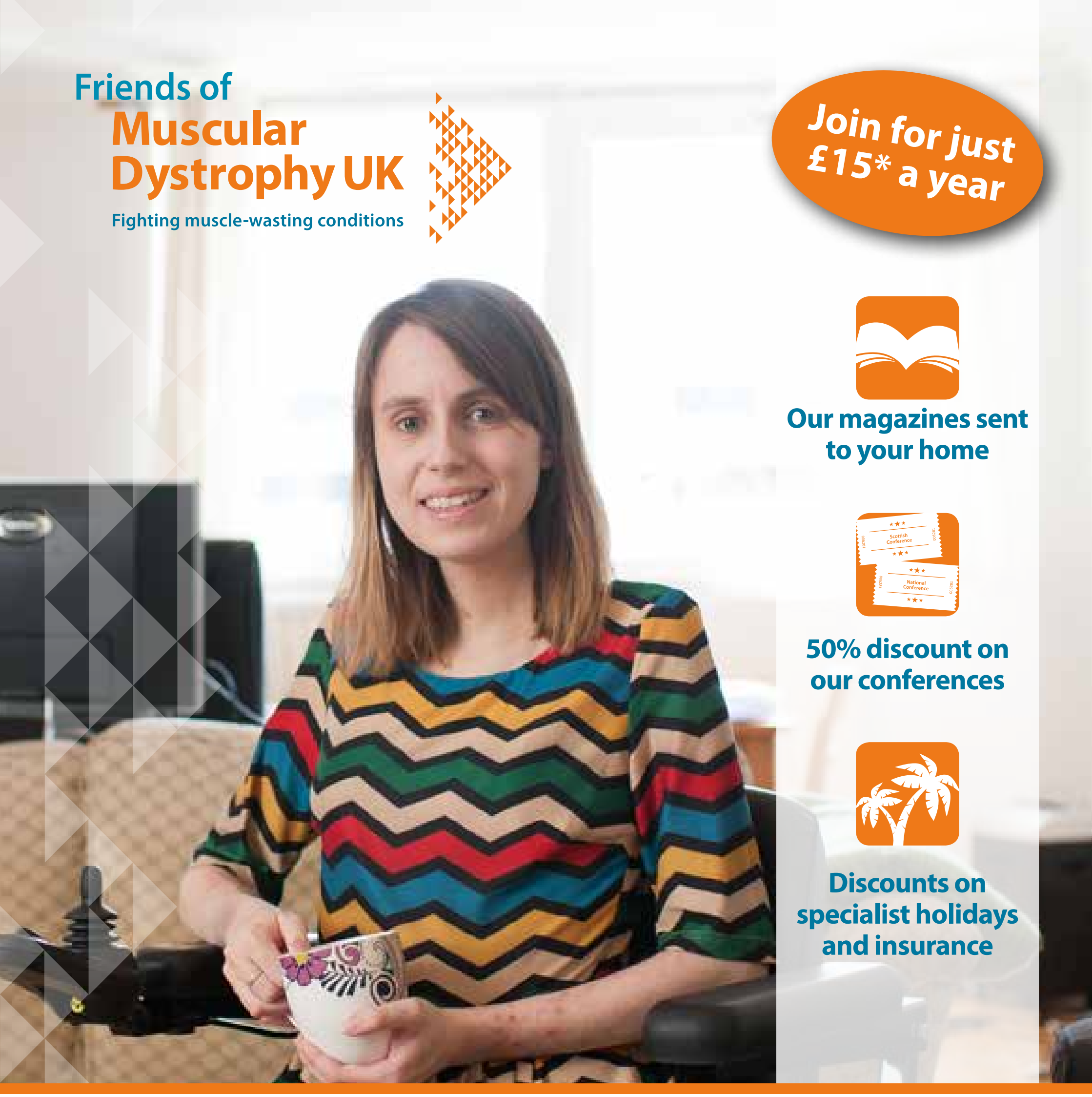
The Cambridge Town and Gown is a 10k, chip-timed run and is ideal for anyone looking to do their first, their fastest or even their most orange run yet!

This scenic closed-road run takes you through the heart of Cambridge past many landmarks, historic University College buildings and along the River Cam. There's a Junior 3k for 9 to15-year-olds too.

Register now for this runner's run at: www.townandgown10k.com/register

Enter before **2 October** to have your race pack sent to you

Enter online by midnight **Wednesday 17 October**, and you can collect your race pack on the day



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Fighting muscle-wasting conditions

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50% discount on our conferences

Discounts on specialist holidays and insurance

Become a Friend of MDUK

Join us in the fight against muscle-wasting conditions, while enjoying a whole range of great benefits for you and your family.

To join today, go online at **www.musculardystrophyuk.org/friends** or call us on **0300 012 0172**. And as a little thank you for joining, we'll send you an MDUK-branded trolley keyring.

*£15 a year when you join by Direct Debit. £18 a year when you join by debit/credit card or cash