

Campaign

The newsletter for our supporters

Airline
victory
for *Trailblazers*



Winning
the fight

How your donations are
helping to develop a treatment
for mitochondrial disease

Thank you

Your support of our young scientists is vital



**Muscular
Dystrophy**
Campaign





Welcome

to the first issue of *Campaign* for 2013, outlining the latest successes and developments within the Muscular Dystrophy Campaign.

It is your support that enables us to do our vital work in fighting muscle-wasting conditions by finding treatments and cures and improving the lives of everyone affected by them. I hope that by reading *Campaign* and seeing the impact of this work on the people all around the country who are affected by muscle-wasting conditions, you will know just how much your support is valued and the difference it makes.

On page 3, we tell you about one of our founders and longest-standing supporters, Lord Walton, who most deservedly won a 2012 Charity Times Award for Outstanding Individual Achievement. We also introduce you to the amazing Peter and Nancy Andrews (page 3), whose support over more than 50 years truly underpins the charity's Christmas trading.

You'll also read of the launch of our patient survey report 2013: *State of the Nation* (page 7), and about the latest work of our young campaigners, the *Trailblazers* (page 6). We also invite you to join us at a range of charity events planned throughout 2013 (pages 14-15).

Thank you, as always, for your continued and valued support. Our fight against muscle-wasting conditions depends on the support of people like you.

Sue Barker MBE

President, Muscular Dystrophy Campaign

Leading
research.
Supporting
people.

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Thank you for your support

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News

More than five decades of support from dedicated Solihull couple

Peter and Nancy Andrews from Solihull have been involved with the Muscular Dystrophy Campaign since it was established 53 years ago, despite having no personal connection with muscular dystrophy or related neuromuscular conditions. Peter, 91, and Nancy, 89, have watched the charity grow into the national charity that it is today.

Peter became involved as the charity's first treasurer when local businessman, Joseph Patrick, started the charity in 1959. Peter and Nancy threw themselves immediately into every aspect of fundraising, and their hard work and dedication to the cause were recognised when they were awarded the first-ever President's Award from Sue Barker in 2006. Peter also received an MBE in 1998 for services to the Muscular Dystrophy Campaign.

They met Richard Attenborough, 'Dickie' as he is affectionately known, when he



joined the charity as President in the early 1960s. His effusive, generous personality, according to Nancy, would see him greet his friends with a hug and a sincere, "You've made my day!"

"That's just Dickie," said Nancy.

They developed and managed the charity's Christmas card sales from the early 1990s, and currently look after the Christmas card shops in and around Solihull.

Thanks to wonderful people like Peter and Nancy, more than £28,000 was raised last Christmas through supporters buying our cards and gifts. We would like to thank all of you who were also able to share in the Christmas spirit while also raising much-needed funds at the same time.

If you would like to get involved in your local branch or committee, our Volunteer Fundraising team would love to hear from you. Please ring 0845 872 9058 or email volunteerfundraising@muscular-dystrophy.org



Success at the Charity Times Awards

Honorary Life President of the Muscular Dystrophy Campaign, Lord Walton, won the Outstanding Individual Achievement award at the Charity Times Awards 2012. The award recognised Lord Walton's dedication, which has spanned almost his entire working life, to improving the lives of people with muscular dystrophy and related neuromuscular conditions.

A lifeline for families

Receiving a diagnosis of a muscle-wasting condition is often the first step into an unknown future for many families. When they make contact with the Muscular Dystrophy Campaign, we put them in touch with their local neuromuscular care advisor who can help them access the benefits, support, treatment and care they require.

Neuromuscular care advisors are key members of specialist NHS teams across the UK. They provide patients and families with essential care, support and advice – and thanks to the hard work of the charity, there are now 32 such advisors around the UK; helping thousands of families affected by muscle-wasting conditions.

Carol Wood is a neuromuscular care advisor in the East of England, based in Stansted. She works with children and adults in Cambridgeshire and Essex, and says that each family has multiple issues that require help:

“The kind of information most of the individuals and families we work with need to know is generally very variable, sometimes dependent on the particular condition. Often what people need is information about their condition, or their entitlements (benefits, housing, health care, equipment) or how to navigate statutory bodies.”

Andrea Russell, a care advisor for Norfolk and Suffolk, said:



“The most satisfying part of my job is in making a difference and improving the quality of life for the patient and their family. The best feedback to get from patients is the knowledge that they feel supported and able to manage the problems that previously felt overwhelming to them.”

Working as neuromuscular care advisors isn't their only connection to the charity. Last year, both Carol and Andrea braced the terrible weather to run the Muscular Dystrophy Campaign Town and Gown 10k in Cambridge, to raise funds for the charity.

Farrell Fox, 56, from Weston-Super-Mare in North Somerset, has benefited enormously from the support of his local neuromuscular care advisor. Farrell has muscular dystrophy and describes the work of his neuromuscular care advisor as a 'joyful necessity', and the help as a 'total revelation'.

“When the consultant first told me of my muscular dystrophy she said that Carla, the neuromuscular advisor, will help you 'manage' your condition. Within two days, she had visited me at home and spent a



lot of time assessing me. Within a week, I had visits from the Falls Prevention Service and two different occupational therapists.

"Shortly afterwards there were visits from physiotherapists and speech and language therapists. I had fire inspections, dieticians and the care agency 'Care and Repair'. Amazing numbers of adaptations, gadgets and equipment turned up and I was made a case study of how a person with neuromuscular disease could be helped to remain in their own home. Carla even came back and filled out forms for me and was always available by phone or email.

"Before this, I was really depressed and had convinced myself that this was the last year in my upstairs flat, my home for over a quarter of a century. Now, a weight has been lifted and I look to the future with total optimism. Most of all, I am safe and secure in the knowledge that as my condition deteriorates, there is help with a whole range of advice, adaptations, gadgets and support. This experience has been a total revelation and I would like to express my gratitude to Carla."

The charity campaigns continuously for more neuromuscular care advisors around the country. With your support, we've been successful in ensuring 32 are in post, but we need more. If you'd like to find out more, or to be put in touch with a neuromuscular care advisor near you, then please call 0800 652 6352 or email info@muscular-dystrophy.org

MEETING supporters

It was a real pleasure to see so many of you at our National and Scottish conferences last October.

More than 350 families affected by muscle-wasting conditions, along with their families, came together to hear from inspiring fundraisers, researchers and campaigners.

At both events, the achievements of inspiring individuals were recognised and celebrated through our President's Awards and Kite Awards.

If you were unable to be there, we streamed much of the National Conference live; an edited version is on our website at www.muscular-dystrophy.org. Do come and join us at our conferences this year in October! If you'd like to find out more, or to book your tickets contact Lyn Inman on 07801 028814 or lyni@muscular-dystrophy.org



Trailblazers leading real change for young disabled people

Overcoming the barriers facing young disabled people is a key aim of the charity's network of young disabled campaigners, the *Trailblazers*.

Public transport is a core campaign issue, and last Autumn the *Trailblazers* began work with the airline and aviation industry around the challenges facing disabled travellers using air travel.

Following the 2012 publication of *Up in the Air*, the latest *Trailblazers* report which revealed problems when booking, boarding and mobilising while on a flight, the group received widespread national media attention.

The report, based on a survey of young disabled people from across the UK, also found:

- nine out of ten wheelchair users are unable to use the airline toilet and therefore have to avoid drinking before and during flights
- more than 60 percent say their wheelchairs have been damaged when using an airline
- half had disability related problems when booking airline tickets.

Improving vital care through campaigning

Since launching the report at a meeting in Parliament with industry representatives and MPs, a major review on access has been announced by the airline and aviation industry.

The *Trailblazers* have since met with Monarch airlines and the Civil Aviation Authority, who are setting up a working group to consider their recommendations, which include a freephone advice line for mobility assistance so disabled people don't have to pay for lengthy telephone calls, an improvement in information about mobility, and better training for baggage handlers to treat wheelchairs as vital, fragile and expensive pieces of equipment.

Commenting on the first meeting, *Trailblazers* Campaigns Officer Tanvi Vyas, said:

"We are excited about finally setting up such an important steering group. Air industry experts will be able to listen closely and action *Trailblazers'* recommendations. We hope to see a real difference in the experience of disabled travellers."

If you'd like to help the Trailblazers improve the experience of disabled travellers on airlines, ring Tanvi on 020 7803 4846 or email t.vyas@muscular-dystrophy.org

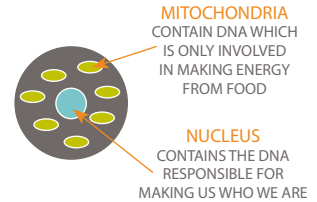
All of our campaigns focus on improving the lives of all people affected by muscle-wasting conditions. Thanks to your support, we have recently had some great successes.

- The NHS has published new guidelines for neuromuscular services which state that people with muscle-wasting conditions should have regular check-ups from a specialist team of health professionals, and underline the importance of neuromuscular care advisors. We hope that this will be another important step towards extending life expectancy and increasing quality of life for people affected by muscle-wasting conditions.
- The appointment of a Northern Ireland care advisor will mean that specialist support in Northern Ireland starts to improve for people with muscle-wasting conditions, and we are working closely with families, clinicians and government officials to address the remaining gaps.
- Our *State of the Nation* report, based on a national survey of 2,000 people living with neuromuscular conditions, was published in January. It revealed that families have huge concerns about handing GPs more control over local care in England. The report was featured by local BBC radio and TV, as well as ITV, and featured people talking frankly about the issues they face. We are now setting up patient-led panels to work with the new GP-led commissioning groups, alongside clinicians and NHS leaders, to make sure that needs of people with muscle-wasting conditions do not fall through the net.

To get involved in our campaigning work across the UK, ring Jonathan on 020 7803 4839 or email j.kingsley@muscular-dystrophy.org

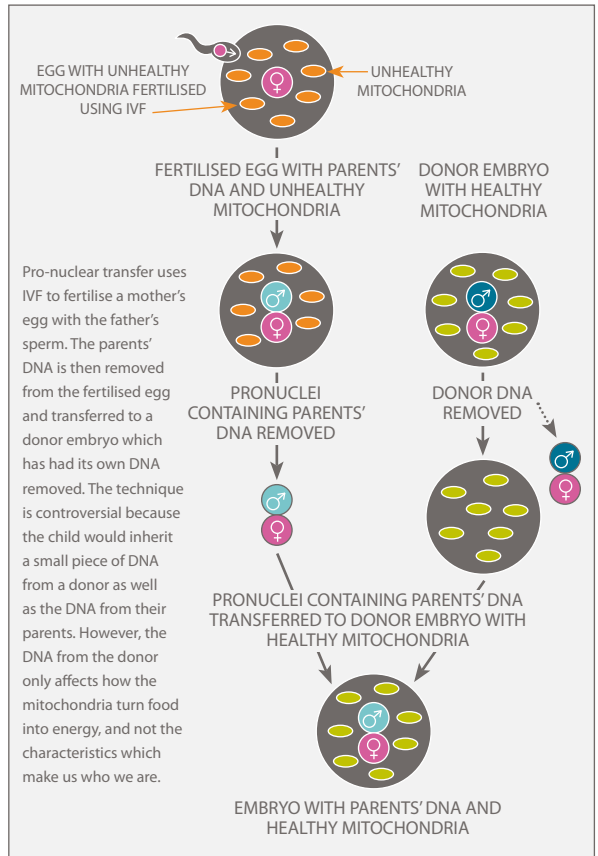
Our pioneering research leading to clinical trials

In the last edition of *Campaign*, we told you how our funding of promising, world-class research has meant that we are moving ever closer to an effective way to stop some forms of mitochondrial disease being passed from mother to child.



Approximately 6,000 people in the UK have a mitochondrial disease, which includes about 3,500 with a mitochondrial myopathy. In the most severe cases these conditions can cause debilitating and life-threatening muscle weakness. There are no treatments for mitochondrial myopathies, and the complex ways in which the conditions are passed from mother to child make it difficult for clinicians to provide genetic counselling. This makes it difficult for people with the conditions to plan for the future.

Over the past 11, years the Muscular Dystrophy Campaign has funded the first important stages of Professor Doug Turnbull's research into developing a technique, named 'pronuclear transfer'. The procedure uses IVF (in vitro fertilisation) to fertilise the egg of an affected woman with her partner's sperm. The DNA –





Professor
Doug Turnbull

carrying the characteristics of the future child – from the fertilised egg would then be transferred to an embryo donated by a woman who has healthy mitochondria. The donor egg would first have its own chromosomes removed.

The technique has been proven successful in the laboratory, but the resulting embryos can be grown only long enough for researchers to perform basic tests to check if the technique worked. To move it forward into clinical trial, a change to the law is required. This would let researchers perform more tests on the embryos and, if the procedure is safe, eventually to implant an embryo into a woman's womb.

The Human Fertilisation and Embryology Authority (HFEA) has consulted public opinion on whether the technique should be made available. We have submitted a response, saying that if the techniques prove to be safe and effective, we would be keen to see them made available to families that currently have to make the difficult decision not to have children; having children at risk of inheriting the disorder; or using a donor egg.

We also highlighted the importance of choice. Making these techniques available to the public would not force anybody to use them. However, it would give women with mitochondrial

disease the possibility of choosing to have a child who is not affected.

One person affected is Val Wintle, from Dorset, who said:

“I myself am affected by mitochondrial myopathy. Until the age of 32 I led a perfectly normal life, before my condition gradually took hold and robbed me of my mobility, my eye-sight and my independence. Now I do not have a life – I have an existence. I cannot tend my garden, walk to the corner shop for a pint of milk or prepare a meal without assistance.

“I, and other people affected by this disease will be backing the Muscular Dystrophy Campaign, Wellcome Trust and Medical Research Council in pushing the Government to avoid further delay in taking this treatment forward.”

Robert Meadowcroft our Chief Executive, also said:

“We are confident that this consultation will help the public understand the urgent need for the development of this treatment for our families. We believe there is a consensus to give people the chance to have healthy children.”

If you would like to learn more about research in this area, please get in touch with Neil on 0207 8034 813 or email research@muscular-dystrophy.org

Help us to fund the Scientists of the Future



Our new Scientists of the Future Fund offers young scientists the opportunity to obtain specialised training in research into muscle-wasting conditions – vital in encouraging a new generation of researchers into this important field.

Funding PhD studentships and Clinical Training and Research Fellowships through our Scientists of the Future Fund supports the development of young scientists and clinicians, resulting in highly trained researchers with the knowledge to develop life-saving treatments for these conditions.

“My hope is that one day a treatment will be possible and that your fundraising and my work will be an integral part in completing the jigsaw that’s needed to get to that stage.”

Louise Moyle

Louise Moyle, 23, is one such scientist, working in London with Professor Peter Zammit on a four-year PhD programme funded by the Muscular Dystrophy Campaign. Louise’s research is investigating the role of muscle stem cells in facioscapulohumeral (FSH) muscular dystrophy. Muscle stem cells are responsible for the repair and regeneration of damaged muscle, and Louise is testing the viability of using muscle stem cells as a treatment for FSH in the future.

Louise said:

“I would like to thank every one of the fundraisers supporting the Muscular Dystrophy Campaign. Fundraising requires a lot of time and hard work, especially in the current economic climate, and I am very grateful for the opportunity that the Muscular Dystrophy Campaign funding has provided for me to train in the field of muscle biology.

“Basic research is very important in order to help scientists take the first steps in understanding FSH, which in turn should bring forward the day when a treatment may eventually be found.

“I am determined to make the most out of the support I have, and use the money as wisely as possible. My hope is that one day a treatment will be possible and that your fundraising and my work will be an integral part in completing the jigsaw that’s needed to get to that stage.”

It’s not too late to support Louise and the other young scientists funded by the Muscular Dystrophy Campaign. Do get in touch with our fundraising team on 0845 872 9058 or VolunteerFundraising@muscular-dystrophy.org. You can register for help from your local Volunteer Fundraising Manager on our website – go to www.muscular-dystrophy.org and search for “Do your own fundraising”.

Bringing people together locally



Our network of Muscle Groups is an effective way of bringing people together in their local areas. Information and advice is shared, and speakers can include people affected by muscular dystrophy or a related neuromuscular condition, clinicians, health professionals, parliamentarians, and NHS decision-makers.

The North West Muscle Group was formed in 2009 and since it started, we've seen many services improve across the region. Joanne Ashton, whose son Liam has Duchenne muscular dystrophy, is a core member of this effective Muscle Group.

“I'm glad I joined the Muscle Group. It means I've got all this information early on and I won't come up against a brick wall later – I feel I've been pre-armed.”

“It's nice to know I'm not on my own and it's good to meet other people at different stages. Every day I imagine how bad things could get, but at the Muscle Group I met young lads with Duchenne muscular dystrophy who are in wheelchairs and they're fantastic, they're doing so well.

“Everything had a real positive spin on it too, and I realised it's not all doom and gloom.”

Members of this Muscle Group have really thrown their weight behind the work of the charity. They have filled out surveys about local care, met with MPs, attended

meetings of the All Party Parliamentary Group for Muscular Dystrophy in the Houses of Parliament, shared their stories with the media and done plenty of fundraising.

Rochdale Muscle Group member, Nicci Geraghty, who has two young nephews with Duchenne muscular dystrophy, took her frustration at the lack of action by North West health bosses to Care Minister Paul Burstow MP in 2011.

Speaking on behalf of all Muscle Group members on the North West, Nicci demanded better support and healthcare for the 8,000 families in the region.

Actions like these have resulted in tangible change for families like Nicci's and Joanne's, who can now access more neuromuscular nurse specialists, and a new neuromuscular team will soon be launched in Preston. Thanks in part to the efforts of the Muscle Group, funding has also been agreed for an additional neuromuscular care advisor post based in Rochdale.

The Groups continue to play a key part in boosting NHS investment into specialist services, as well as helping people to manage their own condition.

Our Muscle Groups would not exist without your support. If you'd like to come along to the next Muscle Group near you, contact Rebecca on 020 7803 2865 or r.johnson@muscular-dystrophy.org

Our advocacy service fights for people's rights



The Muscular Dystrophy Campaign fights for individuals and families living with muscle-wasting conditions in cases where they feel they have been discriminated against or have been denied benefits, services or equipment they are entitled to.

Families come to us for help on benefits such as the Disability Living Allowance (DLA) or Employment Support Allowance (ESA), grants such as the Disabled Facilities Grants (DFG), education issues such as the denial of a statement of Special Educational Needs (SEN), or care package issues.

We also work closely with law firm Hogan Lovells, whose generous pro bono support forms part of our service.

One family we have helped is Robyn Gunner's, from Norfolk. Robyn, 25, has limb girdle muscular dystrophy and this is her story:

"I began experiencing the early symptoms of limb girdle in 2003 when I was 17. After a long wait and countless tests I was diagnosed with limb girdle muscular dystrophy just before my 18th birthday.

"After the birth of my daughter Chloe in 2009, my condition got progressively worse. Stairs were a complete no-go, I couldn't get into a bath, I didn't go out in the winter and I used a wheelchair a lot more. Living in a two-bed bungalow in a rural Norfolk village became increasingly isolating and, with Chloe's future in mind, I contacted the housing association to see what help I could get with adaptations and re-housing.

"After going through a long battle with social

services to get support for me and Chloe, I now faced similar problems with the housing association. I contacted the Muscular Dystrophy Campaign, who wrote to the housing association stating why I needed help with re-housing. While this was going on a house became available opposite my parents. I was told that I wouldn't be shown this property because it wasn't adapted. We fought this and with the help of my occupational therapist we were able to get the housing association to agree to allow me to move into the property close to my parents.

"This whole process took a long time, but with my family, friends and the help of the Muscular Dystrophy Campaign I am going to have a home in which I can live independently."

Thanks to your support, we are able to keep this vital advocacy service going. If you'd like to know more about it, please get in touch with David Moore-Crouch on 020 7803 4831 or email d.moore-crouch@muscular-dystrophy.org

GET ACTIVE!

The Muscular Dystrophy Campaign has a number of exciting events coming up in 2013 and we hope you will consider taking part!

- **We have places in the Belfast Marathon** on 6 May (minimum sponsorship of £250), the Edinburgh Marathon on 26 May (minimum sponsorship of £400 and a registration fee of £49).



- **The Muscular Dystrophy Campaign Town and Gown 10k** race series is back in 2013. Join us in the popular 32nd Oxford Town and Gown 10k on 12 May or our second Cambridge Town and Gown 10k on 6 October. If you would like more information please visit www.townandgown10k.com
- **London 2 Brighton 100km walk**, 25-26 May 2013, is a tough but rewarding walk or run across varied terrain, through day and night. (Registration fee of £80, minimum sponsorship of £400.)

www.muscular-dystrophy.org

The UK's biggest golfing challenge

Chip in, challenge yourself and change lives....

It's the ultimate challenge – playing 72 holes in a single day on Friday 21 June 2013. Tee off as soon as the sun rises on the longest day of the year and try to reach the fourth clubhouse before the light fades. Imagine: 72 holes in 16 hours covering 15 miles of fairways – and that's without any trips to the rough!

We have 400 fantastic courses to choose from, including some of the best in the country, and some great prizes to win.

If you'd like to sign up for the *Four Course Classic*, just visit our website, choose your event and sign up for just £100 per team. The fundraising pledge is £250 per golfer/£1,000 per team, and all sponsorship funds go to the Muscular Dystrophy Campaign.

The registration fee includes:

- four complimentary rounds of golf
- a branded polo shirt
- a comprehensive fundraising and preparation pack.

Last year's *Four Course Classic* raised more than £60,000 towards our vital work in fighting muscle-wasting conditions. Help us raise even more in 2013 and make it the best *Four Course Classic* event yet!

For further information contact Hayley Gill on 020 7803 4824 or golf@muscular-dystrophy.org or visit our website at www.fourcourseclassic.co.uk





Information Day

Congenital muscular dystrophy

Join us in Daventry, Northamptonshire on 27 April 2013 for an Information Day for families living with congenital muscular dystrophy.

The event, organised by the Muscular Dystrophy Campaign and led by Professor Francesco Muntoni, Consultant Paediatric Neurologist at Great Ormond Street Hospital, will give people an opportunity to hear the latest updates in research, diagnosis and management of their condition from expert clinicians.

Consultants and individuals will talk on respiratory issues, nutrition, and physiotherapy, and you will get to meet other families affected by the same condition. There will also be ample time to network, share experiences and find mutual support.

If you're interested in attending the day or would like more information, do get in touch with Katie Mitchell on 0777 137 4839 or k.mitchell@muscular-dystrophy.org The charity will also be organising further information days for people living with facioscapulohumeral muscular dystrophy (FSH), and Becker muscular dystrophy. Watch our website for further information.

- **We have launched** an exciting new cycling portfolio for 2013, including the popular London to Paris bike ride on 4 to 8 September; the 'Moonriders' challenge – a night cycle from London to Brighton on 29 June, and an overseas cycle from Vietnam to Cambodia on 8-20 February 2014.
- **Lace up your trainers** and come and run for us in the biggest and most prestigious half marathon in the world – the Great North Run on the 15 September 2013. (Minimum sponsorship of £300, registration fee of £35.)
- **The Great South Run**, 10-mile road race in Portsmouth on 27 October 2013. (Minimum sponsorship of £250, registration fee of £25.)
- **The BUPA 10,000** – the UK's most prestigious and sought-after 10km road race – on 27 May through central London. (Minimum sponsorship of £250, registration fee of £30.)
- **The Great Manchester Run 10k** road race on 26 May. (Minimum sponsorship of £200, registration fee of £39.)

You will receive full support for all of our events from our experienced team. If you would like to register your interest for any of our 2013 events, please get in touch with Hayley on 020 7803 4824 or h.gill@muscular-dystrophy.org

Muscular Dystrophy Campaign

The Oxford Town and Gown 10k



Sunday 12 May 2013

Lace up your trainers, don some orange, and come and run with us at this year's Muscular Dystrophy Campaign Town and Gown 10k in Oxford.

Join us in one of the best road races in the UK. You and 4,000 runners will have the unique opportunity to run through the closed streets of Oxford city centre, passing historic sites and ending in the beautiful University Parks.

Whether you're a serious runner, or a fun runner, help us to turn Oxford orange in this chip-timed race.

When you do so, you'll be helping the Muscular Dystrophy Campaign fight against muscle-wasting conditions, which affect 70,000 people in the UK. Our work depends on the support of people like you.

Thank you for your support



Register today:

t: 020 7803 4820

e: townandgown10k@muscular-dystrophy.org

w: www.townandgown10k.com

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