Geared up for 2010
WELCOME to the first issue of the new year. It has been a very exciting
time for the Muscular Dystrophy Campaign - our fight for better
services are making an impact with NHS commissioners and we
recently confirmed six new research projects. I enjoyed taking part in
the National Conference back in September. It was great to meet so
many of our wonderful supporters, recognise their achievements and
thank them for all that they do by presenting this year’s President’s
Awards. You can read about one of the winners, Nicola Geraghty, on
page 10.

You may have noticed that the front cover now features a blue and
orange kite. The kite was originally designed for our Tesco Charity of the Year partnership but
we have had such positive feedback it is now a permanent part of our identity. We chose a
kite because people told us they thought it symbolised freedom, family and support.

In this issue you can read about the research we fund in Professor Kate Bushby’s Newcastle
lab. Her work investigating the causes of limb girdle muscular dystrophy is explained on page
six. As you know, as well investing in research we are also working hard to secure improved
access to NHS services for children and adults with muscle disease. Some exciting news on
recent progress of our campaigning work is on page four.

Finally, I would like to thank all our supporters for their generous donations. Your help is
vital to the Muscular Dystrophy Campaign and the thousands of families living with muscle
disease across the UK.

Thank you,

Sue Barker MBE
President, Muscular Dystrophy Campaign

Fundraiser braves ‘world’s most dangerous race’

Paul Dickens, a Tesco Distribution Manager from Newmarket,
overcame the inhospitable environment of the Brazilian rainforest
to finish in an incredible fourth place on his first attempt at the
Jungle Marathon – known as the world’s most dangerous race.

Paul risked life and limb to run the course which tackles rivers,
mountains and swamps over six brutal days. He aims to raise a total
of £20,000 for the Muscular Dystrophy Campaign’s Tesco Charity of
the Year partnership. Paul said, “I was surprised and delighted to be
the first Briton home and I’m looking forward to trying to repeat
that to raise as much money as possible for the Muscular Dystrophy
Campaign in the Sahara marathon in 2010”.

To support us call 020 7803 4837
Trailblazers tackle ‘university challenge’

In August, as the count down to A-Level results and university Clearing began, the Muscular Dystrophy Campaign’s Trailblazers published University Challenge – guidelines which highlight the difficulties disabled students face when trying to access a university education.

The guidelines were published alongside the results of their investigation into disabled access at university. The report revealed that 30 percent of university inter-campus transport is inaccessible to disabled students and that one in ten universities do not have good links with local care agencies and support services.

The Trailblazers also set up a Clearing helpline, to support disabled students and help them avoid the same difficulties they encountered. Kimberley Randle, a Trailblazer who studied at the University of Gloucestershire, said, “I knew that because I am disabled I would have less choice and it would take longer for me to decide on the right university. We hope the report gets universities thinking about how to make their buildings and courses accessible, and that the hotline and guidebook will help other students to make easier, more informed decisions about the university that best suits their needs.”

To join the Trailblazers visit www.muscular-dystrophy.org/trailblazers, email trailblazers@muscular-dystrophy.org or call Bobby Ancil on 020 7803 4807.

Keep your eye out for Bradley

In 1977 a young man with muscular dystrophy called Anthony Dillow was photographed in his wheelchair by eminent British photographer, Lord Snowdon. The image was used in a national poster campaign which achieved iconic status.

Thirty two years on, six-year-old Bradley Addison wheeled his wheelchair along a bumpy path in Kent to recreate the photoshoot, with the original creative director, Peers Carter, and art director and photographer, Tony Muranka. Peers said, “People still talk about the original and it also had a huge impact on me. Snowdon’s photography was incredible; Anthony’s expression really moved me and the advert provoked an overwhelming response from the public. I wanted to revisit it for the modern day and remind people what an important cause this is.”

Bradley’s poster can be seen across the UK from next month. We would like to thank Titan Outdoor for donating the advertising sites and Peers and Tony, who also gave their services for free.

National collection raises £80,000

Thank you to all the volunteers who helped us collect £80,000 for our Tesco Charity of the Year partnership. Nearly 2,000 people collected outside Tesco stores, raising money that will provide specialist equipment for children with muscle disease.
IN AUGUST the All Party Parliamentary Group for Muscular Dystrophy (APPG) launched its first report which raised concerns about the way the NHS plans services for people with muscle disease. Following an in-depth investigation, which heard evidence from people with muscle disease, expert clinicians, researchers and NHS commissioners from across the UK, the APPG published its findings in the Walton Report.

The report, named after one of the Muscular Dystrophy Campaign’s founders, Lord Walton, highlighted the urgent need for NHS Specialised Commissioning Groups to recognise muscular dystrophy as a condition within their remit and to provide adequate services to patients in their region. The report made clear recommendations on what the NHS should do to ensure each child and adult living with muscle disease has access to the services they need:

- Appoint a named person responsible for muscular dystrophy service
- Ensure the Department of Health recognises neuromuscular services as specialised.
- Establish NICE* clinical guidelines for muscular dystrophy.
- Urgently review workforce needs and professional development.

Our Chief Executive, Philip Butcher, was at the launch of the report. He said, “The Muscular Dystrophy Campaign has been urging the Department of Health, ministers and leading NHS officials to improve this situation for a long time. I hope that the Walton Report will help to put pressure on the NHS to start providing the standard of care that these patients so dearly need and deserve.”

Impact in Parliament

The report resonated with the experiences of our local Muscle Groups, who are campaigning for improvements in NHS care in each region of the UK. Caroline Spelman MP met with our West Midlands Muscle Group and, during a debate at Westminster, challenged Health Minister, Ann Keen MP, about the need for specialist multidisciplinary care, she said, “It is totally unacceptable that people with muscular dystrophy are not being offered the full range of care and support that they need. From my many years of experience as a nurse and community nurse before I entered the House, I know the tremendous impact that conditions such as muscular dystrophy can have on patients and their families.

*National Institute for Clinical Excellence
I will not accept excuses that the problem lies with competing priorities or with the availability of resources.”

Chair of the APPG, Dave Anderson MP, intervened in the debate calling for real improvements in services throughout the country and made it clear that the APPG will continue campaigning to make the issue a priority.

Major review in Scotland
In 2008 we published Building on the Foundations in Scotland, a report which illustrated the postcode lottery faced by families who are denied treatment and face major delays in the provision of essential equipment and services. Last September, following our continued lobbying of the Scottish Government, Nicola Sturgeon MSP, Deputy First Minister and Cabinet Secretary for Health and Wellbeing, announced a major neuromuscular services review, she said, “We want to build on the work already done by the Muscular Dystrophy Campaign and the Scottish Muscle Network to take a systematic look at services across Scotland for people living with neuromuscular conditions. The Scottish Government has made funding of £35,000 available to allow the network to take this forward.”

This announcement was welcomed by Scottish families and supporters who had gathered at a lobby of the Scottish Parliament in Edinburgh. Robbie Warner, whose son Eoghan has Duchenne muscular dystrophy, said, “I congratulate Nicola Sturgeon for her Government’s commitment to enhance essential services for families like mine, who live with this devastating condition.

“We’re now calling on the Scottish Government, Health Boards and Councils to build on this commitment and ensure that services urgently improve for patients with rare muscle-wasting diseases.”

Join the fight
If you want to lobby your local health authority for better specialist care, join your local Muscle Group. For details visit www.muscular-dystrophy.org/campaigns, email campaigns@muscular-dystrophy.org or call Alexandra Crampton on 020 7803 2865.
POTENTIAL NEW TREATMENTS could be on the horizon following Professor Kate Bushby’s discovery of a biological process that causes limb girdle muscular dystrophy (LGMD) type 2B, as well as several other conditions all known as dysferlinopathies.

The research, funded by the Muscular Dystrophy Campaign, has identified a new mechanism which causes dysferlinopathies.

The discovery

Professor Bushby’s team showed that a reduction or an absence of the protein dysferlin leads to the development of one of three dysferlinopathy conditions: LGMD type 2B, Miyoshi myopathy, or distal anterior compartment myopathy.

Dysferlin is located in the outside layer of a muscle cell known as the membrane. The membrane separates the inside of the cell from the outside environment and controls what enters and exits the cell. Dysferlin plays a role in repairing the cell membrane after injury, but this study has discovered a much wider role for the protein. Scientists will now be able to target this mechanism in the development of treatments for these conditions.

What does this mean for patients?
The findings of this study will help to increase our understanding of the mechanisms that cause conditions like LGMD type 2B. Following this, researchers can investigate whether white blood cells can be utilised to aid the repair of damaged muscle.

Sharing research worldwide

Muscular dystrophies caused by dysferlin mutations are relatively rare so it is vital that researchers working on the condition in different parts of the world are able to work together to share their results and, in the future, share resources to run clinical trials.

Professor Bushby has been collaborating with scientists in Boston who are investigating Miyoshi myopathy. The Jain Foundation in the USA is a charity that supports research into these conditions and it recently ran a meeting for more than 100 researchers to share their results and promote collaboration in the field. TREAT-NMD, the international neuromuscular research network which the Muscular Dystrophy Campaign is part of, is also planning further collaboration with the Jain Foundation in the future.

The Jain Foundation has a registry of patients with LGMD type 2B and Miyoshi myopathy, both of which can be diagnosed through the
National Commissioning Group (NCG) service in Newcastle. The NCG is commissioned by the NHS and offers a diagnostic and advisory service to all patients in the UK with LGMD. A precise diagnosis is possible in about 70 percent of patients. It is very important that patients with an undiagnosed form of LGMD seek a precise diagnosis. This is because work being done in laboratories all over the world is geared towards trying to develop specific treatments. So by obtaining a precise diagnosis, patients with LGMD increase the potential for future therapies to be developed.

**Limb girdle muscular dystrophies explained**

**What are they?**
LGMD is a group of rare inherited conditions that affect about 1,400 people in the UK. They are characterised by progressive wasting and weakening of muscles, particularly in the large muscles around the tops of the arms and legs.

**What causes them?**
There are around 20 different forms of LGMD, each caused by a fault in a different gene that contains the information for a protein with an essential function in muscles. If a person has a defect in a LGMD gene, then the muscle cannot function properly, causing weakness.

**How is it diagnosed?**
A physical examination, including a muscle strength assessment, can give the doctor a first clue of which muscle groups are affected. However in order to find the genetic defect and identify the faulty LGMD gene a muscle biopsy or a blood sample for DNA testing is generally required.

**Our current commitment to research**
In 2008-09 we invested £1.2 million in research into muscle disease. We funded 27 projects investigating 16 different conditions. To find out more about the research we fund visit www.muscular-dystrophy.org/research
Mary’s legacy

Mary Smith, who had limb girdle muscular dystrophy, left a large legacy to the Muscular Dystrophy Campaign when she died. Her sister Elizabeth remembers her and hopes that such donations will help us to continue the fight against muscle disease.

Elizabeth and her sister Mary shared a lot – their home, their holidays and their support for the Muscular Dystrophy Campaign. The one experience they didn’t have in common was their health. Mary was diagnosed with limb girdle muscular dystrophy in her 20s. Her mobility became worse over time until eventually she had to use a wheelchair to get around, while her sister and brother were free of the condition. “Mary had a great sense of humour and never gave in to her disease. She only packed in doing the ironing a few weeks before she died four years ago, at the age of 68,” remembers Elizabeth. “Life treated Mary cruelly but she was a very positive person and did a lot with her life. She had a successful career as a computer analyst. She also took care of herself on a day-to-day basis. The doctors at Addenbrooke’s Hospital were amazed at how she managed and said that she’d forced them to rethink what having limb girdle muscular dystrophy could mean.”

Both sisters supported the Muscular Dystrophy Campaign over the years. Elizabeth has set up a direct debit to donate each month, while Mary would send in a large amount whenever she received a bonus at work. “Mary’s attitude was that she couldn’t spend the money anywhere else, so she thought it should go where it could do some good,” says Elizabeth. “We hoped that our money would help others in their fight against muscle disease, and even benefit members of our own family in the future. We have had aunts, uncles and a cousin with limb girdle muscular dystrophy, although none as seriously as Mary.”

When she died, Mary left £30,000 to the Muscular Dystrophy Campaign. Elizabeth also plans to leave money to the charity in her will. “Both of us always felt that it’s money we’ve earned and which the Government would only tax or waste! I want to do my bit to help research into this disease. And it’s also my way of remembering Mary.”

If you would like information about leaving a gift in your will, call Sarah West on 020 7803 4834, email giftinyourwill@muscular-dystrophy.org or visit www.muscular-dystrophy.org/giftinyourwill.

If you would like to support us with a regular gift by direct debit, visit www.muscular-dystrophy.org/donate
Rising to the challenge

When Ethan Young, who has facioscapulohumeral muscular dystrophy (FSH), signed up to trek the Sahara in support of the Muscular Dystrophy Campaign, he didn’t realise that it would challenge him to rethink his life and take his career in a completely new direction.

“ In 2007 I was working as an accounts assistant and living with my parents in Denny, Scotland. I needed a challenge so signed up for a fundraising Sahara Trek; there was something about a man in a wheelchair in the middle of a desert that really appealed to me.”

It was a life-changing experience. Meeting the nomads who walk the desert was incredible. They have such happiness without things like houses or cars. It made me rethink what I was doing with my life. I decided against a career in accounting and instead pursued peace and reconciliation work. It’s hard to get work like that unless you have a degree or experience, so I applied to Voluntary Service Overseas and in September 2008 I started its Global Exchange Programme. For the first three months I worked in a Welsh mining village, which had become rundown following the mines closure. After that I spent three months in Rajasthan, India. It was a big thing for the people there to see a white man in a wheelchair. At first the kids would stare and run after me but by the end of my time there I’d built relationships. I could laugh with people, and I could move down the street like a villager. That meant a lot to me.

Since returning from India I have begun working in a long-term volunteer post at a peace and reconciliation centre in Northern Ireland, where I work with former paramilitaries after they leave prison. I help them to build bridges with the community and their own families. Being in a wheelchair can actually help me to do this, as it means I’m not perceived as a physical threat.

My trek in the Sahara helped to teach me that anything is possible if you work hard at it. There’s no point in doing something day in, day out, if it doesn’t make you happy. Just go for what you really want. It’s better to try and to fail than to never attempt it. It’s about bringing the best out of yourself, whatever your abilities.”

If you would like to rise to a challenge like Ethan did, you can find out more on our website: www.muscular-dystrophy.org/events
If you are inspired by Ethan’s story and would like to share your experiences please email donations@muscular-dystrophy.org or call David Pearce on 020 7803 4837
Volunteers

Be a volunteer

Volunteers are an essential part of the Muscular Dystrophy Campaign – without the support of our volunteers we would not be able to do what we do. Thousands of people across the UK give their time to help support our work each and every year. From shaking tins at national collections, making tea and coffee at our events, or talking to the media about our work – volunteers really do make a difference. Last year alone they raised over £1 million for the fight against muscle disease. But it’s not just fundraising, volunteers also contribute to our publications, campaign for improved services and help out at our head office. Thank you to everyone who supports us in this way.

Volunteer of the Year – Nicola Geraghty

Nicola Geraghty is from Manchester. She has two nephews who have Duchenne muscular dystrophy – 11-year-old Damon and seven-year-old Ben. The boys live with Nicola’s mum and dad while their own home is being adapted for their needs.

Nicola visits her nephews on a daily basis to help care for them and ease the load as much as she can, despite working long hours as a nurse. Not only does Nicola offer amazing care and support for others, she also one of the Muscular Dystrophy Campaign’s many committed fundraisers and campaigners.

Nicola has completed two indoor abseils as well as sung at a local Christmas event and helped out with collections.

She is now running a new North Manchester fundraising group. They are organising special events as well as collection days and so far have raised over £3,000. As you can imagine, this takes up a great deal of her time and energy.

Sue Barker, the charity’s president, recognised our fantastic volunteers and the role they play when she presented Nicola with the Volunteer of the Year award at our National Conference. She said, “Nicola is passionate about the Muscular Dystrophy Campaign. Her enthusiasm and commitment are infectious and she motivates so many others to support our cause.”

Volunteer with us

If you want to find out more about how you can volunteer visit www.muscular-dystrophy.org/volunteer, email volunteer@muscular-dystrophy.org or call Laura White on 020 7803 4823
The 2009 President’s Awards

IN SEPTEMBER our President, Sue Barker MBE, was joined by hundreds of supporters in Bradford for our annual National Conference. Sue shared the stage with expert speakers from the charity who updated attendees on research developments, campaigning work and care projects.

Sue was there to recognise the achievements of 13 inspirational children and adults who picked up this year’s coveted President’s Awards. Sue said, “These awards are very special as they are only given to people who have been nominated by others for their outstanding achievements. The winners are all a genuine inspiration to those around them and have made outstanding contributions to the lives of those affected by muscular dystrophy. I feel privileged to be able to meet them.”

Play golf from dawn to dusk

We are once again challenging golfers to play four courses in one day as part of our Four Course Classic golf challenge. This exciting event was launched in 2009 and has already raised nearly £20,000 for the Muscular Dystrophy Campaign. This year hundreds of golf courses from around the country have already signed up to help make this the biggest golf challenge in the UK but we still need more people to join as players. Sign up for the challenge of playing four different courses in your area and we will support you with four complimentary tee-times, a golf kit and a comprehensive fundraising and preparation pack.

To sign up for the Four Course Classic visit www.muscular-dystrophy.org/golf, email events@muscular-dystrophy.org or call David Boorman on 020 7803 4827

Our 2010 conference will be held at the Birmingham Hilton Metropole on Saturday 18 September. For more information email info@muscular-dystrophy.org or call Maureen Winslade on 020 7803 4804

Sue meets Tesco fundraisers Dave Green and Glenn Jefferys at the conference as they set out on a sponsored cycle from Bradford to Daventry

BBC Sport’s Rob Bonnet and friends on the green
Our brand new eCard section is now live on our website, so why not save a tree or two this Valentine’s day by sending you sweetheart a personalised eCard.

You can draw your own, send a ready made card or even upload your own photographs and send them – the perfect way to let that someone special know you care. And it’s not just Valentine’s – you can send eCards on birthdays, Easter, Mother’s Day or any other occasion.

To send an eCard visit www.muscular-dystrophy.org/ecards

Support us at Tesco

Our Tesco Charity of the Year partnership continues until February 2010 and there are several ways for you to support it in store:

Gift cards
Six-year-old Bradley Addison from Birmingham, who has Duchenne muscular dystrophy, designed a playground picture Gift Card. For every one of Bradley’s £10 Gift Cards sold Tesco donates 50p to the charity. We hope that this will raise £20,000.

Visit the cash point
Every time a cash machine at Tesco is used during the partnership we receive a donation from Tesco bank. You don’t even need to get any money out; just checking your balance will help us to reach our goal of raising £50,000 from cash machines.

Adnams Lighthouse beer
Suffolk brewer Adnams has generously agreed to donate 10p for every bottle of Lighthouse pale ale sold in store – a gesture matched by Tesco that is expected to raise at least £20,000.

Say it with flowers
If you are bit more of a traditionalist and prefer to send flowers this Valentine’s, then you can order a beautiful bouquet from Charity Flowers. We will receive a 15 percent donation at no cost to you when you quote ‘MDC’ with your order.

To send flowers to your loved one call 0870 5300 600 or visit www.charityflowers.co.uk

Contact us at: 61 Southwark Street, London SE1 0HL
020 7803 4837
donations@muscular-dystrophy.org

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