Working with schools
fundraising, awareness and support
WELCOME to this winter’s Campaign. It has been another busy few months for the Muscular Dystrophy Campaign, as I saw for myself at our National Conference in September. I was pleased to be able to recognise the achievements of some of our most inspiring supporters – including Zoe Hallam, whose story is on page eight.

In this issue you can read about some of the vital projects we have invested in that provide practical advice and support for people living with muscle disease, including the new Adult Self-Management packs and the ever-popular Family Weekends. Like much of our work, these projects are about empowering people with the knowledge they need to live more independent lives.

Be sure to read the research update on page six. This explains some of the science behind one of the most promising research projects we support – the “exon skipping” clinical trial.

We also continue to raise awareness of muscle disease. On page 10 you can read about the launch of this year’s Young Pavement Artist Competition, which was marked by the creation of an enormous piece of pavement art at the Natural History Museum.

Thank you once again for your generous support – your donations allow us to commit to projects that support thousands of people living with muscle disease across the UK.

Thank you

Sue Barker MBE
President, Muscular Dystrophy Campaign

Back wax fundraiser

Muscular Dystrophy Campaign supporter Dario Persechino is now one smooth fundraiser following a sponsored back wax to raise funds for the charity. Dario was fundraising in memory of his cousin who died from a form of muscle disease. Having already raised nearly £3,000 on the 2007 Sahara Trek, he came up with this creative fundraising idea.

“Being that I’m a little on the furry side, my friends have been threatening to tie me down and wax me for years. So I thought I’d finally give them the chance to see me in pain and at the same time clear their consciences by donating to a fantastic charity which does amazing work.”
Building on the success of our event which supported people with muscle disease in Northern Ireland, we were pleased to launch a series of Family Weekends this year. These events combine families getting together with the provision and exchange of information in a relaxed environment and have proved an invaluable form of support for families affected by muscle disease.

In September, we held a Family Weekend at the Calvert Trust in Kielder, Northumberland, which was attended by 13 families. Thirty two children, parents and family members joined members of staff who spoke on a range of topics including research, care, communicating with your child and how to get involved in campaigning and fundraising.

It is difficult to imagine the true worth of such an event unless you have experienced it yourself. Although it was a hugely successful weekend, as we received excellent feedback from adults and children. What one 11-year-old liked best about the event was, “Learning more about what life will be like for my brother when he gets older and knowing that he will still be able to do activities with me.”

Adult Self-Management packs

In July the Muscular Dystrophy Campaign was delighted to publish our Adult Self-Management pack as part of our ongoing commitment to free expert information. We developed this resource for people who live with muscle disease to enable them to live as independently as possible.

The pack is a groundbreaking toolkit for people with muscle disease, which contains 36 factsheets, covering topics from exercise to hospital admission to holidays, along with a diary and a medical alert card. We have already distributed 1,000 of the free packs to people who have developed a muscle disease in adulthood. We know that there are still more people to reach, so if you know someone who would benefit from this information, please ask them to get in touch with our Support Services team on 0800 652 6352.

Thank you to Virgin Atlantic

The Muscular Dystrophy Campaign was part of Virgin Atlantic’s Change for Children appeal during April and May last year, during which time passengers donated over £90,000 in foreign currency. Virgin has turned those donations back into pounds to be spent on grants for specialist equipment for children with muscle disease. 67 grants have already been issued for equipment such as electric beds, adapted computers and other portable aids.
The State of the Nation – campaigning for better services

THE MUSCULAR DYSTROPHY CAMPAIGN published its first national patient survey in September. The State of the Nation report revealed shocking evidence that many patients are losing out by being denied essential health and social care services. We can reveal:

- Half of patients have no access to a specialist neuromuscular consultant.
- Half of patients had to fund their wheelchair out of their own pocket or by a charity.
- Three out of four families experience financial hardship.
- Three out of four carers lack any access to respite care, such as a hospice or care home.

“For some families, access to specialist care can be a matter of life or death. Their plight is made worse by the delays and variations in the provision of equipment and the barriers that exist to living independently,” said Philip Butcher, Chief Executive of the Muscular Dystrophy Campaign. “The Government must act to establish a specialist neuromuscular service, available nationally, in response to this situation. The time for talking is over. Action is needed now.”

These revelations hit home with Shadow Secretary of State for Health Norman Lamb MP, who said, “Today’s report reveals the shocking lengths families are forced to go to just to get the care they need. Despite the Government’s commitments to ensuring patients with chronic conditions can access the right care and support, it is clear from today’s report that this simply isn’t happening for thousands of families across the UK.”

The report voiced the experiences of almost 1,000 people living with muscle disease. People like Sharon Kitcher, whose son James has Duchenne muscular dystrophy, took part in a number of interviews for news journalists when the report was launched. She said: “It was fantastic to see muscular dystrophy in the news. By working together, families have a louder voice, with the opportunity to make real changes.”
MICHAELA HOLLYWOOD, 18, is the Northern Ireland representative for our Young Campaigns Network, Trailblazers. She has spinal muscular atrophy, uses a powered wheelchair and depends on others for her care needs. Michaela’s ambition is to study genetics at university and needs A-level Chemistry to do so. She was delighted then to attain nine GCSE grades A to C, with a double A in Double Award Science in August 2007.

Michaela and her parents researched and found a school which was wheelchair accessible, had toilet facilities for disabled people and offered the A-level subjects she needed. After a positive response from the school the family believed that Michaela would be able to start her A-level studies in September 2007. They were then taken aback to receive a phone call the next day to explain that Michaela should have undergone a separate and lengthy assessment procedure through the South Eastern Education and Library Board (SEELB) for admission to the school. Michaela’s parents believed that if she did not have a disability, she would have been accepted immediately.

As a Trailblazer Michaela knew the power of campaigning as a way to get her voice heard. When she informed the Muscular Dystrophy Campaign we approached the Equality Commission to help challenge the SEELB’s failure to facilitate Michaela’s transfer to A-level education. The SEELB is now ensuring A-level Chemistry teaching and the appropriate facilities will be available for Michaela at the school.

Michaela said, “I am so glad that this has been settled and I’m now looking forward to starting the Chemistry course. My mum and dad have pushed really hard to help me fulfill my ambitions, and I am just so grateful to them.”

The Muscular Dystrophy Campaign is delighted with the outcome for Michaela. However, we believe it is unacceptable that disabled students should have to go to these lengths just to be able to study the subjects they choose. We continue to campaign on this issue on behalf of people like Michaela.
OVER THE LAST 50 YEARS the Muscular Dystrophy Campaign has played a leading role in supporting research into Duchenne muscular dystrophy by investing over £10 million. Last year the MDEX Consortium began a clinical trial into a gene therapy using “molecular patches” in boys with Duchenne. This means that for the first time results from this type of research are close to being translated into a treatment.

What is the MDEX consortium?
The MDEX Consortium is a multidisciplinary enterprise put together by the Muscular Dystrophy Campaign in conjunction with other charities and led by Professor Francesco Muntoni. The consortium was formed in 2004 with funding secured from the Department of Health and is made up of expert scientists and clinicians, who have joined forces to test this new gene therapy which might halt the progressive muscle weakness in boys with Duchenne muscular dystrophy. The Muscular Dystrophy Campaign is proud to play a vital role in the formation of this scientific consortium, supporting the preclinical work with more than £500,000. Our hopes are high that the outcome of this clinical study will produce positive results, leading to a treatment that will improve the quality of life for many boys with Duchenne.

Why use a “patch”?
Duchenne is caused by a mutation or error in the gene that carries information needed for the production of an essential muscle protein called dystrophin. This mutation can be a missing part of the gene or a change in a single building block of the DNA. The mutation can prevent the information stored in the gene from being retrieved, which means that none of the vital dystrophin protein is produced.

The “patch” technology uses short fragments of DNA which bind to the gene. The body’s “protein production machinery” then ignores this region, a procedure known as exon skipping. This process allows a smaller but functioning dystrophin protein to be produced. The patch will not work for all boys with Duchenne, but depending on the type they have we hope it will work for the majority.
Our current commitment to research

The Muscular Dystrophy Campaign currently funds 30 research projects investigating 16 types of muscle disease. This amounts to almost £1.5 million invested in world-class research in the last year.

Research update

Professor Dominic Wells explains his role in the “molecular patch” trial

What is your work focused on?
Previous experiments have shown that an injection into the muscle is very efficient at restoring the production of dystrophin and improving the muscle physiology, but delivery to all the muscles via the bloodstream requires multiple treatments at high doses. My laboratory is working towards developing methods to increase efficiency and therefore reduce the dose and perhaps the number of treatments required for body-wide treatment.

At what stage is the trial?
In phase I we are testing safety as the main priority, with evidence of successful production of dystrophin as a secondary end point. We have treated the first two patients with an injection into a foot muscle and have seen no evidence of any adverse effects.

What will happen next?
Phase II of this trial will tell us whether this approach is safe and effective in humans. We plan to follow this trial immediately with a second clinical trial to test the safety and success of delivering the drug to all muscles in the body using repeated injections.

Voice from the Lab

A. The part of the gene that carries information for proteins are called exons. During the retrieval of this information the exons join together and the information is translated into a protein, in this case dystrophin.
B. A mutation can prevent the information from being retrieved, causing the production of dystrophin to stop.
C. The patch is designed to bind to a specific exon in a gene that carries the mutation. The exon is then ignored during protein production – “exon skipping”. As a result a smaller partially functional dystrophin protein is produced.
ZOE WAS JUST ONE RECIPIENT of The President’s Awards at this year’s National Conference. Sue Barker presents these awards each year to recognise the efforts of some of our valued supporters.

Zoe is 17 and has limb girdle muscular dystrophy. She uses a powered wheelchair and requires help with most day-to-day tasks. However, as she says, the ‘arms and legs that don’t work properly’ have never daunted her irrepressible spirit. She achieved eight A starred and four As at GCSE and has gained five As at A-level. Last year she was offered a place at St Johns College, Oxford to read Politics, Philosophy and Economics which she started in October. She says she is perhaps the first disabled Prime Minister in the making!

Out of school Zoe loves music and, along with four friends, she plays keyboard and sings. Perhaps a bit wobbly when standing at the keyboard, but still very much live on stage.

She loves having a laugh with her friends and hates being patronised or considered stupid because she uses a wheelchair. She is now enjoying life in Oxford, making good use of her drive-from-wheelchair car and feelingly properly independent.

According to her family, the best part about Zoe is her zest for life – when she comes into a room her smile and laughter are infectious. She always lifts people’s spirits and never seems depressed – never moans or grumbles, never shows any self-pity.

Zoe is someone who has been a genuine inspiration to all her family and friends, and everyone who meets her. This is why she was recognised by Sue Barker in this year’s President’s Awards as our Young Person of 2008.
Stephen Liney is 22 and has Becker muscular dystrophy and is a volunteer for our young campaigner’s network – Trailblazers. Below is an exert from Stephen’s Trailblazers blog.

“Before October 2008 I had been looking for work but found not much luck in doing so, this made me feel quite down. I’d spent a couple of years dwelling on the fact I have muscular dystrophy, in fact most of the time I was worrying what people thought of the way I walk and just not being open about the issue. I finally got the courage in October to change my point of view so I contacted the Muscular Dystrophy Campaign head office to see what guidance I could get. This was a very useful thing as we arranged a time and date to start my work experience.

My first day in the office wasn’t a bad experience as everybody was (and still are) friendly which helped me fit in. Also I met James, another Trailblazer, who has a similar condition to myself. This happened to be the first time I had met somebody who had experienced issues that I could relate to which gave me a confidence boost.

I have been helping out at the head office and I’ve given a few ideas of how to raise awareness to the various teams, which I hope to put in place in 2009. I’ve also called up people from around the country to recruit them as Trailblazers. Since I started volunteering here I’ve found the whole thing an enjoyable experience and I’m looking forward to the future.

Next year I will be leading the Trailblazers south east region and going out and doing research in to the state of support and facilities for disabled people on public transport. As far as my work experience is concerned I will be working with the Joseph Patrick Trust and learning new IT skills. I can’t wait!

For more information about the Trailblazers visit www.muscular-dystrophy.org/trailblazers
WITH AGE CATEGORIES ranging from four all the way up to 19 years of age, this year’s Young Pavement Artists Competition will get kids of all ages raising money and awareness of muscle disease.

Our Young Pavement Artists Competition launched at a fantastic event at the Natural History Museum on 23 September. Children from local schools, along with special guest artists Olly & Suzi and Supermundane, created artworks on the floor of the exhibition room, giving an exciting glimpse into the quality of entries to come.

This year’s theme is endangered species. Children can raise vital funds for the Muscular Dystrophy Campaign by drawing any threatened animal. The winner of the competition will win a family expedition to see the grey whale migrate in Canada.

The competition is open to all schools, community groups and youth clubs. We’re hoping that 25,000 children will take part – so if you know a budding young artist who would love to get chalking, why not get their school or youth club involved? You can hold an event anytime up to 13 June 2009.

There are fabulous prizes for winners in all five age categories and they will also get the chance to meet a host of celebrity supporters at the awards ceremony in July. As well as receiving the family expedition, the winner will also receive a year’s free subscription to National Geographic Kids magazine and get their drawing made into a giant National Geographic Kids poster!

To enter register online at www.muscular-dystrophy.org/pavementart or call 01225 354286 for a competition pack.

Schools Network
As well as raising awareness we also support schools that have pupils with muscle disease via our Schools Network. It provides specialist information and training days so schools can get the guidance they need to effectively support their pupils. More information is available from our Support Services Team on 0800 652 6352.
The Muscular Dystrophy Campaign is calling on golfers to tee off together for our ultimate golf challenge in June 2009. You can take part in a once-in-a-lifetime attempt to play 20 million yards of golf in one day, get the chance to play different courses and challenge yourself, all while raising money for the fight against muscle disease.

If you’re mad about golf, or know someone who plays regularly, we’d love you to help us make this the biggest golf day ever. For an information pack about how to get involved contact the events team today on 020 7803 4827 or email events@muscular-dystrophy.org.

Walk in the footsteps of Olympic Champions in China
We are looking for volunteers to follow in the footsteps of Team GB and head east to China. To enter you pay £200 to register and then pledge to raise £2,650 to join Team Muscular Dystrophy Campaign, and walk a spectacular section of the Great Wall of China from 20 – 28 March 2010. Our trek guides have selected a region of the Wall that is beyond the regular tourist trail and a route that has been travelled by only a handful of tourists over the past 100 years. For more information on this expedition of a lifetime, please email events@muscular-dystrophy.org.

Ada Maddocks’ legacy
Ada Maddocks died in March 2007 leaving a legacy of almost £80,000 to the Muscular Dystrophy Campaign. Ada's connection with the charity was a family one – her nephew’s son, James, had a form of muscular dystrophy and died in 1993. During her lifetime she was President of the Trades Union Congress. Here she is remembered by her nephew Patrick Hoban.

“My aunt had some amazing professional achievements, but that wasn’t the side we saw of her. She didn’t have a husband or children of her own, so Ada was like a second mother to me. My mum, Margaret, was her sister. Ada would often visit us in the Kent village where we lived. I even stayed with her for a while, when I was studying at university.”

At Ada’s funeral, the church was filled with people whom she had inspired in some way, either by fighting for their rights as a trade unionist, or campaigning on their behalf as a charity supporter, enjoying time with them as friends, or simply being a member of a large and loving family. The Muscular Dystrophy Campaign is incredibly grateful for her gift to us.
Search online – the Everyclick Charity Challenge

If you search the internet you could raise funds for the Muscular Dystrophy Campaign at no cost to you as well as help us win the Everyclick charity challenge. Everyclick is a search engine, like Google, with a difference because it donates its profits to charity. To promote this service it is running a charity challenge – the charity that gets the most of its supporters using Everyclick wins a free nationwide advertising campaign at 1,500 locations across the UK. You can get searching with Everyclick here: www.everyclick.com/musculardystrophycampaign

Shop online to fight muscle disease

If you are thinking of surprising your loved one with a bouquet of flowers this Valentines Day, you can order through Charity Flowers and the Muscular Dystrophy Campaign will receive a donation of 15% of whatever you spend at no cost to you. All you need to do is quote ‘MDC’ when you order. To order call 0870 5300 600 or visit www.charityflowers.co.uk.

Valentines Day

There are hundreds of well known retailers who will make a donation to the Muscular Dystrophy Campaign when you shop online via our webshop. Whether you want a pair of socks or a new TV, we will benefit with a donation to support the fight against muscle disease at no cost to you. You can find out the full details online: www.buy.at/musculardystrophycampaign

Donate through eBay

The Muscular Dystrophy Campaign and eBay have joined forces to bring you a unique way to help raise funds for our vital work. Now when you sell an item on eBay, you can choose to donate a percentage of the sale to your favourite charity. Full details of this fun way to support us are at www.ebay.co.uk/ebay-for-charity.

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

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