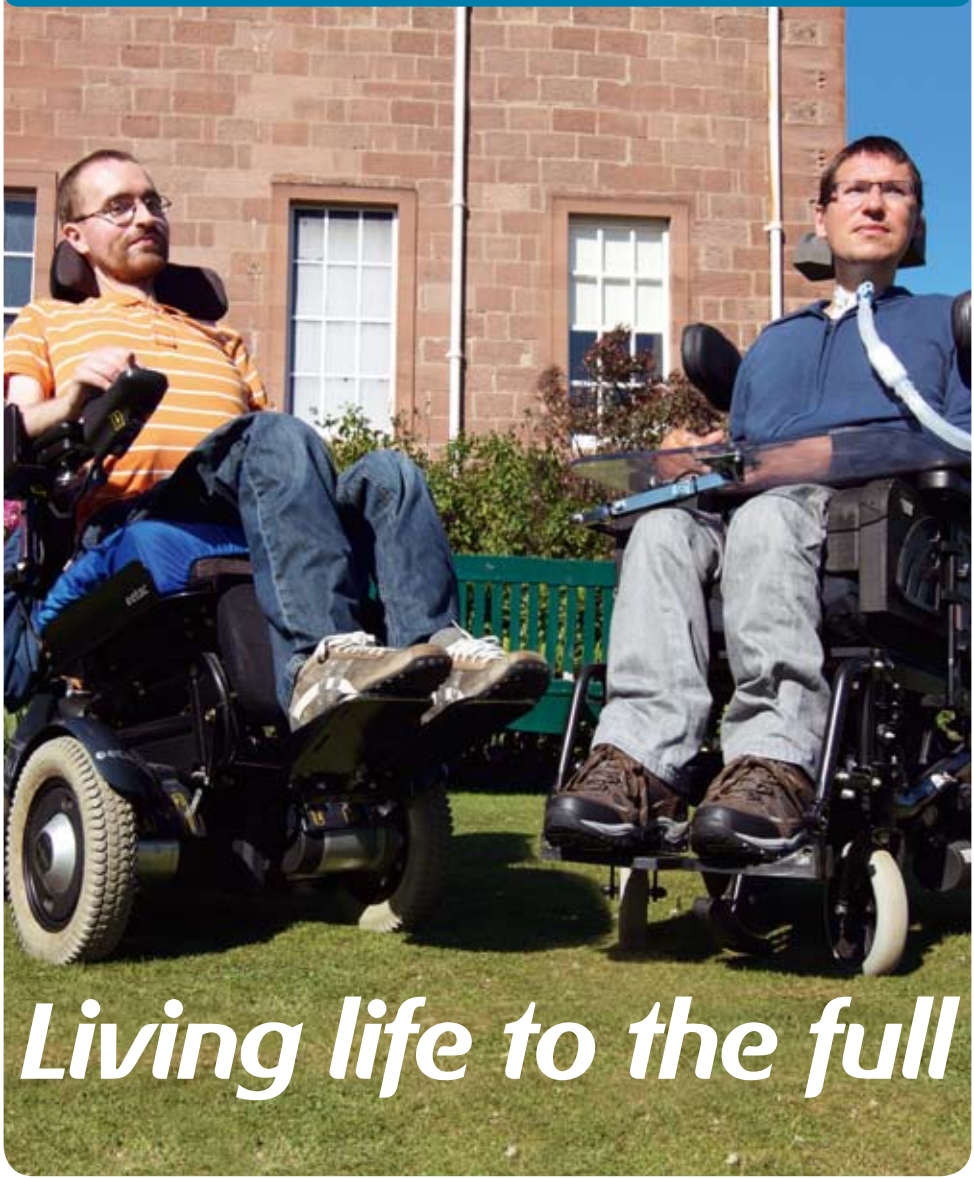
Campaign

Muscular Dystrophy Campaign

The newsletter for our supporters **Autumn 2011**



Living life to the full

www.muscular-dystrophy.org **020 7803 4800**

WELCOME to the autumn issue of *Campaign* – now coming to you three times a year with all the successes and developments from the Muscular Dystrophy Campaign. And it is thanks to the generous support of people like you that the charity is able to continue funding exciting new research; read about the clinical trials into the next generation of 'exon skipping' featured on page six and seven.

I was really pleased to see Chloe Ball-Hopkins take her place on centre court for the coin toss at the Ladies' Singles Final at this year's Wimbledon. Chloe is a wonderful ambassador for the charity and an inspiration to young people everywhere. You can hear from Chloe about the experience on page 11.

In this issue we also bring you news of Jon Hastie's exciting film-making venture, as well as news of our own *Trailblazers'* cinema report. We share news of some fantastic fundraising feats, such as Moira Crichton's trek of the Inca Trail or Ross Sylvester's three marathons in three days. Some of our staff members have also been working hard to raise funds for us; read all about their efforts on page nine.

Don't forget to book for our national and Scottish conferences coming up in October and, as always, read of the many and varied ways in which your support is helping us to continue our vital work in fighting muscle-wasting disease throughout the UK.

Thank you for your continued and valued support of our work.

Sue Barker MBE
President, Muscular Dystrophy Campaign

Riding into the sunset

In May, four self-confessed 'crazy bikers' from Bristol took on the formidable Sahara desert in the name of fundraising for the Muscular Dystrophy Campaign.

Matt Fox and his three friends Geoff, Paul and 'Pirate' spent three weeks in the saddles of their dual sport motorbikes (from Bristol to Morocco) covering an impressive 8,000 miles in the searing heat of the day and below freezing temperatures at night.

Matt, whose wife Liz is a manifesting carrier of Duchenne muscular dystrophy, wanted to set himself a physical and emotional challenge that would raise awareness and funds for the charity that is close to their hearts.

‘Working together’ to fight muscle-wasting disease

Tickets are available now for ‘Working together’, our 2011 conferences that boast a great line-up of speakers and a variety of exciting workshops. There is bound to be something for everyone.

Our National Conference will be held in Nottingham on Saturday 15 October and the Scottish Conference will be held in Glasgow on 1 October, so book now to save your place.

We will focus on research with a workshop and session on translational research, where families will learn how research is being taken from the bench to the bedside.

There will be updates from our young campaigners, the *Trailblazers*, our fundraisers, as well as our care and campaigns teams. And of course our President’s Awards will recognise the outstanding contribution supporters have made to the charity over the past year.

For all information on either the national or Scottish conference please call Maureen Winslade on **020 7803 4804** or email **2011conference@muscular-dystrophy.org**

Rolling out the laughter

Fresh from sell-out success at the Edinburgh festival, critically-acclaimed comedy actress Natasha Wood is putting herself and her individual style of humour to great use by performing her one-woman play in aid of the Muscular Dystrophy Campaign.

Natasha, who has spinal muscular atrophy, says the play, aptly titled *Rolling with Laughter*, offers her humorous and unique take on life, lingerie and sex with a little disability thrown in that will make you cry a little and laugh a lot!

Rolling with Laughter will be performed at The Hawth Theatre, Crawley on Monday 14 November 2011 at 8pm.

To find out more visit **www.muscular-dystrophy.org/rollingwithlaughter** You can book tickets through the box office on **01293 553636**.

Award for ‘committed campaigner’

Sulamain Khan, *Trailblazers* London Ambassador, has received a prestigious national volunteering award for his committed and imaginative work campaigning for the rights of young disabled people.

Sulaiman received his award at a gala event held in London in front of the regional award winners, celebrities and special guest including Baroness Tanni Grey-Thompson.

Sulaiman was elated to receive the award, saying, “I am grateful and ecstatic for being honoured for campaigning for an issue that is close to my heart and circumstances.”

Organisers of the national awards said Sulaiman is a ‘passionate, committed and innovative campaigner for the rights of young disabled people’.

NHS wastes £31 million

IN MAY the Muscular Dystrophy Campaign published a report showing that the NHS wastes £31 million a year on unplanned emergency hospital admissions for people with muscle-wasting disease. The charity believes this is a direct result of a failure to invest adequately in ongoing treatment to manage the conditions and called for a full national audit of emergency care for people with muscle-wasting disease.

The report was presented in Parliament to Health Minister Paul Burstow MP by more than 100 patients, family members and expert clinicians. For many families it was a unique opportunity not only to meet their local MPs but also to have their voices heard in Westminster. They are campaigning with the Muscular Dystrophy Campaign for the NHS to invest in adequate specialist support across the UK in order to dramatically reduce unnecessary hospital admissions and bring an end to the postcode lottery of care that exists.

Lorraine Thompson from Stoke-on-Trent, whose son Raymond, 24, has Duchenne muscular dystrophy says, "Raymond desperately needs physiotherapy. We keep asking for it but at the moment patients in our area can't get it long-term. For muscle-wasting disease patients, if you don't use your muscles, you lose them – it's as simple as that. His condition affects his heart, his lungs and his digestive system. I have no doubt that time with a specialist physiotherapist would help keep him out of hospital."

The Muscular Dystrophy Campaign's report, *Invest to Save: Improving services and reducing costs*, follows major reviews of specialist neuromuscular care in Scotland, Wales and England, where services were criticised as 'inadequate and unacceptable' and is backed by a group of leading clinicians. The charity believes that investing as little at £65 per patient in frontline health services and equipment each year would significantly reduce critical care on hospital wards which are costing the NHS up to

a year

Guests at the Invest to Save reception

£1,925 per patient per day.

"The NHS cannot afford not to invest in muscle-wasting disease care – the cost of doing nothing is far greater. Not only are there concrete and substantial savings to be made and hospital beds to be freed up, but we have the opportunity both to improve quality of life and avoid the overwhelming distress caused by having a partner or family member rushed onto an emergency ward," said Robert Meadowcroft, Chief Executive of the Muscular Dystrophy Campaign.

Lights, camera, access!

A hundred young *Trailblazers* recently went undercover to investigate disabled access to cinemas throughout the UK. While paying the same as any other customers, they found that many major cinema venues across the country offer second-class service to disabled movie-goers.

They also found that many of the worst access and service problems for disabled customers occurred at branches of major UK cinemas, while smaller chain and independent venues fared comparatively well.

Although the *Trailblazers* praised many cinemas – both chain-operated and independent – they found that physical access issues, poor staff training and poorly thought-out support at some venues were unacceptable for paying customers, and needed to be addressed. They have now produced a charter laying out the standards that disabled cinema-goers should be able to expect of cinema operators, and are calling for exhibitors to commit towards this benchmark.

They have also launched a petition, in support of the campaign, which they will present at Westminster in October.

Visit **www.muscular-dystrophy.org/cinema** to sign the petition.

Duchenne research

Groundbreaking research advances you are helping to fund into Duchenne muscular dystrophy are giving hope to families living with the devastating muscle-wasting disease.

Research funded by the charity into Duchenne muscular dystrophy could bring effective treatments with the trial of a new generation of 'exon skipping' drugs, and bring less invasive techniques to the fore for assessing boys with the muscle-wasting disease.

Groundbreaking research brings renewed hope

Some promising research into a new generation of 'exon skipping molecular patches' has shown them to be more than 10 times more effective in mice than current patches, with the capacity to penetrate the heart muscles better and produce dystrophin there.

Boys born with Duchenne muscular dystrophy are missing the protein dystrophin that protects the muscles from damage. Recent clinical trials have shown that injecting a molecular patch into the blood stream or under the skin resulted in the production of dystrophin in the muscles.

Unfortunately, based on previous research in the laboratory, it is not expected to be very effective at treating the heart muscles.

Dr Wood's team at the University of Oxford has developed a new generation of molecular patches and has shown in an animal model of Duchenne muscular dystrophy that they can penetrate and produce dystrophin in the heart muscles. The patches are currently being tested in these mice in Dr Wood's laboratory to determine dosage and long-term effects on the heart and muscles, in time for the clinical trial to begin in 2013.

Research funded by the Muscular Dystrophy Campaign has been vital for a successful bid to the Wellcome Trust who will now provide £2.5 million to conduct the clinical trial.

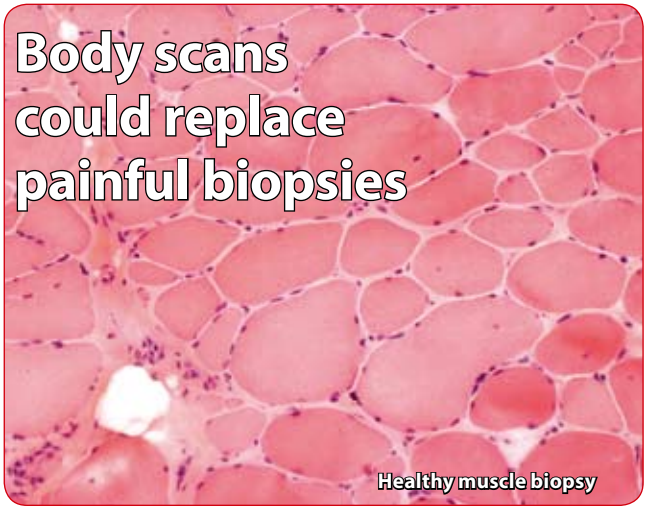
For boys living with Duchenne muscular dystrophy, this potential treatment could halt or slow the progression of symptoms of the disease. The hope is also that, if given to boys at an early age, it will prevent muscle-wasting in the first place.

Our commitment to research

Research remains our first priority and this year we invested almost £1 million to fund 24 research projects covering 16 different forms of muscle-wasting disease

round-up

Body scans could replace painful biopsies


Healthy muscle biopsy

Researchers at the Dubowitz Neuromuscular Centres in London and Newcastle have shown that a non-invasive full-body imaging technique known as an MRI scan is a reliable way of assessing the muscles and could replace some of the invasive and painful muscle biopsies currently being used in clinical trials for Duchenne muscular dystrophy.

The research team, led by Professor Francesco Muntoni, compared MRI scans to muscle biopsies and showed the MRI scan accurately reflected the biopsy result in terms of the amount of muscle degeneration.

This is welcome news for parents and patients alike as muscle biopsies are not only painful, but they provide only a tiny snapshot of what is happening in the whole body. There is also always the danger that the muscle selected to biopsy is not healthy enough to be of value, so more than one biopsy can be required to get a good sample.

"My son, Liam, had his biopsy at aged two and half, under general anaesthetic and he still has the scar today. An MRI scan would have been less invasive and with no painful memory or scar. Boys with this condition have enough challenges to deal with every day, without having to deal with painful muscle biopsies too," said Joanne Ashton.

Top researchers call for newborn screening

As a result of research into potential treatments, national newborn screening for Duchenne muscular dystrophy could be on the horizon, according to Professor Dame Kay Davies, who is calling on the NHS to commit to a plan to introduce it within the next three years.

Professor Dame Kay Davies from the University of Oxford believes an NHS screening programme is essential to identify babies as early as possible so that they can benefit from potential therapies – including 'exon skipping' – currently in clinical trial, that could slow or even halt the progression of the disease.

Our Director of Research, Dr Marita Pohlschmidt, says her team is working with clinicians and researchers – including Professor Davies – to ensure that patients' needs and preferences are central to discussions on the implementation of any new screening programme.

Never give in, never give up

EARLIER THIS YEAR one of our *Trailblazer*'s Jon Hastie, 30, embarked on the journey of a lifetime to produce a documentary sharing his life and the lives of young men with Duchenne muscular dystrophy, and he is appealing for donations to continue to fund the project.

The film, *A Life Worth Living*, follows Jon on a journey around the UK and Europe to meet six extraordinary young men, documenting their lives and how they 'push the limits' of their capabilities living with Duchenne muscular dystrophy.

"I want to inspire a younger Duchenne generation and their parents, by showing them just what can be achieved even under the most crippling of disabilities," Jon said.

Take 40 year old Mark Chapman from Edinburgh, who lives independently and has a full and active life socialising with family and friends. He regularly visits the cinema, theatre and art galleries, walks (or rolls) in the countryside,

Jon with his PA, Jan

and enjoys keeping an aquarium and looking after his cat, Winston.

"Good food is a passion, I love coming up with tasty recipes to cook. I also spend hours on my computer doing administration, graphic design and using the internet (especially Facebook and eBay!).

"Establishing my own life with choice and control is perhaps my main achievement. Like many disabled people, gaining my independence was one of the most significant parts of transition into adulthood. There are of course other achievements along the way but I doubt very little would have also happened without being independent," says Mark.

Jon hopes the documentary will challenge misconceptions and inspire others. "I want to tell the world, especially the Duchenne world, not to give up hope and to live life to the full. I had mentors and shining personalities who inspired me when I was younger and now I really want to encourage others by leaving a supportive, heartfelt message behind: **Never give in. Never give up**. It's time that story was told," he said.

* To read the interviews in full, visit our website **www.muscular-dystrophy.org/yourstories** or you can also read more about Jon's progress on the film and donate money to help complete his documentary at **www.alifeworthlivingfilm.com**

Truly a team effort

When Jonathan Kingsley, 27, awoke at 6am on Friday 24 June 2011, he headed for the Golf Course instead of the office, where he works in our campaigns team at the Muscular Dystrophy Campaign, to take part in the charity's Four Course Classic.

"I regularly meet and work alongside people living with muscle-wasting disease so I wanted to give up a day of my annual leave to raise money that I know will benefit the families we work with," he said.

Jonathan is not alone; there is now stiff competition among staff and departments to take part in events and raise funds for the charity.

Anna Porcherot, who works in the fundraising team at the charity, recently swam a mile in open water in the freezing waters of Cornwall to raise £2,000. "It's great to be able to raise money for research into treatments and cures for muscular dystrophy as there is a possibility one will be found in my lifetime. Having Limb Girdle muscular dystrophy means that I find a lot of sporting activities difficult, so the sense of achievement when I finished was amazing."

Creating a splash in a completely different way were Charles Horton, Sara Benson and Gary Kernahan, who took part in a dragon boat race in Salford in July.

Other worthy mentions from staff this year include Marc Casey who ran not one but two marathons in April, Jen Taylor and Alun Mainwaring who completed the London triathlon; Bobby Ancil and Nic Bungay in the London Marathon and Charlotte Slade in the British 10k.

* If you need inspiration for a fundraising event you can participate in visit **www.muscular-dystrophy.org/events**

Mastering Machu Picchu

Congratulations and a big round of thank yous to our 19 intrepid fundraisers who braved scorching hot days and frozen nights, trekking 15 hours a day in the spectacular Andes and raising an impressive £75,000 for the charity.

The group faced altitude sickness and physical and mental exhaustion to reach the lost city of Machu Picchu, but say the trip was 'overwhelming in scenery, absolutely glorious in nature, with memories that will stay with me forever'.

Moira Crichton says, "In realising my long-held dream to trek the Inca Trail to Machu Picchu, it's been a privilege to do it in support of the Muscular Dystrophy Campaign. Thank you for the experience of a lifetime!"

Charity trek leader Alun Mainwaring said the group were not only great fundraisers but great people and he too extended a personal thank you to them and their sponsors who helped to raise such a tremendous amount of money to help fund the charity's work in research, campaigning, care and information.

Three marathons, three days

Supporter Ross Sylvester completed a gruelling three day running challenge in March, totalling over 78 miles across Dorset, raising over £2,000. Here are some excerpts from his blog diary:

> "My aim was to achieve what people with muscular dystrophy never have the opportunity to achieve. Any pain I felt paled into insignificance compared to what many people with muscular dystrophy go through every day; the muscle fatigue would disappear in a week or so for me."

Ross ran for three days for us

Day one

Studford to Lulworth

It began on a beach of four miles in the sand. I can't tell you much about the rest of the day as I was constantly wiping the sweat out of my eyes but suffice to say there was a lot of ascent. Anyhow, the excitement of the flat beach was soon replaced by 250 steep steps after 18 miles and a horrific hill through a forest to finish.

All of the porridge (yes, I ate porridge which was horrible) and mars bars were entirely necessary. I sweated a small lake but only fell over once.

Nothing compared to what sufferers of muscular dystrophy have to go through day in day out but I was certainly a little delirious by the end. I do, however, have an excellent tan/burn. Pain is the name of the game.

Day Two

Lulworth to Chesil Beach

Searing heat for the first six miles up and down some monster hills – led to excessive sweating and the removal of my well placed Vaseline ergo very painful chaffing on the inner thighs for the next 20 miles.

Next was Portland (more precisely around Portland cliffs). The last five miles were a real struggle but I was determined not to walk and to break five hours (which I hoped would get me into the top 50 entrants).

Very sore and swollen at the end but still no serious blisters and, touch wood, no bad injuries... All will be clear in the morning.

Day Three

Chesil Beach to Charmouth

Done and dusted. Tough day today in the heat (again). Having developed some irritating chaff last night, I started today hoping it would be as painless as possible.

Having literally climbed to the summit we gleefully bounded down to the finish in Charmouth. An ice cream and dip in the river later and I was right as rain again. I could do another tomorrow...

Flying the kite at Ascot

Hayley Gill (above) was flying the Muscular Dystrophy Campaign kite and creating a stir at Ladies' Day at Ascot in June. The kite hat was designed by milliner 'Hats by Billy' and replicates the charity's kite from our logo.

Chloe takes centre court

Chloe Ball-Hopkins took centre court with her tennis idols when she was selected to perform the all important coin-toss for the 2011 Wimbledon Ladies' Singles final in front of a worldwide audience of 375 million people.

Chloe (above) has a muscle-wasting disease called nemaline myopathy which causes weakness in the arm, leg, throat, and face muscles and she has used a wheelchair since primary school. She recently discovered a love of wheelchair tennis which she says has helped her to make friends outside of school and to boost her confidence after two years of bullying by fellow pupils.

Last year she entered the National Junior Tennis Championship for the first time, only to smash all expectations and reach the finals.

Speaking of the event in July, Chloe, 15, said, "I really love tennis so this was like a dream come true. I can't imagine my life without sport and hope to make a living doing it when I'm older.

"I was so excited – everything went smoothly and it was one of the best days of my life."

Chloe was invited to toss the coin for the Ladies' Singles finals at the prestigious sporting event by Sue Barker, the President of the Muscular Dystrophy Campaign.

Adoption with a difference

The Bristol and Bath fundraising team (right) have committed to raising £10,000 a year for three years, to fund a PhD student – Corinne Betts – doing research into Duchenne muscular dystrophy at the Matthew Wood Laboratory in Oxford. In their first year, the team has already raised almost £12,000.

In June, the team's Khurm Arshad and Simon Cooper visited the laboratory and heard updates on all the projects Matthew Wood's team were working on.

Go crackers over our Christmas cards and gifts

The 2011 Christmas catalogue is bigger and better than ever and is bursting with festive cards and gifts to suit all budgets and ages.

This year's catalogue features two exclusive cards designed by Liz Morgan and Alison Walker who won our design competition this year.

The catalogue has a range of cards and gifts that can be ordered by post, over the phone, or even online through our new online shop at **www.muscular-dystrophy.org/shop**. To receive a catalogue, please call Sarah West on **020 7803 4834**.

Celebrate a life

Muscular Dystrophy Campaign Tribute Funds

You can celebrate the life of someone you love by creating a living tribute of memories, photos and messages and raise valuable funds for the Muscular Dystrophy Campaign with our Tribute Funds.

Our Tribute Funds enable supporters to create, share and manage their own personalised web pages in the name of a loved one to keep special memories alive. You can hold special fundraising events or even celebrate anniversaries and birthdays all in one place.

To learn more about our Tribute Funds, please contact the volunteer fundraising team on **0845 872 9058.**

Jeans for genes

Jeans for Genes, a charity that funds research into genetic conditions, is donating over £20,000 towards our research from this year's national awareness day. This year's Jeans for Genes Day takes place on Friday 7th October 2011 and we're hoping you too can get involved.

It is really simple to take part: ask your colleagues at work or children at school to wear their jeans for the day and make a donation. There are also T-shirts available to purchase, in sizes 8 – 20, priced at £11.99. Visit **www.jeansforgenesday.com** to find out more.

Contact us at: 61 Southwark Street, London SE1 0HL
020 7803 4834
donations@muscular-dystrophy.org

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