To support us call 020 7803 4800

WELCOME to this summer’s Campaign. This issue is full of exciting news as well as updating you about some of the key projects your support has helped to bring about. Access to physiotherapy services is vital for people with muscle disease as it really helps slow the effects of muscle wasting. Read about our campaigning efforts to improve access to these services on page 4. Equally important is our commitment to attract young scientists into the field of muscle research – recent progress in that area is detailed on page 7, along with an interview with current research fellow, Dr Saiju Jacob.

On page 10 there is news of some new events and opposite you can read about some of the exciting fundraising going on during this year’s Muscle Week. I am also excited about the announcement of the President’s Awards at the forthcoming National Conference, where I am looking forward to meeting more of our hard working supporters to recognise the real benefits their support brings to the Muscular Dystrophy Campaign.

Thank you once again for your continued support – your generous donations have really helped to make a difference for people living with muscle disease in the UK.

Thank you

Sue Barker MBE
President, Muscular Dystrophy Campaign

P.S. You’ll find this year’s Christmas card and gift catalogue inside. Why not get your order in early for Christmas cards this year and support the fight against muscle disease.

Joe Logue, a 23-year-old communications student who has Becker muscular dystrophy, recently organised a fundraising concert for the Muscular Dystrophy Campaign. Part of Joe’s degree course required him to organise his own project and he set his hopes high! On a budget of just £117 he set up an event at the Glasgow Barfly called Rockability. Featuring live bands and comedy, the night was a great success and raised £700 for the charity. Thanks to Joe and everyone who came along on the night.
A new muscle enterprise for the North East

The Neuromuscular Centre (NMC) in Cheshire continues to go from strength to strength. This year it provided a record number of physiotherapy treatments, as well us continuing to run a successful print and design business staffed by people with muscle disease.

The Muscular Dystrophy Campaign is now building on the fantastic success of the NMC by setting up another social enterprise where people with muscle disease can receive vocational training and physiotherapy under one roof. The new centre will be based in Newcastle, where we hope to add to the already excellent services we support at the Muscle Centre there.

The President’s Awards

At this year’s National Conference on 27 September, Sue Barker will be presenting awards to some of the hard working people who have made an outstanding contribution supporting people with muscle disease over the last year. As well as the awards, the National Conference will be full of interest for the whole family; including advice surgeries and workshops covering clinical trial updates, physiotherapy support, mobility issues and campaigning. There will also be a crèche facility available, leaving parents free to get involved.

If you would like to attend the conference call 020 7803 4800 for details or email 2008conference@muscular-dystrophy.org.

This year’s Muscle Week is running from 20 – 27 September. This is an important week for the Muscular Dystrophy Campaign, as we raise awareness of issues affecting people with muscle disease and ask new supporters to help us in the fight against muscle disease.

Places of work across the UK will go ‘muscle-tastic’ by encouraging staff to become their favorite superhero for a day and getting colleagues to sponsor them. There are also sporting and other great fun events to get involved with.

If you or a company you know would like to get involved and become Muscle Heroes by fundraising for us please call Wendy Gupta on 020 7803 4822 or email w.gupta@muscular-dystrophy.org.

50 years fighting muscle disease

The charity has been supporting people with muscle disease and their families for 50 years. Beginning as a small group of scientists and families, the charity has grown into a national organisation which is now fighting muscle disease on all fronts. Look out for news of special events over the coming year.
AS PART OF our Building on the Foundations campaign, families from across the UK went to Westminster in May to highlight the lack of physiotherapy for many people living with muscle disease. Physiotherapy is essential for people living with a neuromuscular condition as it helps keep them mobile for longer, maintaining the best quality of life possible.

What are the issues?
Margaret Jones from Teesside, who has spinal muscular atrophy, attended the lobby because of her experiences: “I used to receive physiotherapy regularly. Four years ago I was told that because I could not be “cured”, my physiotherapy would be stopped.”

Margaret’s situation is just one example of how people living with muscle disease do not get the ongoing support they need from the NHS. To get to the root of these issues we used a Freedom of Information request and a patient survey to compile and publish the report Focus on Physio. The report was written by a group of leading physiotherapists, pediatricians and neurologists. It highlighted several worrying trends:

- Many patients with muscle disease do not receive continuous, specialist physiotherapy or any physiotherapy at all.
- Physiotherapy is often restricted to patients where an improvement can be measured. Patients with neuromuscular conditions fail to meet these criteria and are often refused physiotherapy.
- Almost two out of three NHS Trusts say they do not have any physiotherapists with specific training in neuromuscular conditions.
The situation is particularly difficult for young adults making the transition to adult services – their physiotherapy is often immediately withdrawn when they reach 18.

**Taking action**

On 15 May more than 100 families, clinicians and campaigners lobbied Parliament and presented a petition of 2,500 signatures to 10 Downing Street. We called on the Government to recognise the specialist nature of neuromuscular services and improve access to ongoing therapies as a matter of urgency.

Before the march to Downing Street, we hosted a reception attended by 45 MPs and peers where we launched the *Focus on Physio* report. The report was subsequently a subject of debate in the House of Commons. Speaking during the debate the Minister for Health, Ivan Lewis, also made the point:

“It is clearly unacceptable that there are still such large variations in care and that access to specialist diagnosis, treatment and on-going care services can far too often still depend on where people happen to live.”

The Muscular Dystrophy Campaign is urging UK Governments and the NHS to:

- Ensure that all people with a muscle disease be offered and have access to ongoing and timely physiotherapy when they need it.
- Provide more physiotherapists who have an in-depth understanding of neuromuscular conditions.
- Better understand the positive impact physiotherapy has on the health and wellbeing of people with muscle disease.
- Enable physiotherapists to access specific training in neuromuscular conditions.

The above conclusions come from evidence in the report which combined responses from the NHS, patient feedback and input from leading clinicians. By bringing together evidence from these three key resources the report highlighted the concerns of people living with muscle disease and delivered the impact needed to influence the Government and the NHS.
THE HUMAN FERTILISATION EMBRYOLOGY (HFE) Bill was approved by Parliament this summer but the issue of hybrid embryos being used to aid medical research remains controversial and has polarised opinion between those voicing concerns and the scientific community. The Muscular Dystrophy Campaign worked hard throughout May to make sure the media and politicians were also considering the views of people affected by muscle disease.

What are stem cells?
Our body is made up of various types of tissues, such as liver, muscle and brain. These tissues are made up of various kinds of cells, which are specialised according to the function they perform. A liver cell cannot do what a muscle cell does and vice versa. Stem cells, however, have the ability to develop or “differentiate” into any type of specialised cell. This makes them especially valued in medical research as they can be developed to replace cells that are not working properly in people with a wide range of disorders.

The potential impact on muscle research
Muscle stem cells that are capable of steadily regenerating damaged muscle are known as satellite cells. Research has shown that the initial muscle weakness caused by muscle disease is compensated for by the activity of satellite cells. Over time though the muscle becomes depleted of satellite cells and can no longer regenerate, meaning that the progressive muscle wasting continues to get worse and worse. By adding functioning stem cells back into the muscle, its ability to regenerate could be restored. Research into this area is still at an early stage, but it is possible that in the future stem cell treatment could develop into a powerful therapy for people living with muscle disease.

Projects we fund
The Muscular Dystrophy Campaign supported the HFE Bill and was pleased that MPs recognised the importance of stem cell research. The charity recognises the very real hope that stem cell research represents for people living with conditions for which there are currently no cures. At present we support four research projects that are looking at the biology of satellite cells to explore how muscle stem cells can be developed into a treatment.
Dr Saiju Jacob is a clinical research fellow funded by the Muscular Dystrophy Campaign in partnership with Myasthenia Gravis Association. Here he explains some of what he is working on and the importance of the financial support he receives from the charity.

What is your research about?
I am investigating myasthenia gravis, an autoimmune disease which disrupts the neuromuscular junction. The neuromuscular junction is the part of the body where the nerve transmits messages to the muscle. The disruption of the signals from the nerve to the muscle causes progressive muscle weakness. I am working to establish exactly what causes the condition, what scientists call the ‘pathological mechanisms’.

What do you do on a typical day?
The majority of my time is spent in the research lab. I perform muscle biopsies, which is where a small piece of muscle tissue is removed with a needle so that it can be examined in detail. I also attend clinics on a regular basis. I find this very rewarding as meeting with patients is a useful experience that allows me to collaborate the laboratory findings.

What is the impact of the Muscular Dystrophy Campaign funding?
I think the charity is doing a tremendous job in bridging the gap between clinical training and research. I know of several physicians in the UK providing excellent neuromuscular services, who were initially funded by Muscular Dystrophy Campaign.

How important has the support of the Muscular Dystrophy Campaign been for your work?
What I find most attractive about the charity are its efforts to integrate clinicians and scientists working in the national neuromuscular field. This is done through regular meetings, conference and symposia. The Muscle and Nerve Centre in Oxford continues to provide research facilities, largely due to the support provided by the Muscular Dystrophy Campaign, whose fellowship has nurtured my passion for providing a good clinical service.

Our current commitment to research
The Muscular Dystrophy Campaign is currently funding 25 research projects – this amounts to approximately £2 million invested in world-class research every year.
In July the Muscular Dystrophy Campaign medical research committee approved seven new research projects. This includes funding for two new PhD students, as we continue our commitment to get the best young minds involved in muscle research.
For many people drawing can be difficult, for most drawing with the “wrong” hand would be impossible. For young artist Alexandra Baily this is the only option. Alexandra has congenital muscular dystrophy and because of her condition she needs to support herself with her right arm and so had to teach herself to paint with her left hand. Each picture takes a long time to produce as she needs regular breaks and needs someone to help her by holding her wrist while she paints.

Enclosed with this edition of Campaign is our Christmas card catalogue, which includes a design drawn by Alexandra. Alexandra has been interested in art since she was a little girl, although for a time she couldn’t decide if she wanted to be an artist or a circus lady! Having decided that she would concentrate on art rather than pursuing a life under the Big Top, Alexandra went onto spend six years studying art at Chichester College where she completed an Art Access course, an Art Foundation course, a National Diploma in Graphic Design, and a Fashion and Textiles course.

In 1999 Alexandra set up Anda Cards (named after her family nickname) to sell her designs. Each year she produces around eight new cards, which are available on her website. Alexandra paints on silk using watercolour and acrylic, as well as using her computer to help with the different stages of some of the designs. She sells her cards from her website, in local shops and to friends and family from her home. You can find out more about Alexandra’s art and card business online: www.andacards.com

What is congenital muscular dystrophy?
The congenital muscular dystrophies are a group of conditions which have a common muscle pathology, which means that if you look at the muscle under a microscope you will see similar, disease-related features in these conditions. The symptoms of a congenital muscular dystrophy, like poor head control or dislocation of the hip, are often present at birth or in the first few months.

There is currently no cure for congenital muscular dystrophy but we are funding research into the condition.

You can order your Christmas cards right away
Order your Christmas cards from our catalogue, which features Alexandra’s specially designed card. Please see the enclosed catalogue or call 01462 735 745.
Not just a girl in a wheelchair

Laura Merry, who has congenital muscular dystrophy, is one of the first people to join our Young Campaigners Network, Trailblazers. Here is how she describes her life.

“Hi, I’m a girl in a wheelchair. Well that’s what some people might see me as. Not the fact that there is a person sitting in the blue electric wheelchair. This person is Laura Merry, I’m 18 years old and can think, feel and talk surprisingly!

My outlook on life is positive, be grateful for what you have and not what you haven’t. There’s only so much you can change and some you just can’t. One phrase I often repeat is ‘get over it’. This is mostly to myself when I start to feel sorry for myself. I remind myself that I’m lucky as I am and that there is always someone who is worse off than me.

However it can get annoying and frustrating when very minor things get in the way of my independence. A simple step will prevent me from going into a shop because that shop hasn’t bothered to provide a ramp. Some shops will find a way around it and are happy to bring items out to you on the street, thinking they’re helping you when in fact it is embarrassing. You don’t want people passing you by or observing you while you try on shoes! At least it was on a sunny day.

It still amazes me how some people react to me. Some will simply stare, children I don’t mind as they do not know any better and this is where they need to be educated in understanding how to treat people who are different to them, not just people with disabilities.

In spite of all of this I enjoy and love my life to the full. You only have one to live. The way I see it is if I wasn’t the way I was I would never have experienced and done the amount of things I have been given the opportunity to do. I have been taught that within reason and being realistic I can do anything I want. Yes, I may have to fight for it, but things are never easy for anyone in the first place.

At the moment I am currently waiting for my A-level results. I also am in the midst of a business venture with my sister, which we hope to get going some time soon. Other than that I am basically your normal teenager. I like my lie-ins, hanging out with friends, going shopping, the cinema and concerts. Reading is my biggest passion and why I’ve chosen to study literature. Even though there have been plenty of low points there are just as many high points to make up for it. I have a plan to do as much as I can to prove people wrong, that I do have ambitions and hope to achieve some of them. I’m not just a wheelchair. There is a person who controls that wheelchair, who can talk, think and feel. I love being different, I revel and celebrate it. And hey, who wants to be the same?”
In November 2007 24 supporters, some able-bodied and some with muscle disease, raised £80,000 by trekking across the Sahara Desert. The event was such a success that we are planning another overseas challenge – this time to the jungles of Central America. Are you ready to take on the quest?

We are now recruiting a team of adventurers to spend nine days trekking, camping and white water rafting in the Costa Rican rainforest. The team will meander through the valleys of cloud forests on the border of the Atlantic/Pacific continental divide. This challenge will offer spectacular scenic views of the great forestland, penetrating the cloud covered wilderness 2,000 metres above sea level.

You will also learn about this Latin American culture and the diverse wildlife surrounding you from your guides and from locals during your travels. This area is a tough environment to live in for over a week, with a typically tropical and humid climate. However it’s an experience that you’ll remember for the rest of your life.

Following a fantastic effort in the Sahara, husband and wife Bharti and Bharat Shah have signed up and raised nearly £8,000 already. They are looking forward to getting back into training and taking on the jungle.

There are still a few places to fill including places for wheelchair users, so if you or someone you know would like to be part of it contact the events team on 020 7803 4829 or email events@muscular-dystrophy.org.

Run for Muscles leaps forward
Following the success of running events organised by the Muscular Dystrophy Campaign, we have launched a UK-wide race series called Run for Muscles. The initiative will raise money as well as engage the running community with new, challenging and top-class events and will build on the enthusiasm of our local branches and friends and families of people affected by muscle disease.

Anyone can support Run for Muscles, whether you’re a seasoned runner looking for a challenge or an enthusiastic amateur looking for a fun run, there will be something for everyone – including places for wheelchair-using participants wherever possible. For more details call National Race Manager, Anne Jackson, on 01787 313 913 or email annej@muscular-dystrophy.org.

Top runners
Huge thanks to the 115 runners, including our chief executive, head of communications and policy and campaigns officer, who braved the rain to run the 2008 London Marathon for the charity. So far they have raised £190,000 and money is still coming in.
Raising awareness with Art

In January we curated our first ever portrait exhibition. *Perspectives on Muscle Disease: Life in Pictures* at the Novas Gallery in London raised awareness of muscle disease and featured the work of renowned photographers and artists.

Britain’s most acclaimed portrait painter, Jonathan Yeo, displayed portraits of three of the charity’s most distinguished supporters: Patron HRH Prince Phillip Duke of Edinburgh and Honorary Life Presidents Lord John Walton and Lord Richard Attenborough. Jonathan, whose previous subjects have ranged from the likes of George Bush to Dennis Hopper, said: “It has been a privilege to meet and paint these three men who have done so much to help such an important cause.”

Also featured was Lesley McIntyre’s work *The Time of Her Life*, a photographic biography of her late daughter Molly, and Jacqueline Donachie’s installation *Tomorrow Belongs to Me*. Jacqueline’s work was the result of a five year collaboration with Muscular Dystrophy Campaign funded scientist Professor Darren Monckton.

In memory of Mark Speight

We were sad to hear of the passing of Mark Speight earlier this year. Mark was a loyal supporter of the Muscular Dystrophy Campaign’s Young Pavement Artists Competition for eight years. As President of the competition he always showed great enthusiasm for the cause and raising the profile of muscle disease. Mark will be greatly missed by all of us.

In memory of Mark we are creating a special prize for our 2009 Young Pavement Artist competition. *The Mark Speight Award for Originality* will be given to the entrant who chalks the most original interpretation of the “endangered species” theme. For more information on the competition, which launches on 23 September, visit [www.muscular-dystrophy.org/pavementart](http://www.muscular-dystrophy.org/pavementart) or email pavementart@muscular-dystrophy.org for details.

Are you on Facebook…

…because we are! You can interact with the Muscular Dystrophy Campaign on Facebook right now. We enjoy connecting with people affected by muscle disease, supporting fundraisers and doing our best to raise awareness about muscle disease. If you search for Muscular Dystrophy Campaign on Facebook you can get in touch today – go on give us a ‘poke’!
A message from Lord Attenborough

“The measure of anyone’s life or achievements is what they leave behind. My life has been filled with many moments I treasure and achievements of which I am proud. But what’s most important to me is knowing that when the final credits roll I will have left something to the Muscular Dystrophy Campaign.

A legacy can bring new life to those who wait in hope.”

Lord Attenborough Kt CBE
Hon Life President, Muscular Dystrophy Campaign

To find out more about leaving a gift in your will to the Muscular Dystrophy Campaign call 020 7803 4800 or email legacies@muscular-dystrophy.org.

Gift inspiration

Although it’s only August, Christmas is still coming and when you start your shopping this year you can help raise money for Muscular Dystrophy Campaign at no cost to you. You can get almost anything from our webshop from most major retailers; take a look at what’s on offer here: www.buy.at/musculardystrophycampaign

Say it with flowers

If you prefer to send flowers rather than a gift that too could raise much-needed funds for Muscular Dystrophy Campaign also at no cost to you. All you need to do is quote ‘MDC’ when you order and Charity Flowers will donate 15% of the cost of the bouquet to us. To place an order call 08105 300 000 or visit www.charityflowers.co.uk

From time to time we may pass your name to other charities to help raise funds. If you do not wish your name to be passed on in this way please complete the form and return it to the address below.

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Address_______________________________________________________________________________
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Please send to: FREEPOST RRLL-YZEX-THXT, Muscular Dystrophy Campaign,
61 Southwark Street, London SE1 0HL

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