STAR TREKKERS
How four people challenged the wild in the name of charity

THE HARDEST WORDS
Talking to children about their condition

UNDEFEATED
Living with Duchenne muscular dystrophy at the age of 40

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Welcome

2008 is going to be a huge year for your charity as we deliver more of what you want and need. You can read about recent successes further on in this issue, but keep an eye open for new developments this year including: Family weekends this autumn; after a number of years’ success in Northern Ireland, these are now coming to Great Britain. Better research communications – finding out what is happening in research is hard work. We will make it easier through our website, TargetMD and new publications including e-newsletters. Regional campaigning – as well as working with the NHS nationally, we are also working with the Health Commissioners in the regions. Campaigning groups to improve services are setting up in Wales, the South West and elsewhere. More will follow. Children’s network and website – due to launch this autumn, this will be a fun way for children with muscle disease to learn and play together. And this is only the tip of the iceberg. None of this would be possible without your support and encouragement. Thank you very much for everything you have managed to do, both big and small, that has taken us to where we are. Together we are stronger.

Philip Butcher, Chief Executive

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Target MD
The magazine for supporters of the Muscular Dystrophy Campaign

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www.muscular-dystrophy.org

Target MD 3
NEW CLINICAL TRIAL FOR BOYS WITH NONSENSE MUTATIONS

PTC THERAPEUTICS, a US-based biopharmaceutical company, is initiating a multi-centre clinical trial to test its investigational drug, called PTC124. The drug could help boys with Duchenne or Becker that carry a certain type of mutation called a “nonsense mutation”. Around 10 to 15 percent of boys have this type of mutation, which prevents production of dystrophin, the protein that is missing in the muscles of affected boys. Three sites in the UK are planning to participate in the trial.

SECOND CENTRE IS UNVEILED

A NEW NEUROMUSCULAR CENTRE providing services for people with muscle disease is to be established in Newcastle. The city was chosen as the site of NMC2 because of the world-leading expertise in muscle disease at its Centre for Life. This is where the Muscular Dystrophy Campaign muscle centre is located, with an internationally renowned clinical team led by Professor Kate Bushby and Professor Volker Straub. An initial grant of £78,000 has enabled the project to get under way. Links have been forged with a range of educational and business organisations that will be crucial in making the Newcastle NMC a worthy replica of the existing centre in Cheshire.

Other locations were considered for the new centre and we hope very much to continue to work in those areas and to build a national network of NMCs.

At the heart of the NMC in Cheshire is a Social Enterprise and Training Centre providing work and training opportunities for people with muscle disease. The Centre also provides physiotherapy, hydrotherapy and a range of support and advice. This is the exciting and powerful model we plan to replicate.

For more information, contact Matthew Lanham on 01606 861733 or email matthew.lanham@nmcentre.com

ARRESTED FOR CHARITY

LOCAL POLICE and the town crier assisted in the mock arrest of eight Chester business managers, with a further 12 expected to be detained on 12 March in Ellesmere Port. Each ‘felon’ was handcuffed at their place of work and led away to a waiting police vehicle, then had their fingerprints and mugshots taken. To ensure release, each felon was required to raise a minimum of £500 bail money prior to the event. They were then treated to a champagne lunch by local French restaurant Chez Jules. The Lord Mayor and Lady Mayoress were in attendance and the event was covered by the local press. The two parts of the event are expected to raise in excess of £10,000 for Muscular Dystrophy Campaign.

LET’S HEAR IT FOR MARATHON HEROES

GOOD LUCK TO ALL 110 members of our fantastic London Marathon team who will be participating in the world’s most popular marathon on 13 April. The dedicated and inspirational fundraisers have been training through the winter to make their muscles count for the Muscular Dystrophy Campaign. Come and show your support on the day at one of the Muscular Dystrophy Campaign cheering points. We will be based at Tower Bridge and Parliament Square (look for bright orange clothes and balloons).

UNIQUE WAY TO WORK AND STUDY

A UNIQUE INITIATIVE to give people with muscle disease access to education and employment at home was set in motion in December at the NeuroMuscular Centre in Winsford, Cheshire.

Launching the Home Study and Home Working project, Shadow Minister for Health and MP for Eddisbury, Stephen O’Brien, said, “I am delighted to be launching this Home Study and Home Working project, which will offer people with muscle disease, from all across the country, the opportunity to gain greater independence and future employment.”

Matthew Lanham, Executive Director of the NeuroMuscular Centre, said, “I hope we will be able to extend our services to hundreds of people who have difficulty in travelling far and wide for training.” The project was made possible by funding from Bank of America and the Morgan Foundation.
**NEWS IN BRIEF**

**TRANSLATIONAL CONFERENCE**
See page 20 for news from Muscular Dystrophy Campaign’s recent Conference on translational research, attended by scientists and clinicians from around the world as well as patients’ groups. To download a conference podcast, visit [www.muscular-dystrophy.org/research](http://www.muscular-dystrophy.org/research)

**SPONSOR FOR YOUNG PAVEMENT ARTISTS**
We are pleased to announce that GlaxoSmithKline will be sponsoring the Young Pavement Artists Competition for 2009. The competition, to be launched in September this year, will continue to raise money for Muscular Dystrophy Campaign.

**LAUNCH OF YOUNG PEOPLE’S NETWORK**
Vinvolved, the national youth volunteering programme has awarded £250,000 to the Muscular Dystrophy Campaign, to set up regional networks of young people with muscle disease. Turn to page 11 to find out how you can get involved in campaigns in your area.

**SIGN UP FOR OUR NEWSLETTER**
The Muscular Dystrophy Campaign sends out a monthly e-newsletter with updates on our research, events and activities. You can sign up online by going to the web address below and clicking on the link in the top right corner of the page: [www.muscular-dystrophy.org/newsletter](http://www.muscular-dystrophy.org/newsletter). Your email address will never be passed to a third party and you can unsubscribe at any time.

---

**RUN FOR MUSCLES LEAPS AHEAD**

- **On your marks: Anne Jackson heads the Race Team**

A UK-WIDE RACE SERIES called Run for Muscles has been launched following the success of running events organised by the Muscular Dystrophy Campaign.

We want to raise significant funds as well as engage with the running community via new, challenging and top-class events.

The Muscular Dystrophy Campaign Race Team is led by Anne Jackson, regional fundraising manager for Anglia, who has extensive expertise in this area. Her work will be underpinned by the enthusiasm of local branches, and of the friends and families of people with muscle disease taking part as wheelchair-using participants, marshals and committee members. The commitment of people with neuromuscular conditions to our current races, such as the Oxford Town and Gown, has made these events hugely popular.

Anyone can support Run for Muscles. Why not take part in a Fun Run in your area? For more details, call Anne Jackson, National Race Manager, on 01787 313913 or email annej@muscular-dystrophy.org

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**TRAVEL INSURANCE FOR PEACE OF MIND**

THE MUSCULAR DYSTROPHY CAMPAIGN has launched a new partnership with Unique, a company that is now offering travel insurance and life assurance products for people with muscle disease, their families, friends and carers. The policies are quick and easy to purchase, with no referrals for medical screening and no age limits on single-trip policies. For a quote or more information, call 01603 828218 or visit [www.muscular-dystrophy.org/insurance](http://www.muscular-dystrophy.org/insurance)

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**AIRLINE DONOR FLIES IN TO GIVE £2,000**

JAY KUMAR, who works as a Terminal 5 Project Manager for British Airways, has given £2,000 to the Muscular Dystrophy Campaign. Jay donated the money after being recognised by the British Airways Community Relations team for his charitable endeavours over the past 10 years. He was presented with a Community Volunteering Award and a cheque for £2,000 at a special ceremony with television presenter Ben Shephard. He immediately passed on the money to the charity.

Jay previously raised £600 for the Muscular Dystrophy Campaign in 2006, with a Bollywood song supporting the England team during the World Cup. The song was inspired by Jay’s teenage daughter, Anjali, who has a form of muscle disease. As a long-time supporter of our work, Jay said, “I am delighted to have been able to make a significant contribution to the work of the Muscular Dystrophy Campaign.”

We would like to thank Jay and British Airways for their generosity.
The power of art to reflect the lives of people with muscle disease was demonstrated this January in the first exhibition curated by the Muscular Dystrophy Campaign, Perspectives on Muscle Disease: Life in Pictures. The show at London’s Novas Contemporary Urban Centre featured paintings, photographs and an installation by artists including one of Britain’s most acclaimed portrait painters, Jonathan Yeo. Muscular Dystrophy Campaign Honorary Life President, Lord Walton of Detchant, who was painted by Yeo, said: “I am delighted to be a part of this exhibition. I could not be more excited about the future of the organisation, but above all about the developments which carry such outstanding hope for our patients and their carers.”

The charity’s Patron HRH Prince Philip Duke of Edinburgh and Honorary Life President Lord Richard Attenborough (right), were also painted by Yeo who was commissioned by the Muscular Dystrophy Campaign thanks to a private donation. “I am delighted to be a part of this exhibition. I could not be more excited about the future of the organisation, but above all about the developments which carry such outstanding hope for our patients and their carers.”

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A personal story
Documentary photographer Lesley McIntyre exhibited The Time of Her Life, a photographic biography of her daughter Molly (below), who died of an undiagnosed form of muscle disease. In the first few days of Molly’s life a biopsy revealed an abnormality in the formation of her muscles. McIntyre was told that her daughter was unlikely to survive more than a few months. In fact, Molly lived an inspiring life until she was 14 and the work on show includes 52 poignant images of her. “I am delighted that the Muscular Dystrophy Campaign invited me to participate,” McIntyre said. “Molly and I were in regular contact with the charity and received invaluable support from a Regional Care Advisor.”

Although the images of Molly are personal, McIntyre hopes they will speak to other parents who have a disabled child. “I have met many children and their parents facing similar problems,” she said. “Although I realise that the story revealed in this set of photographs is about one human being, I hope the work resonates for all of those who know and understand the enormity of the issues that The Time of her Life attempts to address – those of attitudes to disability and child mortality.”

To read the full article, go to www.muscular-dystrophy.org/news/
Benedict Cumberbatch as novelist Alexander Masters and Tom Hardy as his friend Stuart Shorter, in the BBC film drama

Where can I get travel insurance and life assurance cover to suit my needs?

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Facing the challenges

Last year we invited Muscular Dystrophy Campaign supporters to have their say as part of our Strategic Plan, mapping out our beliefs and goals in our fight against muscle disease. Here’s our feedback on what we have achieved and what we still need to do.

CARE
Objective: Empower those living with muscle disease through self-management and self-care

We held seven Information Days and three Family Fun Days, 10 education and training days for professionals, plus our first Occupation Therapy (OT) Conference. Our packs for adults managing their condition are due to be launched in Summer 2008. We have updated the Muscular Dystrophy Campaign Information Pack. There are also new publications: Guide for families with a child newly diagnosed with a muscular dystrophy, a Guide for those with a child diagnosed DMD age 5-12 years and five new factsheets.

Trailblazers, a peer-to-peer group for young people, has been set up in Northern Ireland.

MDC directors attended eight patient group conferences and funded or part-funded a Support Group training day for CMT members, a conference Information & Support day for the OPMD group and the FSH annual conference. We also invited all of the Groups to two meetings in London. Spending on welfare grants increased by 10 percent to £132k.

Clinical & Care services
Objective: Work in partnership with healthcare professionals to ensure those living with muscle disease receive the highest quality of care available

We have continued to support muscle centres with an audit of muscle centre grants planned by the new Clinical Research & Care Committee for 2008-09. We have invited our previous research fellows to our symposium in 2009. Continuing to develop our Care Advisor network, we have agreed joint funding with the NHS for a new Birmingham Care Advisor post. We have funded information days for families and training days for professionals in South Wales.

Spending on Clinical Research grants increased from £354k p/a to £377,596 with four out of the six applications successful.

Best practice development

We are continuing our programme of symposia and workshops with the next symposium planned for 2009. We have distributed our Wheelchair Guidelines to therapists, training colleges and universities and we have updated and reprinted our Education Guidelines in response to demand.

We now have an OT network with more than 120 people and more than 100 delegates attended our first Occupational Therapy Conference. Our care team will be at the Naidex homecare, disability and rehabilitation event in April to meet therapists.

As part of our work towards developing minimum best practice guidelines, we held a workshop with young people to identify several areas of concern.

Clinical data has been captured for over 100 Duchenne muscular dystrophy patients via the NorthStar patient group. Support to TREAT-NMD by funding cost of part-time UK Implementation Manager.

“We now have 334 registered patients; up 12 percent on the year before”
NEUROMUSCULAR CENTRE  
Objective: Home Working and Home Study  
A long-standing strategic aim of NMC was fulfilled last year when this project secured funding from Bank of America and a regional trust, the Morgan Foundation. We are offering up to 15 places for home study this year. We have 10 home students already enrolled; the level of interest sparked by the article in Target MD has exceeded expectation.

Objective: Growth in physiotherapy service at NMC  
Our aim has been to provide more treatments for more people. We aimed to grow at 10 percent a year, which we have achieved. We now have 334 registered patients; up 12 percent on the year before. We have provided over 3,100 treatments in 2007; over 10 percent up on the previous year. We continue to work with NHS partners and commissioners to ensure progress towards our goal of full cost recovery for the physiotherapy service at NMC.

Objective: NMC Newcastle  
The goal was to support and nurture the replication of NMC. We promoted the model and the opportunity to interested groups across the UK. We chose Newcastle to be the first location and hope to explore others.

POLICY AND CAMPAIGNS  
Objective: National specialised neuromuscular service  
We have urged the Department of Health and the NHS to recognise the need for a national specialised neuromuscular service. We are also working at a regional level to underline the gaps and weaknesses of the current national services. We have taken a similar position in Wales where services are weak in many areas and have also raised concerns with the Scottish Government. We will undertake work in Northern Ireland, now that the devolved Assembly has been re-established.

Objective: Action on “postcode lottery”  
Working with individuals, families and condition specific groups, we have highlighted evidence from national surveys and published data that shows how life expectancy and quality of care are influenced by a “postcode lottery” of services. This work has been backed by leading clinicians. A House of Commons launch secured press and media coverage.

Objective: Influence policy with focus on transition  
We have commissioned research to determine how many people are affected by neuromuscular conditions and we are working to improve support for young people as they move to adult services. We have secured a major grant to develop the skills and confidence of young campaigners.

Objective: Campaign for new treatments  
We have linked our call for a national network of specialist neuromuscular centres to the need to ensure that resources will be available to undertake trials looking at potential new treatments, taking research “from the laboratory bench to the bedside”.

Objective: Support individuals  
We provide advice and support for individuals who have difficulty in accessing services from local councils and in education. We have also addressed failings in healthcare working with Regional Care Advisors.

RESEARCH  
Objective: Facilitate the formation of scientific information platforms to encourage interdisciplinary networking

We strive to facilitate communication and collaboration between scientists and clinical researchers to speed up the process of transferring promising technology into the clinics. The charity organised, in partnership with MRC Centre for Neuroromuscular Diseases, a conference to provide updated information on translational research. More than 300 clinicians and scientists took part in this meeting, including presentations from researchers currently supported by the charity, as well as other international experts.

Objective: Invest in high-quality research Fellows aimed at addressing the cause, cure and symptoms of muscle disease.  
We will continue to invest in high quality research projects. Plans have been agreed and we are committed to spending over £1.5 million. To attract young scientists to work in the field of muscle disease, studentships will be available in the next grant round.

Objective: Raise the profile and awareness of the charity in the scientific community.  
We continue to raise our profile within the scientific community by participating at scientific conferences and visiting our grantees every year.

Over to you
What are your views on what we’ve achieved? If you’d like to comment on any aspect of our programme and future plans, please get in touch:

Philip Butcher, Chief Executive  
• 020 7803 4801  
• p.butcher@muscular-dystrophy.org
Muscular Dystrophy Campaign has published a hard-hitting report, which we launched in Parliament, on the uneven provision of care nationwide. Have your say and help us improve the lives of young people with muscle disease.

Act now on inadequate care, lack of specialists and poor services.” This was the call for immediate action made by the Muscular Dystrophy Campaign at an All Party Group meeting in the House of Commons in December. Launching a hard-hitting and damning report, Building on the Foundations: The Need for a Specialist Neuromuscular Service across England, we highlighted widespread failings in the current provision of care for people with muscle disease. The report revealed that patients with muscle diseases are faced with a fragmented, substandard system of care, with significant variations in survival rates across the UK.

Key findings from the report include:

- Patient care is delivered by a fragmented, multi-agency system of care, with significant variations in access to care, treatment and support.
- Neuromuscular care is often patchy, with patients facing a postcode lottery for access to treatment.
- The provision of support services is inconsistent, with patients often left feeling isolated and unsupported.

At the meeting in Parliament, we called on the Government and the Department of Health to recognise neuromuscular care as a specialised service and to end the appalling postcode lottery of access to treatment.

Local campaigner Steve Ledbrook, who lives in the South West, has struggled to find appropriate care to treat his Becker muscular dystrophy. He met his local MP, John Penrose, at the All Party meeting. Steve said: “After being diagnosed with muscular dystrophy I found the South West to be a desert for the treatment of conditions such as mine. Expecting disabled people and their families to travel long distances just to gain access to the clinical care they need is shocking. Provisions

Shelia Hawkins (right), Chair of the FSH Support Group, meets former Health Secretary Patricia Hewitt at the House of Commons launch
“Expecting disabled people and their families to travel long distances just to gain access to the clinical care they need is shocking”

should be made to help us all receive necessary treatment, not make life more difficult. I was delighted to meet my MP, John Penrose. It is really important that he recognises the difficulties people with muscle diseases have in receiving specialist care and support in our area.”

Professor Mike Hanna, co-author of the report and a Consultant Neurologist at the Institute of Neurology, said: “Specialist care is essential to improve the quality of life of patients with neuromuscular disorders and yet it is not available for many patients. Too often specialist care is vulnerable and heavily dependent on a handful of leading clinicians with a research interest in this field, rather than embedded in a properly resourced, long-term service.”

Speaking at the meeting in Parliament, Philip Butcher, Chief Executive of the Muscular Dystrophy Campaign, said: “This report illustrates the challenges facing Government, the NHS and Commissioners. People with chronic disabilities are living longer thanks to medical advances, and yet local NHS services are failing to meet this demand. It is essential that the Department of Health recognise the specialist nature of the care needed by patients with neuromuscular conditions and ensures that such services are available to all patients, regardless of where they live.”

Next steps: taking Building on the Foundations forward
Parliamentary Motion: We tabled a House of Commons Motion calling on the Government to improve services for patients with muscle disease. The motion received support from 80 Members of Parliament.
Local Campaigns Network and Coalitions: We are setting up coalitions in those areas we identify as being the most poorly served – the South West and the East of England.

These coalitions will consist of people living with the condition, clinicians and Members of Parliament. By working together, we can ensure that we maintain momentum on this important campaign and continue to put pressure on both local and national decision makers. If you would like to join one of our local coalitions, please contact Elizabeth Hoyle on 020 7803 4846.

Working with the Department of Health and local commissioners: We are also committed to working with the Department of Health and local commissioners to improve services across England. We recently met with civil servants at the Department of Health and also health commissioners in the South West. They have made a commitment to working with us.


Campaign round-up
The fight in Wales
In February, Muscular Dystrophy Campaign supporters heard from the First Minister, Rhodri Morgan AM, when we lobbied the Welsh Assembly in Cardiff. Joining forces with the Genetic Interest Group, we presented him with a major report, Building on the Foundations The Need for a Specialist Neuromuscular Service across Wales. The report highlights the inadequate provision of health services for people in Wales with muscle disease. The Muscular Dystrophy Campaign plans to work with the Welsh Assembly Government, NHS Wales and the Health Commission Wales on the issues raised, involving people with muscle disease, families and clinicians.

Join our new Youth Network
If you are aged between 16 and 30 and want to make a difference to the lives of people living with muscle disease, get involved in our Young Person’s Campaigning and Information Network. Launching later this year, the network is an opportunity to learn new skills and to help others. If you feel strongly about a particular issue, such as treatment at schools, doctors’ services, or getting the right wheelchair, the network will give you the chance to talk to other young people in your region about these concerns. Together you will decide how you can improve the lives of young people living with muscle disease. You will then organise your own lobby of Parliament – that’s when the Government and Members of Parliament will listen to your concerns and see if they can do anything to help. You will also be able to chat to others living in your region through a brand new website.

If you want to get involved, please contact Nic Bungay on 020 7803 4847 or email n.bungay@muscular-dystrophy.org

Get in touch
If you would like to share any relevant experiences or if you need the campaign team’s help or advice, please get in touch with Robert Meadowcroft using the contact details below.

Robert Meadowcroft
• 020 7803 4848
• campaigns@muscular-dystrophy.org
Jonathan Colchester is 40 and has Duchenne muscular dystrophy. He talks to Andréa Childs about his remarkable life, and why he believes he’s still alive today

Jonathan Colchester is the last person who would want to be defined by his disability – he was diagnosed with Duchenne muscular dystrophy at the age of five. For better or worse, though, it’s the condition that people usually talk about when they first meet him. Jonathan’s next birthday is in May and he believes he may be the oldest man in Europe living with a condition that causes the death of many people in their mid-20s. “I’m a fighter, that’s why I’m still here,” he says.

The fact remains that no one quite knows why Jonathan is alive today. For a man who is so positive and pro-active about his health, it’s a constant source of frustration to him that scientists aren’t more interested in how he manages on a day-to-day basis. “I’m not involved in any research programmes at the moment,” he says. “Most of the experts are interested in the cutting-edge science and finding cures, which of course offers great hope for the future. But I think the practical stuff about how you live with the condition is important too.”

For Jonathan, living with Duchenne muscular dystrophy means eating well, keeping up his physiotherapy, maintaining effective care and having the equipment he needs. “I’ve been very lucky, in that I’ve had the right equipment at the right time,” he says. “Getting my first ventilator when I was 22 really helped, particularly overnight when my breathing is shallower. And as soon as a portable ventilator came on to the market, in 1994, I bought that and it made a huge difference to my life, as I was able to leave home for much longer periods and follow my interests in bird-watching and art.”

For a man who loves food, getting his diet right has also been important. At 24, Jonathan was still able to manage easy-to-chew foods such as cereal, fisherman’s pie and yoghurt. But by 29, difficulty in swallowing meant that he switched to a diet of liquid supplements, with the addition of small amounts of soft cheese and chocolate.

“I realised that wasn’t meeting my nutritional needs, though, so for the past five years I’ve used a really powerful liquidiser to puree my meals, which means I’ve been able to eat a greater range of foods. It’s given me much more energy because I’m eating more calories and it’s meant that my immune system is stronger, so I can fight off infections.”

There’s also the pure pleasure in choosing what he wants to eat – or drink. “I’m a big fan of Irish coffee,” he laughs.

A Life Worth Living

Giving people an insight into living with muscle disease is important to Jonathan, and was the inspiration for his autobiography called A Life Worth Living, which he wrote in 2002. It’s an incredible read, not least because he has packed an incredible amount into his 40 years. A Life Worth Living details Jonathan’s childhood and the progression of his condition, but also includes the trips he has made around the world with his family (mum, dad and sister Christine), his interests in nature, painting and drawing and the friends he has met along the way.

“I want to demonstrate that it is possible to overcome severe disability and lead a fulfilling life, while at the same time adapting to the changing patterns the disability imposes” he explains in the book’s preface.

Positivity and adaptability are two themes that resonate throughout the book. Jonathan may no longer be able to travel widely – a family holiday to the Canadian Rockies and Yosemite is remembered as a particular favourite, especially for the mountainous landscape, wildlife and incredible sense of peace – but he can still indulge his love of bird-watching in the UK, with trips out to wildlife spots or simply watching the birds in his
garden. Visits to gallery exhibitions have replaced actual painting and drawing, but his artworks decorate the walls of his flat (one of his paintings, of a kingfisher, has been printed on a card and sold hundreds of copies to raise money for various charities, including the Muscular Dystrophy Campaign). Moving into his own home, six years ago, has given him more independence and responsibility.

Jonathan also has a busy social life, with friends dropping in to see him, or trips out to the cinema. “It is difficult sometimes,” he admits, “as a lot of my friends died younger; part of the reason I wrote the book is as a tribute to them.

His parents and sister are there too as well as Jonathan’s niece Lauren, who is five and nephew Nicolas, who is eight. “Being an uncle has provided a whole new experience for me” he says happily. “Nicolas and I play Nintendo DS together and the children will often climb up on to my lap and sit with me.”

A matter of faith

A turning point in Jonathan’s life came when he was 19 and read a book called Choices and Chances by the American author Joni Eareckson, who was paralysed from the neck down in a diving accident at the age of 17. Her courage and faith in God inspired him and his faith now underpins his life.

“My belief gives me hope for the future and something to get up for” says Jonathan. “It helps me to get through the day, knowing that I’m being looked after. I was happy in myself before, but it has given me a lot more joy and meaning in my life.”

Regular prayer and study of the Bible are all parts of Jonathan’s everyday existence that he shares with friends and fellow believers. “One thing I can look forward to is the day when I get my new body in heaven. I will not be in a chair” he says. “I sometimes have quite a bit of physical pain. It often makes me think of heaven where there will be no pain or tears for anyone.”

My message

When Jonathan was asked what message he would like to bring to readers of Target MD, his reply was predictably uplifting. “Keep fighting for the future” he said. “I still have hope that a cure for muscular dystrophy can be found. The way research is going is very hopeful. Positivity is really important and being patient with your physical condition.”

Jonathan’s friend, Professor R Edwards, echoes this sentiment. He says that Jonathan is living proof that “the full life is lived by and through an active mind.” To finish, Jonathan simply quotes from the speech he gave at his fortieth birthday party: “The best thing about the future is that it comes one day at a time.”

For a copy of A Life Worth Living (£9.99, plus p&p), email jonathan@colchester2390.fsnet.co.uk. Proceeds are donated to the Muscular Dystrophy Campaign; more than 700 copies have been sold so far.

Book extract

“In 1984 [when I was] at Hebden Green special school, I had a girlfriend named Katherine who had Spina Bifida. When I first set eyes on her, I didn’t have enough courage to chat to her because I was nervous. My heart kept beating faster and faster. I heard somebody mentioning her name, and I was sure they said Katherine. A few days later I chatted to her friend to make sure her name was Katherine. She said it was and asked me why I wanted to know, so I said “because I like her!”

The following day I talked to Katherine and my words came out fast because I was nervous…. Katherine talked about her driving lessons. She drove a Mini Metro which had been specially adapted with hand controls. I chatted to her on a number of occasions and on my 17th birthday I asked her out. I just couldn’t believe it when she said yes! The following Saturday afternoon Katherine came to my house in her car. It was a beautiful sunny day when she first arrived and I took her down the garden to see the menagerie — our sheep, lambs and ducks.”
The challenge of a lifetime

From trekking the Sahara to scaling the peaks of Snowdonia, supporters of the Muscular Dystrophy Campaign have faced incredible challenges to raise money for the charity. We speak to four individuals and learn the stories behind their achievements.

1. "I climbed Kilimanjaro"

Mark Disney, aged 40, lives in Surbiton with his wife Jude and three daughters: Jessie (nine), Maddie (six) and Evie (two). He climbed Kilimanjaro in October 2007.

"Thankfully, I haven't been touched by muscular dystrophy. My interest in raising money for the charity came about because I'm on the fundraising committee for the Microscope Ball, so I know a little about the condition and wanted to help.

"Climbing Kilimanjaro appealed because I wanted a challenge but, with three children, I didn't want to do anything dangerous. Being at altitude presents risks, but these are minimal if you take a guide and approach the experience responsibly. It took us seven nights and there were six of us in the team, including my colleague Malcolm Dalgliesh. The guidebooks officially describe the climb as a 'walk', but I exercised four or five times a week in the months beforehand. I didn't want to have to face the office having not reached the summit.

"One of the biggest surprises was how arduous it was each night, camping out on the slopes of Kilimanjaro. It's a dormant volcano, so the terrain is harsh with temperatures dropping to around -7 degrees at night. I struggled with altitude sickness, experiencing headaches and disorientation. It wasn't severe, but we could see others coming down the mountain in a distressed state, so we were aware of failure and of the difficulties suffered by others.

"On the seventh night we began climbing at midnight and reached the peak at 7am, just at sunrise. When we reached the summit we were hit by complete elation coupled with exhaustion. Due to the altitude, we could stay only a few minutes to take pictures and enjoy the view before our guides hurried us down the mountain. After days trekking up, the descent to base camp took just two and a half hours. We were so excited that, once there, we didn't know whether to eat, drink or sleep, so we did a bit of each before completing the final three-hour walk to the last camp. It was wonderful to see my family all waiting for me at the airport on my return."

Amount raised: £55,000, divided between the Muscular Dystrophy Campaign and African charity, Partners in Health.
Kelly Matthews, from Carmarthen, is 28 and has myotonic dystrophy. She joined last year’s Sahara trek, completing it in memory of her mother who also had the condition and who died just one week before the event began.

“I made a promise the day my mum died that I would carry on with the trek regardless. Her funeral was just two days before I left, so it was immensely difficult to find the strength to continue with my preparations. But I wanted to make sure that I would make my mum proud.

“I was excited about taking on this huge challenge and apprehensive about how I would cope in the intense heat. My friend Lynda decided to come with me so we trained together, beginning by walking three or four miles a day and building up to 12 or 15 miles in one stint. Before she died my mum spent a considerable period in intensive care, so I wasn’t training as much as I should have been, but my family and friends were very supportive. The night before I was due to leave, my friend and my sister helped me pack my bag and double checked to make sure that I hadn’t forgotten anything. Leaving my dad at the airport was incredibly emotional, but I soon realised that everyone on the trek had personal reasons for being there. It was almost like therapy walking every day and taking time away from everything going on back home. Each of us on the trip seemed to understand when someone wanted to talk and when they wanted to be left alone.

“We walked between 12 or 14 miles for five days. We would begin at 6am with breakfast and crossed a variety of terrain, from sand dunes up to our hips to a dried-up seabed. Sometimes we’d come across camels or nomads in the middle of nowhere. One day we saw a man on a moped! Being in the desert was difficult at times, especially being so far away from my family, but when we reached the finish line as a group, I felt an incredible sense of achievement. The Sahara is an amazing place and I learnt such a lot about myself. It really was a life-changing experience. I’m hoping to take part in next year’s event in Costa Rica (see page 16) and continue campaigning for muscular dystrophy.”

Amount raised: £6,000, including £3,000 from a charity barbecue.

On 4 May last year, David Stockdale and 19 of his friends attempted to climb the 15 peaks in Snowdonia higher than 3,000ft – all in one day. On the same date, his son, Lawrie (12), daughter Freya (eight) and their pals set themselves the goal of swimming 15km in the local pool. Here, David describes their challenge.

“My son Lawrie was diagnosed with Becker muscular dystrophy in 2006. Muscular Dystrophy Campaign has provided support for our family and also does a huge amount of vital research, so I was motivated to do something constructive and give something back to the charity. I decided to raise money by ascending the 15 highest peaks in Snowdonia and I recruited work colleagues and chums to climb with me. I felt a lot of responsibility for their welfare, especially as there are two particularly dangerous parts of the walk with a real risk that someone could lose their life, but there was a huge amount of camaraderie on the team. Most of us undertook a rigorous fitness regime in the months beforehand and at 3am on 4 May we were ready to begin the first part of our adventure – the dauntingly steep and dangerous Crib Coch. Of the 20 people starting out, nine completed the whole challenge, finishing at 11pm that night.

“Reaching the end of the event to be greeted by the guys that hadn’t made it, plus the four people who had worked as our support team, was incredible – we all felt tired but emotionally charged.

“I was relieved too, as three-quarters of the way through my knees had started to give up! Lawrie, Freya and their friends also smashed their goal in their own challenge. They had planned to swim 15km – 600 lengths – with Lawrie completing the final kilometre. In the end, they achieved almost double that.”

Amount raised: £17,000.

* David, his wife Helen and their friends are now preparing for a new challenge – they plan to walk the length of Hadrian’s Wall (84 miles) in two days, on 3 and 4 May. On 17 May, Lawrie and his friends aim to swim 2,000 lengths (54km) in three hours. Together, they hope to raise £20,000 for the Muscular Dystrophy Campaign. If you would like to sponsor them, go to www.justgiving.com/helenstockdale1
After a few hours, the going started to get really tough. We were high enough to be caught up in blizzard conditions with high winds and whiteouts. To get a rhythm going, I counted my steps in sets of 300, but as the air became thinner my brain ceased to function properly and I couldn’t count past 10.

We pushed through the cloudline and as visibility improved, the temptation to stop became too great and I paused to look breathlessly into the valley below. It was an incredible sight – with heavy snow still swirling around the rolling blanket of low-lying cloud. That picture will stay with me forever.

5 July 2007
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The last 150ft were the hardest. Adrenalin took over, but even that was not enough to stave off the impact of extreme altitude and I began to cough violently. Hands on knees, I staggered on towards the top, vision blurring slightly. Negotiating the narrow ridge that leads to the top was terrifying, with a sheer drop and a 1,500ft fall into nothingness on either side.

Finally we reached the patch of jagged rock that is the summit. We stayed there – wordless – for about 15 minutes, sitting on the cold, snow-covered rock and staring out into space as the blazing sun finished its own ascent in the skies behind us. We then began the descent. Among many other things, this experience has made me thankful for my health and the opportunity to experience things denied to so many by illness. I hope our contribution helps those less fortunate and I look forward to my next challenge: Mount Elbrus in Russia, 5,670m…

Amount raised: £2,400.

To read Nathan’s full account, log on to www.muscular-dystrophy.org/your_story and click on Fundraising.

Could you face the challenge?
Sign up to our Costa Rican Quest and explore the rainforest while helping to raise valuable funds for the Muscular Dystrophy Campaign

Following the incredible success of our 2007 Sahara expedition, in which 24 supporters raised £75,000 and much-needed awareness for the charity, we are pleased to announce our Costa Rican Quest, taking place in January 2009.

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To find out more, contact our events team on 020 7803 4300 or email events@muscular-dystrophy.org

Gran Paradiso or bust: Nathan Calcott, left, with Gary Fuller, centre, and a fellow climber
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Driving for Perfection
What is myasthenia?
The term myasthenia describes muscle weakness that gets worse with exercise. Frequently the patient feels worse at the end of the day and climbing stairs is difficult. This type of weakness is characteristically seen in people who have a defect in the transmission of information from the end of their nerves to their muscles. The site at which this information transfer takes place is termed the neuromuscular junction. Myasthenia can result from an autoimmune response in which one’s own body reacts against proteins at the neuromuscular junction, or more rarely it is inherited. This latter form, usually called ‘congenital myasthenic syndrome’ will be the subject of this article.

How our nerves and muscles communicate
When we tell our muscles to contract, the electrical signal must jump across a small gap from the end of the nerve to the muscle. This is achieved by converting the electrical impulse into a chemical transmitter that rapidly crosses the gap and binds to special receptors on the muscle surface, which in turn signals the muscle to contract. Nature has evolved the neuromuscular junction to enable this process to occur rapidly and efficiently.

The role of proteins
A large number of different proteins is involved in the communication process between nerves and muscles and if they harbour defects (mutations), then muscle weakness can occur. The major interest of my group is in patients who retain the ability to receive nerve signals, but only at a reduced level. For any one patient we aim to identify which protein is defective, to find out why it is not working efficiently, then to tailor drug therapies accordingly. The field has advanced rapidly in the past 15 years and we now know that defects in at least 11 different genes can give rise to inherited myasthenia. Even so, we are unable to locate the genetic defect in approximately 40 percent of cases of congenital myasthenic syndrome seen in clinic.

Our research discoveries
The work of my group mainly focuses on what can go wrong on the muscle rather than in the nerve, as the majority of cases are due to muscle defects. On the muscle we find we can divide the defects into two types – those of the neurotransmitter receptor itself (the acetylcholine receptor), and those in the protein responsible for locating and clustering the receptors immediately below the nerve.

Mutations in the genes that code for the acetylcholine receptor subunits were the first to be identified. Electrical recordings found that these changes could cause either the central pore of the receptor to be open for too long, the ‘slow channel syndrome’, or for too short a period of time, the ‘fast channel syndrome’. This is an important first finding since it implies that patients with a slow channel syndrome should have treatments that partially block the receptor, whereas patients with a fast channel syndrome should have treatments that enhance the receptor activations.

Following on from these discoveries it was noted that the majority of mutations were...
located in the adult α-subunit of the receptor (see diagram above). Moreover, most of these mutations nullified the activity of the adult-type receptor. How could patients survive if they have no adult receptors to receive the nerve signal? The answer is that the fetal form of the receptor, which usually stops being generated in large amounts late in gestation, is able to take over. However, it is made only at low levels in adult muscle and thus this subset of patients has what is called ‘acetylcholine receptor deficiency syndrome’—there are just too few receptors on the muscle to receive a full signal. Like the fast channel syndrome, we would look to treat these patients with drugs that enhance or amplify the signal to the muscle.

**Why further study is needed**

As mentioned above, a second crucial prerequisite for efficient signal transmission is aligning and packing the receptors just below the nerve terminal. This process is not yet well understood. In fact, we hope that the study of our patients will provide clues about which proteins are key players in this pathway. One protein that we have been able to study is called ‘rapsyn’. It is crucial for clustering of the receptor and acts as a sort of anchor to keep the receptors correctly located. We believe that many of the rapsyn mutations cause the densely packed clusters of receptors to disperse—without an ‘anchor’ they drift away from their correct location. The result is a syndrome we call ‘acetylcholine deficiency due to RAPSN mutations’.

Finally, the focus of our most recent research has been on a new protein called Dok-7. It is early days in the study of this protein, but it appears to be involved both in the initial stages of forming the neuromuscular junction and also in maintaining the integrity of the structure once formed. Patients with mutations in this protein appear to have junctions that are much smaller than normal, although the receptors are packed at normal density. At present this condition is termed ‘Dok-7 congenital myasthenic syndrome’.

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**View from the lab**

Muscular Dystrophy Campaign in partnership with Myasthenia Gravis Association, is funding Dr Saiju Jacob, a neuromuscular fellow at the John Radcliffe Hospital, Oxford. Here he explains why such funding is so important to him and his fellow clinical researchers.

**Can you explain what your research is about?**

I am investigating the disease mechanisms of seronegative and ocular myasthenia gravis. Myasthenia gravis is an autoimmune disease affecting the neuromuscular junction, causing muscle weakness. In around 90 percent of patients we can identify the antibody causing the disease. The remaining patients have clinical features similar to an autoimmune disease, but the exact antibody is unknown (hence it is called “seronegative”). I am working to define the pathological mechanisms in this group of patients. In addition, I am looking at the clinical and neuropsychological abnormalities in those patients who have only ocular (eye) symptoms due to this disease.

**What does a typical day at work involve?**

The majority of my time is spent in the neuroscience research lab. I also attend neuromuscular clinics (including myasthenia and muscle disease clinics) with Dr David Hilton-Jones and neuropsychology clinics with Dr Robin Kennett. I perform muscle biopsies and we have a muscle biopsy review meeting once a month. It is very rewarding to see the patients, then to correlate the laboratory findings.

**Do you think the Muscular Dystrophy Campaign should continue to fund clinical fellowships?**

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 all initially funded by Muscular Dystrophy Campaign.

**How important has the support from the Muscular Dystrophy Campaign been for your career?**

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 in the form of regular meetings, conferences 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.

**Translating lab work into treatment**

A national service for mutation detection and treatment of congenital myasthenic syndromes, part of a consortium for the diagnosis of rare muscle diseases, is based in Oxford. The service provides rapid translation of discoveries in the laboratory into clinical practice. Although congenital myasthenic syndromes are often difficult to diagnose in the young, study of the clinical features of patients is helping us to identify clues for diagnosis and for pinpointing the location of the underlying genetic defect. But much still needs to be done. There are more genes to find and present treatments are only partially effective. We hope advances in the understanding of these conditions will be maintained for the next decade.

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**Get in touch**

If you have any questions about any of our current research projects or want to get in touch with the relevant clinicians, contact Dr Marita Pohlschmidt, Director of Research.

Dr Marita Pohlschmidt
020 7803 4803
research@muscular-dystrophy.org
Scientists, clinicians and patient groups from around the world recently attended the first Muscular Dystrophy Campaign conference on translational research.

Dr Marita Pohlschmidt, Director of Research, reports

A two-day conference organised by the Muscular Dystrophy Campaign, in partnership with the new MRC Centre for Neuromuscular Diseases, took place on 1 and 2 February 2008 at the Institute of Child Health in London. This inaugural scientific meeting celebrated the first MRC-funded Centre for Translational Research in Neuromuscular Diseases. The programme included international experts in the field of muscle disease, with some 325 clinicians, scientists, representatives from government organisations and patients’ groups attending. Professor Dominic Wells, Imperial College, said: “This conference represents probably the greatest concentration of clinicians and basic scientists for neuromuscular disorders in the UK I have come across so far.”

As well as informing delegates of the latest advances in basic and clinical research, the conference updated them on the research projects currently being funded by the Muscular Dystrophy Campaign. More than 60 scientists, a third funded by us, displayed information on their newest research advances.

Working together to fight muscle disease

The new MRC Centre for Neuromuscular Diseases is a joint venture between University College London and the University of Newcastle-upon-Tyne. It has been set up to address the various barriers that currently hinder a speedy “bench-to-bedside” transfer of technology. Activities include the establishment of clinical trial centres, tissue and cell banks, as well as assessing the most suitable animal models to test newly developed treatment approaches. The activities of the centre are monitored by a Scientific Advisory Committee, which comprises researchers from Europe and the USA. And it was those international experts who contributed to the high scientific standard of the meeting by presenting the latest research.

The delegates were welcomed by Professor Mike Hanna, Director of MRC Centre for Neuromuscular Diseases and Professor Malcolm Grant, President of uCL. Chief Executive of the Muscular Dystrophy Campaign, Philip Butcher, expressed the charity’s support and expectations for this new initiative.

Adrian Pollitt OBE, Head of the National Specialised Commissioning Group, shared his ideas and views on how new advances in translational research can be efficiently implemented into NHS services.

In the evening, participants attended a gala dinner in Lincoln’s Inn, Holborn.

International input

The conference continued with fascinating presentations from Dr John Porter, Programme Director for Neuromuscular Disease at the National Institute of Health, USA and Dr Serge Braun, Scientific Director of the Association Française contre les Myopathies (AFM) in France. Both talked at length about the various initiatives and plans to support translational research in neuromuscular diseases in their own countries, while emphasising the requirement for an international collaboration to achieve their ambitious commitments. In the afternoon, Condition Specific Groups and other networks expressed their thoughts on how to accelerate the transfer of scientific results into the clinics so that patients may enjoy an immediate benefit.

The conference ended with the MDC’s award of travel grants worth £750 for the best scientific poster presentations to groups headed by Dr Janet Smith, from the University of Birmingham and Dr Lyndsey Craven, working with Professor Doug Turnbull at the University of Newcastle. Baroness Thomas of Winchester, who has limb girdle muscular dystrophy, said: “I am very impressed with the research advances presented at this conference and how well the Muscular Dystrophy Campaign is supporting the scientists in this country.”

We would like to express our thanks to Genzyme, Summit Plc, Bio Products Laboratory, Bioteost, Grifols and PTC Therapeutics, for sponsoring the conference.

To download a podcast of the conference, visit: www.muscular-dystrophy.org/research

For support call 0800 652 6352

Dr Doug Turnbull is interviewed for a podcast about the conference

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Children of the Year

In the last issue of Target MD, we asked you to nominate a child who inspires you. Meet our final Inspiration Awards 2007 winners, Matthew Berry and Adam Weatherill

Child of the Year: Matthew Berry
Nominated by: his mother, Sue Berry
Matthew Berry is only 12 years old, yet he’s already a seasoned campaigner for the needs of disabled people. Matthew lives with his mother Sue and 15-year-old brother Andrew in Angmering, West Sussex. He was diagnosed with Duchenne muscular dystrophy when he was four and was just seven when he first talked about his experiences of living with the condition, giving an interview to his local paper to help promote Jeans for Genes.

The following year he was asked to speak to Sussex University medical students studying musculoskeletal anatomy, a trip that’s been repeated every year since. He’s also appeared on TV in support of his local hospice, Chestnut Tree House, attended lobbies of Parliament with Muscular Dystrophy Campaign and helped support younger boys with Duchenne muscular dystrophy. “He doesn’t come across as a boy in a wheelchair who needs help” says Sue. “He is doing everything he can to get on with his life.”

It’s Matthew’s presence that marks him out as an inspiration, says his mother. “People can be uncomfortable around a disabled child, but Matthew is so positive and there’s such humour in the way he speaks that it’s an uplifting experience.” Matthew and his mother make sure that he makes time to fulfil his own needs. “He’s interested in everything from Star Wars to Picasso. He soaks up information and that’s important because it’s using his ability, which shines out of him” says Sue. “He wants to show people that they can look beyond his disability. He’s extremely bright, with a wonderful sense of humour and always keen to speak to people – and that’s nothing to do with his wheelchair. It’s a mark of his own character.”

Child of the Year: Adam Weatherill
Nominated by: his mother, Christine Weatherill
Adam, who lives with his family in Winchester, was diagnosed with Duchenne muscular dystrophy at the age of two. The past couple of years have been particularly challenging. Two years ago, when he was 14, Adam had an operation to correct a 90° curve in his spine. The following year he was diagnosed with mild cardiomyopathy. “He was put on night-time ventilation, medication for his heart and painkillers, but nothing helped” says his mother, Christine. “It then turned out he had a life-threatening infection caused by the original spinal operation. The only answer was a three-hour procedure to remove the metalwork that had been inserted into his spine. It was thought the bones in his back would have fused, so his posture would no longer be a problem.”

Following the gruelling operation, Adam’s posture began to deteriorate again; his spine now has a 70° curvature and his surgeon says the only solution is an eight-hour procedure to replace the metalwork.

“If he opts for further surgery, there’s a good chance he will not survive” says Christine. “If he does nothing, the curvature will affect the internal organs and shorten his life dramatically.”

It’s Adam’s approach to his difficulties that is so inspiring, says his mother. “When he was in hospital, he said he felt sorry for his sisters Hannah and Charlotte, because he was getting all our attention.” He also showed true grit when taking his GCSEs. He would sleep in the morning, then Christine would read textbooks to him in the afternoon. For the tests, she says, “One teacher came to invigilate and another to write down his answers, as Adam was too weak to do that himself.” Incredibly, Adam achieved two A* grades, five As and two Bs.

Christine says, “Adam manages to get on with life without any anger, bitterness or self-pity.”

Matthew and Adam will receive a one-year subscription to Mojo or Grazia magazine and a Body Shop Gift Box for their parents.

Get in touch
If you know an inspirational person who should feature on this page, contact Ingrid Ambrose at the Muscular Dystrophy Campaign.

Ingrid Ambrose
• 020 7803 4838
• ingrida@muscular-dystrophy.org

www.muscular-dystrophy.org
Talking to children

Telling a child that he or she has muscular dystrophy or a related condition can be the hardest conversation a parent ever has. But ongoing communication about the condition can really help your child – and you – to cope with the challenges. Jane Stein explains

One of the biggest concerns for a parent whose child has muscle disease is how to talk to the child about their condition. It is such an important thing to get right. Often parents say nothing because they want to protect their child (sometimes indefinitely), but this is rarely a good idea. It is best to give the child truthful, simple, honest explanations that address the current issues and which you can build on at a later date.

To a child, a parent avoiding a discussion can send a message that their condition is too bad to talk about. This can cause the child more worry and might prevent them from telling you how they feel. Achieving a balance is important; it is equally unwise to burden children with information they may not yet understand or want to know.

One expert, David Waters from the University of Virginia suggests that you follow three golden rules when talking to children: listen more than you talk, use questions more than answers and follow more than you lead. As he points out, “the hardest thing about talking to kids is that you don’t know what they’re going to say.”

It is essential to get in ‘sync’ with your child’s thinking and to start where your child is, not where you are or where you think your child should be. At the end of your conversation, check that your child has understood what has been said and that they know you can talk again at any time if they have further questions.

Good questions to ask include: “What do you know about…?”; “What have you learned or guessed about this…?”; “Do you have any ideas why…?”; “So you’re wondering…?”; “Do you have any questions you want to ask me?” and “What do you think about what I’ve been telling you?” If your child finds the information upsetting, you might agree that it’s sad and say, “I’m sorry I had to tell you this.” Remember that it’s fine for a parent to share emotional feelings with their child.

“He never asks questions”

Like many children with Duchenne muscular dystrophy, 11-year-old Josh Ison from Reading never asks questions, although he does sometimes say, “It would be good if I could walk.” His parents Laura and Lee try to take the opportunity to explain the need for physiotherapy and check-ups but otherwise do not try to initiate discussion. They agree that if Josh asks questions they will answer them honestly, but until then they respect his right not to talk.

Josh is moving to secondary school in September and it might well be then that he will want to know more (when children he doesn’t know ask questions). For the moment, Josh seems happy and enjoys a good range of activities. As the Australian Muscular Dystrophy
hospice, Helen House. I’ve shown them pictures and they’re both keen to visit. I’m really glad we’ve talked.”

“He talks in a negative way”
Sometimes having too much information too early, or having inaccurate information, can cause distress. One professional contacted us about this issue: “I am working with a teenager with Duchenne muscular dystrophy who is concerned about his future and talks about his life in a negative way. He will not plan activities or get involved in anything. What can we do to help him?”

The Muscular Dystrophy Campaign’s advice would be to talk gently to the young man to try to assess what his understanding of the situation is. Listen carefully and try to discover exactly what his concerns or fears are. Perhaps there are things he would like to do but which seem impossible to achieve? Don’t rush to give false reassurances but look for constructive ways forward.

As AMDS says: “There is a need for a balance at all stages between practical realism and acceptance of what is happening; understanding and sharing the negative emotional reactions and still allowing everyone space for optimism, hope and encouragement.”

“I talked to our children using the booklets from the Muscular Dystrophy Campaign”
Benjamin Hafeez is 11 years old and lives with his family in Buckinghamshire. Benjamin has Duchenne muscular dystrophy and started at a new school in September. The school was keen to support Benjamin, but felt they needed to be clear about what he did, and did not, understand about his condition.

Benjamin’s mother, Danielle, took the opportunity to talk to Benjamin and his seven-year-old (able-bodied) brother Ross with the help of booklets produced by the Muscular Dystrophy Campaign. “I read the booklets myself first and then I sat the boys down separately and talked with them. I explained to Benjamin that he was born with Duchenne muscular dystrophy and that it wasn’t his fault that he had it. We went through the booklets together. At the end of our discussion I asked, ‘How do you feel?’ He said, ‘Okay’, and gave me a cuddle. I reminded him, ‘If you ever want to talk more about it, just tell me.’ He seemed happy with that.

“I talked to Ross when we were walking home from school together. I asked, ‘Do you know why Benjamin goes to a special school?’ He said, ‘No.’ We talked about muscular dystrophy and when we got home we looked at the booklets and I said to Ross, ‘If there’s ever anything you want to know, just tell me and we’ll talk.’

“I’ve left the booklets lying around and both boys pick them up and look through them — and Ross has read all through them. Benjamin’s school is really pleased — it helps the teachers to know that Benjamin understands more about his condition and that we can be open with others, too. I’ve also spoken to both boys about going to look around our local children’s hospice, Helen House. I’ve shown them pictures and they’re both keen to visit. I’m really glad we’ve talked.”

“IT helps the teachers to know that Benjamin understands more about his condition and that we can be open with others”

Be open to discussion. Sometimes the help of someone outside the family can be valuable – it is often easier to share upsetting thoughts with someone who is less emotionally involved than a parent. Hospices for children or young adults may offer valuable support or a clinical psychologist might assist.

“The key thing is to know your child”
Mike Gibson from Oxfordshire is 26 and has a diagnosis of Duchenne muscular dystrophy, so he is well placed to provide an adult perspective. Since leaving school, Mike has obtained a degree in aeronautical engineering.
and is now studying for a PhD. He writes: “Even as someone with Duchenne muscular dystrophy, I find it hard to say how much you should tell others about their condition and when. As an adult I always follow the ‘know your enemy’ path, but with children (including myself when I was younger) the approach has to be tempered. First, children don’t always have the experience to swallow the enormity of being diagnosed with Duchenne muscular dystrophy without it having an even greater impact on them. Second, their parents have also been given some of the worst news imaginable, so at that time they might not be able to give the support their son will need.”

Mike continues: “I feel it’s important to make sure that boys with Duchenne muscular dystrophy understand that the cause is genetic, and doesn’t in any way single them out. Also, while they don’t need to know the exact cause, they should be told what they can do to combat Duchenne muscular dystrophy – exercise, stretches, diet, medication and so on. The key thing is to know your child, and understand how best to help him come to terms with the condition. Luckily, especially for those newly diagnosed, the prognosis is in my opinion very hopeful these days – hang in there!”

“There is a need for a balance at all stages between practical realism and acceptance of what is happening”

For further information

- The following booklets are available from the Muscular Dystrophy Campaign: Everybody’s Different, Nobody’s Perfect; Same but Different; On the Ball (for 11 to 14-year-olds); Hey, I’m Here Too! (for siblings). To request copies, call 020 7803 4800 or visit www.muscular-dystrophy.org

- www.brainpop.com has a great little show on Duchenne muscular dystrophy which is free and suitable for children.

- The Australian Muscular Dystrophy Society has advice at www.mda.org.au

- Counselling Children with Chronic Medical Conditions by Melinda Edwards and Hinton Davis is a textbook for professionals that might also be helpful to parents: British Psychological Society 1997, ISBN 978-1-85433-241-7.

More resources and contacts on page 38.

For support call 0800 652 6352
Our care agenda for 2008

In our first issue of Target MD this year, here’s an update of how the Muscular Dystrophy Campaign plans to support people with muscle disease via care grants, conferences and support events in 2008

Clinical Research & Care Grant funding for 2008-2011: £377,596
The following centres will benefit from the charity’s support for their work:

Dubowitz Neuromuscular Centre and Institute of Neurology, London
Grant Holder, Professor Francesco Muntoni
The Dubowitz Neuromuscular Centre (DNC) and the Institute of Neurology (ION) Neuromuscular Centre made a joint bid this year to set up a larger facility between the two collaborating centres. The DNC is one of the largest paediatric neuromuscular centres in Europe and the ION is one of the largest adult neuromuscular centres in the UK. This collaborative grant provides a great opportunity to take advantage of the expertise provided by both centres for the benefit of the patients.

The two centres will provide a training environment for future neuromuscular neurologists and will be involved in scientific and clinical research and development. One important focus will be the generation of best practice development for both adults and children, including the establishment of best clinical practice guidelines for transition of care between children and adults.

Newcastle Muscle Centre
Grant Holder, Professor Kate Bushby
For many years, the Newcastle Muscle Centre has been involved in developing the best possible standards for care and diagnosis in neuromuscular diseases. This expertise is applied to the local multidisciplinary clinics and diagnostic services and also has been disseminated to the national and international community, via care guidelines and pivotal papers on natural history and the result of interventions. The centre intends to invest in the future by training new neuromuscular specialists in the best standards of diagnosis and management, as well as research. The administrative and clinical research coordinator roles provided for by the grants will enable the centre to develop outreach and communication activities further, as well as providing the platform for more research, including clinical trials.

Oxford Muscle and Nerve Centre
Grant Holder, Dr David Hilton-Jones
The principle aim of the Muscle and Nerve Centre is to provide an integrated approach to the management of patients with neuromuscular disorders. They have demonstrated the benefit of working in close collaboration with research colleagues and the benefit to researchers in providing them with material from patients. This has been particularly evident in trying to identify genetic mutations and in using results from the laboratory in aiding clinical management, including genetic counselling.

Patients in the clinics are seen by specialised staff, including a dedicated neuromuscular nurse and physiotherapist along with our Care Advisor. The centre will provide training for a clinical research fellow, allowing him or her to gain laboratory and clinical training. These fellows then go on to become the neuromuscular specialists of the future.

Wolfson Centre for Inherited Neuromuscular Disease, Oswestry
Grant Holder, Dr Rosalind Quinlivan
Dr Quinlivan was awarded a grant to provide clinical psychology support for neuromuscular patients attending the Wolfson Centre. The service will support families at the time of diagnosis, loss of walking, transition to adulthood, times of crisis and bereavement. Other issues addressed will be behavioural concerns, especially in children with Duchenne muscular dystrophy receiving steroid therapy and children with congenital myotonic dystrophy. The service will provide strategies to assist patients and carers in dealing with stress, behaviour difficulties, chronic illness and disability. The overall aim is to improve quality of life and enable full participation in society.

Dates for 2008
Make sure you don’t miss out – get these important dates in your diary now!

• Naidex 2008
NEC, Birmingham, 29 April-1 May
The UK’s largest exhibition of equipment and services to aid people with disabilities. Come and meet our Care team at our stand.

• Muscular Dystrophy Campaign Professionals Network Meeting, Leeds, 14 May
The day is designed for health and social care professionals working with children and adults with neuromuscular conditions in a variety of disciplines: care staff, physiotherapists, occupational therapists, and school and nursery teachers/support staff are all welcome. Cost is £30 including lunch and refreshments. For a booking form, please contact Peter Lawson at info@muscular-dystrophy.org

• Conference for people with Becker muscular dystrophy and LGMD Network Meeting, Brentwood, 7 June
For enquiries, please contact Jane Stein on 01865 234221 or jane.stein@cneuro.ox.ac.uk

• Family Weekends, various locations in England, Autumn 2008 including:
19-21 Sep, Calvert Trust, Keilder Water, NE
10-12 Oct SHARE Centre, Northern Ireland
Thanks to the generous donation of £50,000 by the Garfield Weston Foundation, we are planning three Family Weekends. These are tremendous fun for all ages – they reduce the feeling of isolation, offer vital peer-to-peer support and address key issues for individuals and families. Contact Peter Lawson at info@muscular-dystrophy.org

www.muscular-dystrophy.org TargetMD 27
Regional round-up

Muscular Dystrophy Campaign Regional Fundraising Managers, Branches and supporters all over the country have been busy organising events to raise money to help fight muscle disease. Turn the page for news on upcoming events.

1. Scotland
SPIRIT OF CHRISTMAS
Carol concerts were enjoyed in Edinburgh with top young musicians from St Mary’s Music School, in Aberdeen with footballers Jackie McNamara and Zander Diamond and in Glasgow with River City favourites. Thanks to all who supported these moving events.

THANK YOU
Hamilton Sports Council raised £500 and has adopted the Muscular Dystrophy Campaign as one of the charities to benefit from the annual Hamilton Fun Run.

FUNDRAISING, ETCETERA, ETCETERA
East Renfrewshire Rep Reg Mackie and a team of collectors raised more than £1,600 at the Glasgow Light Opera Club’s performance of The King and I. A trust donation gave East Renfrewshire’s effort for 2007 a boost, bringing the total amount to over £15,000.

2. Northern Ireland and the Isle of Man
THANK YOU
• A Question of Thought took place 29 February–9 March 2008. Thanks to everyone who took part.
• Magheragall Presbyterian Church raised £1,700 for Muscular Dystrophy Campaign by organising a concert on the theme of Classic Musicals.

WELCOME
We welcome Jenny Lee, who joined the team in December and is looking after all the Rupert Bear collecting tins across Northern Ireland.

3. North West
IN THE SWIM
Lynda Price of Manchester swam a total of 2007 lengths of the pool at her local gym, completing her challenge three weeks before the end of the year and managing to raise over £2,200. Lynda thanks her sponsors and the staff at Total Fitness, Walkden.

THANK YOUS
• Val Rigby, Joanne Ashton and Amy Hayes, who took part in the Hydro Active Women’s Challenge race in Liverpool, raising over £800.
• The Maghull Musical Theatre Company, who raised £400 from their concert.
• Eddie Bradley and everyone at the Plough Inn, Liverpool. Eddie had his head shaved and raised a total of £900.
• Lisa and Richard Morley of Tottington, who organised a rock night in Bury raising over £800.
• Steve and Bev Slack, friends and family, who took part in the annual 15-mile Wirral Coastal walk. As a result over £2,700 was raised.
• Christine Ogden of Bolton who organised a Christmas German concert, which raised over £1,500.

4. North East
BULLSEYE
• The Harley Davison Geordie chapter raised £2,000 from rallies and various other events.
• Ken Sparron organised a darts challenge and is set to hit the bullseye with £1,000.
• Alan Dawes and Phil Temperley raised £905 with a sponsored walk of the West Highland Way.

FEELING GROOVY
Mick Curry’s Jazz Night grooved in with £400; Bob Jones’ All Day Rock Music at Bradford Polish Club raised a rockin’ £900. Margaret Bowerbank’s line-dancing sessions also raised £135. Well done to you all!

5. West Midlands and Wales
THANK YOU
• Congratulations to a group of Year 10 students from Wolverhampton Grammar School for raising £6,459.22 from their Coast to Coast relay run from St. Bee's Head in Cumbria to Robin Hood’s Bay in Yorkshire. 180 miles, which took 25 hours.
• Thanks also to Roy Mercer, Steve Heath, Gareth Adams and Brian Welfare, who raised £3,098 by walking the entire 184 miles of the River Thames from its source near Kemble, Cirencester to the Thames Barrier in London, and to John Graham who followed the walkers in a support boat.
• Thanks to Louise Slaughter and the Aga Shop in Stratford, who put on a scrummy demonstration for us on 31 October and raised over £1,000 in one morning.

CHRISTMAS SPIRIT
Our successful Spirit of Christmas took place in Llandaff in Cardiff, Worcester and Gloucester. All three events raised well over £15,000.

JAIL4BAIL
On 26 February, 14 members of...
the Shropshire business community paid a minimum of £500 to be arrested by the local constabulary. These volunteer ‘felons’ were then wined and dined before their release.

6. East Midlands
REMEMBERING A FRIEND
Hope Valley College, raised £1,000 in memory of Mark Cotterill.

THE BIG PUS

THANK YOU
• David Croker from Sleaford, Lincolnshire carried out a Big Push 20 Mile Cycle Ride and raised a total of £1,208.
• A big thank you to Steve, Lisa and Jacob Gratton, Dale Cooke and Natalie Jones, who completed a 10k run in Nottinghamshire, raising £1,374.50.
• Thank you to all who took part in the Rutland Round in September 2007. The event raised a magnificent total of £2,500.
• Thank you to Amy Sutton from Ashbourne, Derbyshire, who held a couple of fundraising events and raised a fantastic £1,211.

7. Anglia & Bordering Counties
THANK YOU
• Chelmsford, Brentwood and Rochester Muscular Dystrophy Campaign Branches teamed up for the Spirit of Christmas carol service at Chelmsford Cathedral. Grateful thanks to Margaret Cozens, musical director of The Fidelio Singers and the wonderful choir Sine Nomine from Southend High School.
• Maths teacher Nick Rees has raised £1,376.15 through a sponsored abseil off a 130ft high hotel in Bedford. Nick has rigid spine syndrome, one of the rarest forms of muscle disease.
• Audrey Hatcher (our very own Auntie Wainwright), who manages the Muscular Dystrophy Campaign charity shop in South Woodham Ferrers. Contact Audrey on 01245 329735.
• All who took part and helped out at the Bury 20 road race on 24 February and The Forest Challenge, Rendlesham Forest on 9 March.

8. South East
THANK YOU
• Christ Church Primary School in Surbiton Surrey held an Art Day, raising £436.30.
• Bookham and Horsley Inner Wheel had a supper dance and raffle, which raised over £2,000.
• Francesca Wright held a car boot sale and a charity lunch, both of which raised £515.
• Christine Barker has taken her fairground organ to various events throughout year and collected a total of £245.
• £200 was received from Redhill Carnival committee.

9. South West
THANK YOU
• Freddie Morris aged 11¾, and friends Ralph Lawson and Alexander Woolcock, raised £157.50 on a sponsored cycle around Dartmoor.
• Mandy Thompson raised £100 in the Fastnet yacht race, from which she unfortunately had to retire due to bad weather.
• Thanks to the Dreamweavers Line Dancing Club of Salisbury for their £210 donation.
• Michael and Hilary Brown donated over £500 in lieu of presents to celebrate their silver wedding anniversary.
• Dairy Crest donated £1,000 to the Power Pack football team for wheelchair bumpers.
• Plymouth Mayflower Rotary Club for marshalling the Pedal for a Medal cycle ride.
• Gordon Fletcher for raising over £800 from donations to view the festive Christmas lights displayed at his home in Keynsham, Bristol.

GIFT FOR DONATIONS
Special thanks to Dr Price of the Exmouth Health Centre who asked patients and colleagues to make donations to Muscular Dystrophy Campaign Exmouth Branch instead of buying presents to mark his retirement from the practice.

AULD LANG SYNE
Tavistock Muscular Dystrophy Campaign branch held a New Year party including a pastie and pudding tea, games and music.

10. London
SPORING LEGENDS
Ex-Chelsea FC and ex-Charlton Athletic FC players took part in a charity football match to raise money for the Muscular Dystrophy Campaign on 2 March. The day included pre-match entertainment and a memorabilia auction.

THANK YOU
To all who attended our first Spirit of Christmas at Southwark Cathedral, which was a fantastic evening.

11. Home Counties North
THANK YOU
A big thank you from Caroline Kehoe to everyone in the Home Counties North region for making her feel so welcome since she started as Regional Fundraising Manager. Watch out for Muscular Dystrophy Campaign on Facebook in March, where Caroline will be advertising events and giving you an opportunity to see what’s going on in the North Home Counties.
Upcoming Events

Please join in and help to generate valuable funds for the Muscular Dystrophy Campaign

1. Scotland
   **GREAT SCOTTISH WALKS**

2. Northern Ireland and the Isle of Man
   **28 MARCH – NORTHERN IRELAND BALLOT DRAW**
   Tickets £1 each; £1,000 prize.
   **SWIMMING WITH SHARKS:** Dive with sharks in Scotland. Minimum sponsorship £350.
   **AUGUST – JAIL 4 BAIL**
   Have your boss arrested, cautioned, handcuffed and led away by the police. All your boss has to do then is raise £500 bail money.
   **31 MAY & 16 JUNE – DIVING WITH SHARKS**
   Other dates can be arranged.
   **JUNE – ABSEIL**
   An abseil is planned in Coventry. Using the Ladder is a choice of 6 or 12 miles, and a 59-mile bike ride.

3. North West
   **14 JUNE & 20 SEPTEMBER – DIVE WITH SHARKS**
   Learn scuba-diving with sharks in Cheshire. Dive for free if you raise the minimum sponsorship.
   **18 MAY – WIRRAL COASTAL WALK**
   A leisurely 15 miles.
   **18 MAY – GREAT MANCHESTER RUN**
   A 10k run through historic Manchester. Minimum £200 sponsorship guarantees a place.
   **13 JULY – MANCHESTER TO BLACKPOOL CYCLE RIDE**
   59-mile bike ride.

4. North East
   **5 OCTOBER – BUPA GREAT NORTH RUN**
   Last year our fantastic runners helped raise over £55,000 for research and care in the world’s most popular half-marathon. To take part this year, call the events team on 020 7803 4800 or email events@muscular-dystrophy.org
   **For other North East events, call Glenn Oakes on 02890 751497 or email northeast@muscular-dystrophy.org**

5. West Midlands and Wales
   **14 MARCH – DINNER DATE WITH JOOLZ**
   Saxophonist Joolz Gianni entertains in Bewdley. Call Haydn Bebb on 07807 548968 (mobile) or 01562 631858.
   **31 MAY & 16 JUNE – DIVING WITH SHARKS**
   Other dates can be arranged.
   **JUNE – ABSEIL**
   An abseil is planned in Coventry.
   **6 JULY – MALVERN WALK**
   The next scenic Malvern Walk.
   **SEPTEMBER – FIREWALKING**
   Firewalking in Birmingham. Call Penny Weir on 01432 360373 or email midlands_wales@muscular-dystrophy.org

6. East Midlands
   **EAST MIDLANDS SKYDIVES**
   Opportunities throughout 2008 to make a giant leap for a good cause.
   **5 APRIL – LEICESTER BRANCH ANNUAL DISCO**
   Call Stephanie Henderson-Barrett on 0115 249 4797 or email eastmidlands@muscular-dystrophy.org

7. Anglia & Bordering Counties
   **19 MAY – OXFORD TOWN & GOWN**
   A 10k Fun Run around Oxford’s historic centre and university parks. One of our Run for Muscles events.
   **18 JULY – BRANDON FOREST CHALLENGE**
   An 11-mile Run and Bike event through Thetford Forest. www.runbikeevents.com
   Call Anne Jackson on 01787 313913 or email anglia@muscular-dystrophy.org

8. South East
   **26 OCTOBER – BUPA GREAT SOUTH RUN**
   Enjoy this 10-mile run along the breezy flat coastline of Portsmouth.
   Contact events@muscular-dystrophy.org
   **24 APRIL – JAIL 4 BAIL**
   Get arrested at work by the Town Crier and led away to HMS Warrior until £500 bail is paid.
   **4 MAY – BASINGSTOKE CANAL RIDE**
   A 32-mile sponsored ride along the Basingstoke Canal with transport back to the start.
   **10 MAY – JUST WALK**
   A 20km or 60km walk along the South Downs; www.just-walk.co.uk
   Contact Eileen Wellings on 01372 375906 or email southeast@muscular-dystrophy.org

9. South West
   **25 APRIL – I’M A COMPANY DIRECTOR…**
   Get Me Out of Here! A subterranean expedition beneath the Mendip Hills. No previous experience is necessary.
   **18 MAY – ROLL & STROLL**
   Along the Camel Trail from Bodmin to Wadebridge. Suitable for wheelchairs and buggies.
   **13 JULY – ABSEIL THE SEA WALLS**
   Abseil 100ft cliffs at Avon Gorge in Bristol. Full training given.
   **14 SEPTEMBER – PEDAL FOR A MEDAL**
   The 17th cycle ride from Plymouth to Dartmoor National Park. A choice of 7, 20 or 35 mile routes.
   **26 MAY – BUPA LONDON 10,000**
   The organisers of the London Marathon bring you a new 10k event.
   **6 JULY – ASICS BRITISH 10K LONDON RUN**
   Join Olympic athletes and celebrities in the 8th annual British 10k London Run. Call the events team on 020 7803 4800 or email events@muscular-dystrophy.org
   **JUNE – THE MIGHTY ABSEIL**
   Are you up to the Challenge?
   **SEPTEMBER – JUBILEE WALK**
   A fantastic six-mile walk, suitable for all the family, around some of London’s amazing sights.
   **25 SEPTEMBER – PEDAL FOR A MEDAL**
   Cycle from Watford to Windsor.
   **24 APRIL – JAIL 4 BAIL**
   Get arrested at work by the Town Crier and led away to HMS Warrior until £500 bail is paid.
   **4 MAY – BASINGSTOKE CANAL RIDE**
   A 32-mile sponsored ride along the Basingstoke Canal with transport back to the start.
   **10 MAY – JUST WALK**
   A 20km or 60km walk along the South Downs; www.just-walk.co.uk
   Contact Eileen Wellings on 01372 375906 or email southeast@muscular-dystrophy.org

11. Home Counties
   **JUNE – DARE TO DANGLE**
   Abseil to raise funds.
   **JULY – TEDDY BEARS’ PICNIC**
   At Black Park, Buckinghamshire.
   **JULY – DICK TURPIN CHASE**
   Cycle from Watford to Windsor.
   **27 SEPTEMBER – CHESTER GHOST HUNT**
   Get sponsored to stay the night in a haunted house.
   Call Charles Horton on 01244 403012 or email northwest@muscular-dystrophy.org

For more details about events, or if you are interested in organising your own, contact Melinda Polidario on 020 7803 4824 or regions@muscular-dystrophy.org
In good company

Make the Muscular Dystrophy Campaign your workplace charity or remember us when you change a printer cartridge: every little helps

Can you help us?

In our efforts to increase funding from companies we have found that many welcome employees’ nominations for their Charity of the Year schemes. In 2006 Norwich Union chose Muscular Dystrophy Campaign as their charity of the year, following an advocacy by employees Andy Bode and Keith Dunsire, both of whom have sons with Duchenne muscular dystrophy. Andy and Keith helped organise a popular armwrestling competition. If you have friends and family who work for the following companies, or if you would like to become proactively involved in fundraising for Muscular Dystrophy Campaign, please get in touch: NM Rothschild, Balfour Beatty, Alliance & Leicester, Baker McKenzie, Gardiner & Theobald, Deloitte & Touche, Morgan Stanley, Britannia, Jones Lang LaSalle. Please call a member of the corporate team on 020 7803 4800. We look forward to hearing from you.

Printer cartridges raise money for MDC

Our new affinity scheme, MyCartridge™, means our supporters can buy replacement printer cartridges at a competitive price while helping us. MyCartridge™ is giving a donation to MDC for every replacement cartridge bought through the scheme. There is an extensive range of laser and inkjet cartridges available, suitable for most office and home printers. MyCartridge™ offers competitive prices with friendly service, 100 percent secure online ordering, fast delivery options and a no- quibble product guarantee. You can check out what’s available by visiting our website at www.muscular-dystrophy.org/cartridges.

Alternatively, contact MyCartridge™, on 01635 587064, quoting ‘Muscular Dystrophy Campaign’. Give the details of your printer model and they will provide you with a competitive quote. It’s really that simple.

Loose change helps charity

Muscular Dystrophy Campaign is delighted to be working with Virgin Atlantic in April and May 2008 as part of the company’s ‘Change for Children Appeal’. During flights, the cabin crew make an announcement encouraging passengers to donate any loose change – in any currency. So, if you or anyone you know plans to travel with Virgin Atlantic during these months, please look out for the charity and donate!

We would like to say a special thank you to Christine Ogden, one of our dedicated members, who championed our cause to Virgin Atlantic many months ago.

Every click counts

Muscular Dystrophy Campaign can now benefit from everyclick.com, an Internet search engine with a big difference – it donates half its revenues to charity.

Simply visit www.everyclick.com/musculardystrophycampaign and make it your homepage. It does not cost you – or us – a penny, so please use it whenever you search the web. Thank you!

Neuromuscular network for schools

Inside this edition of Target MD you will find a form that you might like to pass on to your child’s school. We aim to build a database of all the schools in the UK that have a child with a neuromuscular condition. This will allow us to offer training, relevant literature and updates. We also want to create a schools forum for the exchange of information and ideas. Information about individual children will not be kept on the database and schools will not be permitted to discuss children without the written consent of parents/guardians concerned.

Please encourage your child’s school to participate. Contact Regional Care Advisor Jane Stein, on 01865 234221 or email jane.stein@cneuro.ox.ac.uk

A will to help

The Muscular Dystrophy Campaign receives just under £1,000,000 a year from legacies. This income sustains our current research projects and care services and helps us to plan for the future. This is why we are asking all our supporters to consider leaving a gift in their will to the Muscular Dystrophy Campaign. For more information, contact Ingrid Ambrose on 020 7803 4838; if you live in Scotland, contact Ken Brown on 01809 511313; or email legacies@muscular-dystrophy.org

Get Involved

www.muscular-dystrophy.org

TargetMD 31
Muscular Dystrophy Campaign Information and Support Manager Eva Wall answers your questions

REFUSING HELP FOR CONDITION

Q My son is in his thirties and was diagnosed with Becker muscular dystrophy when he was nine. I’m worried that he hasn’t seen anyone about his condition for years – he says that as there’s no cure, there’s no point. He’s having more difficulty getting around and is struggling at work. What’s your advice?

A Many adults are in this position and we would advise them to ask their GP to refer them to a specialist muscle centre or clinic. We can provide details of such clinics across the UK. The fact that there is no cure for muscular dystrophy at the moment does not mean that there are not many things that can be done to help.

From a medical point of view, advice on the condition and its likely progression, plus the management of related issues for which there may be treatment (for example, cardiac problems), is important. Genetic counselling may be a concern for anyone planning a family and accurate advice is essential. At most specialist clinics, your son would have access to other professionals with a particular interest in muscular dystrophy – for example, a Regional Care Advisor and a physiotherapist. Advice on exercise, discussing issues with employers, claiming benefits or adapting a property might all be available at the clinic and could be beneficial.

Finally, maintaining contact with a specialist clinic would enable your son to receive advice about which health problems are related to his dystrophy and to keep up to date with the progress of research.

AM I TOO OLD TO CLAIM DISABILITY LIVING ALLOWANCE?

Q I’m 64 and I have Inclusion Body Myositis. I’ve been advised to put in a claim for Disability Living Allowance, but I’m reluctant to do so as I understand DLA stops at 65. I also have a private pension – won’t this be taken into account?

A If you are having difficulty with walking and/or need assistance with personal care or with cooking yourself a meal, it’s important that you put in a claim for DLA before your 65th birthday. While claims for DLA can be made only by those under 65, if you are receiving DLA when you are 65 (or if a claim that is later successful is made before you are 65), you will continue to receive DLA indefinitely as long as you still meet the criteria. After the age of 65 it’s possible only to claim for Attendance Allowance (AA), which is less generous. There is no mobility component to AA so it’s not possible to claim for problems with getting around unless they affect your ability to cope with your care needs.

Neither DLA nor AA is means-tested, so earnings from private pensions, savings and employment are not taken into account. If you are turned down for a benefit you feel you are entitled to, consider making an appeal – your local Citizens Advice Bureau should be able to assist you. For general advice on benefits you can call the Benefits Enquiry Line on 0800 882 200. If you are in Northern Ireland, the number is 0800 220 674.

HOW HOSPICE CAN HELP KIDS

Q Our son is 11 and has Duchenne muscular dystrophy. People around us keep suggesting we use the local children’s hospice for respite care but this idea really scares us. Do other families use hospices for children this young?

A Many parents are concerned when the idea of using a children’s hospice is first put to them. They picture somewhere dark, dreary and quiet, with lots of acutely sick children. The reality is very different. All children’s hospices are bright, warm places that offer respite care (often over the course of many years) to children with conditions such as Duchenne muscular dystrophy. They also provide support to the whole family and try to assist in times of crisis.

Children’s hospices cater for children of all ages and staff will certainly be familiar with 11 year olds. Usually parents and other children can stay in separate accommodation at the hospice. Most children love attending their local hospice for respite care as there is a lot for them to do and they get one-to-one attention. To find your nearest one, call 0117 989 7820 or see www.childhospice.org.uk
Ingenious!

Designed and developed over a number of years the ingenious Genie is the most advanced wheelchair of its kind.

Providing independence both for yourself and your carer is a key feature of this affordable product.

Available in a choice of fabrics and complete with hygienic, easy-to-use toilet facilities the Genie will revolutionise your quality of life.

Further Information from Easy Care Products Limited, Park Lane, Old Park, Telford, TF3 4TE.
Fax: 01952 616588
www.easycareproducts.co.uk

01952 610300
Feedback

Soapbox

We have received two letters that highlight the concerns of people with muscular dystrophy in other parts of the world. Here are extracts from them...

STAR LETTER
THOUGHTS FROM NIGERIA
My two brothers, Esien, 60, and Eyo, 56, were both diagnosed with muscular dystrophy around the age of 16, although they do not know which type. Esien took up employment with the Nigerian Ports Authority in Lagos, supporting himself and his siblings as our father had died. With the chaotic transport services in Lagos, one should imagine Esien struggling to board a bus amid a teeming crowd of able-bodied commuters. He did this every working day for nine years, until his legs could no longer effectively support him.

Leaving employment in Nigeria means absolute loss of income as there is no social welfare scheme. For 32 years, Esien has had no source of livelihood, except through his efforts in investments and the support of his family. Eyo has been luckier. After finishing his education, he was employed in the Government Coastal Agency, Lagos, He retired in 1989, on grounds of failing health, and received a pension of around £40 per month. He has had no paid regularly – sometimes for up to one year.

No one can recollect any other members of our family suffering from muscular dystrophy. We have also not come across any other people with the condition in Nigeria. We guess that there must be others just like us, but in Nigeria there are no programmes available for the disabled to actualise themselves and be part of the overall society.

Last year, Esien and Eyo joined a disabled cooperative association that holds monthly meetings. Through this association they were at last able to get motorised wheelchairs from the state government – for Eyo, it was his first wheelchair; Esien had previously had a manual one.

My brothers hope an affordable cure for their condition will be found within their lifetime. Reading Target MD keeps us informed and helps us keep hope alive.

Ekpe Ita
Brother of Esien and Eyo
To read the full letter go to: www.muscular-dystrophy.org/your_story

FRIENDS OF CUBA
I visit Cuba every year with the charity Friends of Cuba, which provides medical and financial aid (I received a commendation for my work last year). I have befriended a lovely young woman named Asmara, who has an undiagnosed form of muscular dystrophy (I have FSH). She is always smiling, laughing and jolly, despite her troubles. Her husband deserted her last year; her house is sorely in need of repair and she has little to occupy her time.

A wheelchair or scooter would greatly improve Asmara’s quality of life. Is there any Muscular Dystrophy Campaign supporter out there who could help? If anyone can, or if anyone would like to find out more about Asmara or the work of Friends of Cuba, please telephone me on 028 437 24746, and ask for David Allister.

Competition Winners

- Ronald Ives, Co Durham
- Thomas McCracken, NI
- Ruth Henry, NI
- S Hamilton, West Midlands
- Toni Abram, Cheshire

Each win £100 off the total cost of a Virgin holiday, plus 5 percent off the remaining total, plus a Kodak EasyShare C310 digital camera. Readers can get 5 percent off any Virgin Holiday by phoning 0871 222 0052 and quoting MDC.

*CLASSIFIEDS*

FOR SALE
- Adapted Peugeot Expert 1.9 Diesel car. Manual controls, silver chassis, low mileage, 5 registration. Seats five, plus one wheelchair user, via rear, ramped access. £5,000. Contact Mrs E Weston on 020 8856 8828.
- Spectra Plus powered wheelchair with tilt, five years old, good working order, £200 ono. Contact Debra England on 01993 385559.
- Guldmann Flexus electric bed. Single, fully adjustable, pine finish with mattress and tray. Fully serviced and in very good condition. £350 ono. Contact Richard Bright on 01258 472837.

TO RENT
- Guesthouses and 10 cottages, all of which are accessible for disabled people: The Marine Hotel, Aberystwyth. Seafront hotel with lift to all floors. One bedroom adapted for wheelchair use; easy access to the main entrance and all public areas, including bar, dining room and function room; disabled toilets on ground floor.
- Lilyceio Country Guest House, Aberystwyth. Award-winning accommodation with one bedroom specially designed for disabled guests; accessible rooms.
- Bryncarneedd Cottages, Aberystwyth. Self-catering accommodation on the outskirts of Aberystwyth. Contact Nerys Evans on 01970 612444 or email marinehotel1@btconnect.com

If you have equipment you want to sell, please send your copy for the next issue by 20 April, 2008.
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Clothes & shoes

Fashion isn't just for able-bodied people. Here's what to wear to feel comfortable and look good in a wheelchair and how to find it.

From design collections to the high street, it's clear that most clothes aren't designed with wheelchair users in mind. Sitting in a wheelchair presents specific challenges when it comes to getting dressed: your body is bent at the knees and waist; your proportions may change, becoming thicker at the waist, hips and thighs; lack of mobility may make getting into clothes difficult; and postural problems can make items less likely to fit well. Some clothes and styles work better than others. You may find that clothes from a particular high-street store fit you well, or you might prefer to buy from a company specialising in clothes for disabled people. Here's our guide to what to look for:

Coats and jackets
• Look for short styles, such as anoraks, blousons or bodywarmers, which you won't need to sit on. Hip-length jackets with splits at the side are also good options.
• Double-ended zips mean you can open the bottom of a jacket to the waist, making it more comfortable.
• Capes, ponchos and shawls are trendy and can be slipped on easily.
• Specialist suppliers stock coats and jackets with longer fronts and short backs for wheelchair users, plus rain capes and coveralls.

Skirts and dresses
• Loose-fitting, flared and pleated skirts are the most comfortable and flattering.
• For a more body-conscious look, choose an A-line skirt – it will give the appearance of a straighter style when you're seated, without pulling across the hips.
• Slightly longer styles that fall below the knee often look better than shorter designs.
• A matching top and skirt can give the look of a dress but will be easier to wear.
• Choose longer length styles that won’t ride up when you sit down.
• Pleat-front trousers give more space around the bottom and hips.
• Specialist suppliers make trousers with a longer back and shorter front seam for wheelchair users.

Shirts & tops
• Designs with large armholes and plenty of fabric across the shoulders and chest will be easier to slip on.
• Longer tops with side slits from hem to waist are smart without being restrictive.
• Knits and jersey fabrics will adapt to your body shape and stretch as you move.
• Velcro-fastening or slip-on shoes are easiest to put on.
• Wide-fitting styles that finish below the ankle are most comfortable.

Trousers
• Elasticated waistbands make dressing easier and can be hidden by a slightly longer top.
• High waists are back in fashion, and won’t gape at the back when you’re sitting in your wheelchair.
• Front pockets are more accessible than back pockets (these can also be uncomfortable to sit on).

Shopping
• Most high-street stores have websites, so you can browse or even buy online before you go out.
• Many online-only stores offer a no-quibble returns policy, in case your chosen items don’t fit once you try them at home.

In the next issue of Target MD, our Buyers Guide will feature adapted computers.

Specialist suppliers

ABLE2WEAR
Tel – 0141 774 8000
www.able2wear.com
Trousers, skirts, tops, waterproof and protective garments for wheelchair users. Some items for children. Catalogue available.

AWEAR (UK) LTD
Tel – 0115 953 0439
www.awear.org.uk
Information on accessible high-street stores, along with details of independent specialist clothing services.

BASSETT LAW FASHION SERVICES
Tel – 01777 860206
www.bassettlawfashionservices.org.uk
Bespoke clothing and alteration service for disabled people, at high street prices.

CLOTHING SOLUTIONS FOR DISABLED PEOPLE
Tel – 01274 746739
www.clothingsolutions.org.uk
Offers purchasing advice, a bespoke design service and tailoring of existing clothes for disabled people.

DRESSABILITY
Tel – 01793 485374
www.communicate.co.uk/wilts/dressability
Local charity offering alterations and a dressmaking service for disabled children and adults. Home visits in Swindon available.

ROLLI-MODEN
Tel – 0049 6226 960 203
(English spoken)
www.rollicompany.de
Casual and formal clothes for wheelchair users, plus alterations and made-to-measure items. Catalogue available.
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www.disabilityequipment.com
Need more help?

To contact the Muscular Dystrophy Campaign Information Service, call Freephone 0800 652 6352 or email info@muscular-dystrophy.org. Looking for information, support and advice services? Then log on to www.muscular-dystrophy.org/supportsearch

resources

BOOKLETS

- We have an extensive range of factsheets and other publications which can be down-loaded from our website together with other useful sources of help. Visit www.muscular-dystrophy.org.

- New Muscular Dystrophy Campaign factsheets (all free):
  - Making breathing easier
  - Fibrodysplasia Ossificans Progressiva (FOP)
  - Surgical correction of spinal deformity in muscular dystrophy and other neuromuscular disorders

- An introductory guide for families with a child newly diagnosed with a neuromuscular condition. Written by MDC Care Advisors Jane Stein and Julie Cassell for parents and/or carers. www.muscular-dystrophy.org/publications

- Scope has produced Celine’s New Splints to help children to understand their condition and experiences. www.childreninthepicture.org.uk

- Carers UK’s booklet New to caring, on all aspects of caring and the range of help available. To obtain a copy, visit www.carersuk.org or telephone 0845 241 0963

- Disability Alliance has published a booklet called Claiming Disability Living Allowance, a self-help guide to disabled people aged 16-64. Order it on 020 7247 8776 or at www.disabilityalliance.org


DIARY DATES 2008

- 19 April CMT AGM, Coventry.
- 10 May Myotonic Dystrophy AGM, Telford
- 14-15 May Network Meetings and series of workshops, Leeds
- 7 June BMD conference and LGMD network meeting, Brentwood
- 12 June Launch of Isle of Women Bookclub and support group, Isle of Man. Contact Laura McKeown on 028 9083 9153 or email l.mckeown@muscular-dystrophy.org
- 19-21 September Family Fun Weekend, Keilder Water

For further details, contact Peter Lawson on 020 7803 4800 or email info@muscular-dystrophy.org

USEFUL WEBSITES

- www.muscular-dystrophy.org  Our own website, with information on conditions, life experiences, support and news
- www.daytrippers.org.uk  Funds group daytrips and events
- www.disability.gov.uk  Government information
- www.diss.org.uk  Information site from Queen Elizabeth’s Foundation
- www.dmchat.org.uk  An online discussion initiative by the Myotonic Dystrophy Forum
- www.dmdtrust.com  Fundraises to fund worldwide research into muscular dystrophy
- www.kidsout.org.uk  Gives grants to make life more fun for children

SUPPORT GROUPS

- ACTION DUCHENNE  020 8556 9955 www.actionduchenne.org
- ASSOCIATION FOR GLYCOCEN STORAGE DISEASE 01332 669670 www.agsd.org.uk
- BECKER UNITED  www.beckerunited.com
- CHILDREN LIVING WITH INHERITED METABOLIC DISEASES 0800 652 3181 www.climb.org.uk
- CMT UNITED KINGDOM  Helpline: 0800 652 6316 (free)  Other queries: 01202 481 161 www.cmt.org.uk
- DUCHENNE FAMILY SUPPORT GROUP 0870 241 1857 www.dfsg.org.uk
- FSH SUPPORT GROUP 0800 652 4800 (via MDC) www.fsh-group.org
- GBS SUPPORT GROUP 01529 304615 www.gbs.org.uk
- THE INFORMATION POINT FOR CENTRONUCLEAR AND MYOTUBULAR MYOPATHY www.centronuclear.org.uk
- THE JENNIFER TRUST FOR SPINAL MUSCULAR ATROPHY 0800 975 3100 www.jtsma.org.uk
- LGMD NETWORK 01865 234221
- MYASTHENIA GRAVIS ASSOC 01332 290219 www.mga-charity.org
- MYOTONIC DYSTROPHY SUPPORT GROUP 0115 987 0080 www.mdsguk.org
- MYOTUBULAR TRUST 07813 200 298 www.myotubulartrust.com
- NEUROPATHY TRUST 01270 611828 www.neuropathy-trust.org
- NM SUPPORT GROUP 01968 674998 www.nemaline.org
- OPMD SUPPORT GROUP 0113 275 3048 www.opmdsupport.co.uk
- SBMA 01829 771266 www.sbma.org.uk
- THE INFoRMA TIoN PoINt FoR CENTRoNuCErAL And MYoTuBLAr MYoPATHy www.centronuclear.org.uk
- THE JENNIFER TRuST FoR SPINAL MuSCuLAR ATRoPHY 0800 975 3100 www.jtsma.org.uk

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