Welcome to our 2011/2012 Impact Report

We are delighted to report on the significant progress made by the Muscular Dystrophy Campaign despite the very difficult financial environment we are facing.

The work of the charity continues to have a hugely positive impact on individuals and families living with muscle-wasting conditions and we are pleased to report the charity generated a financial surplus in 2011/12 to help to support our work in future years. This progress reflects the determination and commitment we share with our supporters and donors to win the fight against muscle-wasting conditions.

The Muscular Dystrophy Campaign is the leading UK charity fighting muscle-wasting conditions. We are dedicated to beating muscular dystrophy and related neuromuscular conditions by finding treatments and cures and to improving the lives of everyone affected by them.

Our work has five main focus areas:
• we fund world-class research to find effective treatments and cures
• we provide practical information, advice and emotional support for individuals with muscle-wasting conditions, their carers and families
• we campaign to bring about change and raise awareness of muscular dystrophy and related neuromuscular conditions
• we award grants towards the cost of specialist equipment, such as powered wheelchairs
• we provide specialist education and development for health professionals.

We continue to identify and fund promising research, often providing the initial funding for the important first stage that establishes the ‘proof of principle’. We are delighted our funding supports innovative science carried out by leading researchers and can lead to further grants from major funders such as the Medical Research Council. We have backed pioneering studies in exon skipping and utrophin studies, for example, and as you’ll read on page 7, our support for Professor Turnbull’s groundbreaking research into preventing the inheritance of mitochondrial disease has led to a major investment of £5.8 million from the Wellcome Trust to establish a new Centre for Mitochondrial Research.

Further, we support the training and development of the next generation of scientists through PhD studentships and Clinical Research and Training Fellows at leading centres. We believe our continued support for clinical trials co-ordinators at Newcastle and London is essential as we continue our drive towards potential treatments.

While we remain committed to raising funds needed to support research, we know the quality of life today for many children and adults with muscle-wasting conditions depends on whether they have access to good quality care and support. Our campaigns team was established to tackle this issue and we are pleased to report that the NHS is now investing more than ever before in specialist neuromuscular nurses and care advisors, as well as neuromuscular physiotherapists and psychologists.

We play a leading role in Scotland and Wales, and in several English regions, in driving NHS support for neuromuscular networks which ensure clinical knowledge and expertise are shared, leading to improved care and patient outcomes. We engage effectively at the strategic level with Health Ministers, parliamentarians and assembly members ensuring that Parliamentary groups (such as the recently-established Cross Party Group in the Northern Ireland Assembly) give opportunities for members and supporters to engage with MLAs (Members of the Legislative Assembly) and Ministers in the Assemblies.

We are supporting a growing number of individuals and families through our direct services, and our work with health, social care and education professionals helps to ensure that information and support are increasingly available across the country. Our advocacy service and grants from the Joseph Patrick Trust continue to make a huge difference to many people’s lives.

Although the tough economic times appear likely to continue, we remain optimistic and determined to win the fight against muscle-wasting conditions. We are so pleased the dedicated community of families, volunteers, funders, professionals, trustees and staff remain committed to making this happen and we give our warmest thanks to you all.

Bill Ronald
Chairman
Robert Meadowcroft
Chief Executive

Thank you for your support.
As a leading research charity, we have a unique strength in ensuring that our research focuses on finding effective treatments and potentially cures for muscular dystrophy and related neuromuscular conditions. Research we have funded over the past 50 years - and which we continue to fund - has laid the path for the development of pioneering technology currently being tested in clinical trials.

Exon skipping is a technology that aims to restore production of the dystrophin protein that is missing in boys with Duchenne muscular dystrophy, and slows the breakdown and loss of muscle cells. The charity has spearheaded this line of research since the early 1990s with more than £2m of investment. In 2003 we facilitated the establishment of the MDEX consortium – a group of scientists and clinicians – to accelerate the development of this promising potential treatment and to secure funding from the Department of Health.

Since the first clinical trial began in 2006 there has been great anticipation in the scientific community about this potential treatment. It is a highly personalised approach that encourages the cell to skip the site of the mutation and produce a functional copy of a protein called dystrophin. While it could work for about 85 percent of all children with Duchenne muscular dystrophy, the first clinical trials concentrated on mutations in the dystrophin gene that affect about 13 percent of those with the condition.

In July last year, the MDEX Consortium published encouraging results of a phase 2 clinical trial whereby the molecular patches were delivered to the whole body by injection into the bloodstream. It showed that the dystrophin was produced with no significant side effects and there were indications that the protein was working correctly in the muscle.

Taking part in clinical trials can be exciting and daunting in equal measure. Katie Arnott's 12-year-old son, William, took part in the phase 2 trial and took the experience in his stride, focusing on the treatment's potential to benefit the next generation of children born with Duchenne muscular dystrophy:

"He was incredibly brave and made me incredibly proud. His attitude was even if it doesn’t help me, it could help other people." Francesco Muntoni, Professor of paediatric neurology at the Institute of Child Health, who led this research and whose original, foundational research was funded by our charity, said:

"This is the first time we can say with confidence that we’ve made a significant breakthrough towards finding a treatment." Dr Marita Pohlschmidt, Director of Research at the charity, was equally positive:

"We have fought to find a treatment for this devastating condition for the past 50 years. Today we can say with confidence that parents can have real hope for the future: Exon skipping, however, is only the first step. Although it has the potential to develop into an efficient treatment, it will not be a cure. We need to continue funding research to ensure we develop a combination of therapies – this will ultimately be the key to conquering Duchenne muscular dystrophy."
With advances made in research over the last 20 years, the scientific community is facing new challenges to transfer the promising technology from bench to bedside (also described as translational research). The conditions the charity supports are rare and getting clinical trials under way requires a co-ordinated international effort of researchers, clinicians, health professionals and industry. The establishment of patient registries is part of this process and is vital for finding patients that are suitable to test new potential treatments. This is particularly important for rare conditions, because any one Muscle Centre will look after only a small number of patients – not sufficient to carry out a clinical trial. Several Muscle Centres nationally or internationally need to work together and this requires a certain infrastructure.

With a generous grant of £250,000 from the Garfield Weston Foundation, we are delighted to be in a position to fund further significant research at Newcastle, as well as a package of services that ensures progress in translational research. The funding for a PhD studentship, a clinical research fellow and a clinical trial co-ordinator also included provision for a curator to establish a patient registry for individuals with facioscapulohumeral muscular dystrophy (FSHD), at the Institute of Genetic Medicine in Newcastle. The charity also partnered with the Myotonic Dystrophy Support Group to fund an extension of this registry curator post to establish a patient registry for individuals with myotonic dystrophy. This key co-ordination role now exists to implement, manage and maintain UK patient registries for both FSHD and myotonic dystrophy. The aim is to collect genetic and clinical information and also promote these patient registries among clinicians and geneticists to encourage recruitment on to clinical trials.

The team in Newcastle has unique expertise in setting up patient registries. Professor Hans Loechmuller, one of the Centre’s directors, has developed national and international registries within the scope of TREAT-NMD and is a leading expert in this area.

“There are already registries for FSHD and myotonic dystrophy in the US, Netherlands and Italy and other countries and national registries for these conditions are urgently required in the UK, so that patients are not being left out of studies that could provide early access to treatment.”

Blaydon MP; Dave Anderson, (see p7) lost his sister, brother and two of his nephews to myotonic dystrophy and has a further six family members living with the condition.

So many of us hit by myotonic dystrophy have experienced losing not just one person but many that we love dearly to this cruel and unpredictable disease. Myotonic dystrophy has run riot through my family, and I have seen first-hand the pain and devastation it can cause. Research into treatments for muscular dystrophies is coming forward in leaps and bounds. The more people that become part of this registry, the more hope that we have to beat myotonic dystrophy in our lifetimes.”

Dave Anderson MP

Preventing inheritance of mitochondrial disease

Our funding of promising, world-class research to find effective treatments and cures for muscular dystrophy and related neuromuscular conditions received a further boost in early 2012.

The Wellcome Trust together with Newcastle University announced a significant investment of £5.8m into a Centre for Mitochondrial Research. The funding will allow its Director, Professor Doug Turnbull, to lead a team in taking forward groundbreaking research that has the potential to allow women affected by mitochondrial disease to have children who are unaffected by the condition. The technique would work for mothers whose genetic mutation is in the mitochondria DNA only, and would not be suitable for those with a nuclear DNA mutation.

Over the past 11 years the Muscular Dystrophy Campaign has funded the first important stages of Professor Turnbull’s research into developing this technique, named ‘pronuclear transfer’. The procedure would use IVF (in vitro fertilisation) to fertilise the egg of an affected woman with her partner’s sperm. The genetic material of the fertilised egg that determines the characteristics of the future child (the chromosomes) would then be transferred to an egg donated by a woman who has healthy mitochondria. The donor egg would first have its own chromosomes removed.

The technique has been proven successful in the laboratory, but the current law prevents it from being tested in a clinical trial. The resulting embryos can only be kept in the laboratory for up 14 days. To move it forward into clinical practice, a change in the law is required so that the embryo can be placed back into a woman’s womb.

The government has asked the Human Fertilisation and Embryology Authority (HFEA) to seek public opinion on the use of such a technique. The charity is working with the HFEA to ensure that the complicated science behind this research is correctly communicated and that the patients’ voice is heard.

“We are confident that this consultation will help the public understand the urgent need for the development of this treatment for our families. We believe there is a consensus to give people the chance to have healthy children.”

Robert Meadowcroft, Chief Executive

Leaving a legacy

Gifting in Wills enable us to provide around one in four of our research projects and services. Without these gifts, we would be unable to continue our vital research and work supporting individuals and families affected by muscular dystrophy and related neuromuscular conditions.

During the past year, the charity received a total of £1.1m through the generosity of individuals remembering the charity in this way.

One such legacy came from Mrs Edith May Dyke from Bristol. Mrs Dyke generously left to the Muscular Dystrophy Campaign the whole of the residue of her estate. We received almost £400,000 from Mrs Dyke’s estate, and this considerable gift will help us to support children and adults to gain greater independence and an improved quality of life.

All gifts, big and small, make a huge difference. We would like to thank all those who remembered the charity in their Will this year. From the supporter in County Durham who left us £50, to the nine supporters who left us £1,000 and to all those who left us a part-share of their estate. These valuable legacies enable our important work to continue.

TREAT-NMD

is a network of excellence, co-ordinated from the Newcastle Muscle Centre, for rare inherited neuromuscular disorders. The aim is to create an international infrastructure to ensure new therapies reach patients as quickly as possible. Since its launch in January 2007, the network’s focus has been on the development of the infrastructure to help industry, clinicians and scientists bring novel therapeutic approaches through pre-clinical development into the clinic.

Research we funded leading to potential treatments

Mitochondrial diseases are caused by problems with the mitochondria - the batteries that power the cells in our bodies. It is estimated that 3,500 people in the UK have mitochondrial myopathies, a group of mitochondrial diseases which, in the most severe cases, can cause debilitating and life-threatening muscle weakness.

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The Muscular Dystrophy Campaign is committed to ensuring that everyone affected by muscular dystrophy and related neuromuscular conditions has access to specialist care. Through our parliamentary work across all four UK parliaments and assemblies, we campaign to boost NHS investment and neuromuscular care advisor support.

During the last year, we launched our Invest to Save campaign: three reports were launched at parliamentary lobbies in Westminster, Cardiff and Edinburgh, where people with muscle-wasting conditions joined forces with clinicians, campaigners and parliamentarians. The reports highlight how the NHS is spending around £31m every year on potentially avoidable hospital admissions for people with neuromuscular conditions. Our message to the NHS was clear: if you invest a little, you’ll save a lot.

In May, families from across the country affected by muscular dystrophy and related neuromuscular conditions met with MPs and Peers, campaigners, clinicians and NHS commissioners to launch the report, Invest to Save: Improving services and reducing costs, at an event in the Houses of Parliament.

The report revealed that the NHS spends millions of pounds each year on unplanned emergency admissions to hospital for neuromuscular patients. This expenditure could be reduced through proper access to specialist care and equipment. The report argued that by investing in frontline health services and equipment each year, the cost of critical care on hospital wards would be significantly reduced.

Health Minister Paul Burstow MP spoke about the compelling evidence for investment, highlighting the need for timely intervention to prevent unplanned emergency admissions to hospital.

When we launched the Invest to Save: Improving services and reducing costs in Wales report at the Welsh Assembly in November, we highlighted that as much as £3.9m was spent by the NHS in Wales each year on emergency care for patients, owing to falls, chest infections and heart problems that could have been reduced through proper access to ongoing care.

According to the report, many of the 3.500 people in Wales living with devastating neuromuscular conditions were going without vital, life-saving healthcare, while millions of pounds were spent each year on emergency hospital treatment when their conditions became critical.

Henry Langen from Narberth has facioscapulohumeral muscular dystrophy (FSH). After learning this diagnosis in his late twenties, Henry said he faced a total lack of advice and support on managing his condition, eventually leading to heart failure.

“There was simply no-one there to tell me how to manage my health - or to spot problems. The only contact I had was a brief appointment with a specialist consultant once a year. Her time was so overstretched. Not knowing what to do, I tried to carry on as normal, but my heart paid the price. I was rushed into hospital three times due to heart failure, which they tried – unsuccessfully – to treat with drugs. Finally they realised that my lungs were being affected by my condition. I was barely breathing at night, putting pressure on my heart. None of the hospital staff had much knowledge of muscular dystrophy, and they also had nowhere to turn to get it.”

First Minister of the Welsh Assembly, Carwyn Jones AM, when challenged by Berthan Jenkins AM on specialist care improvements in Wales, commented that as well as two care advisor posts being filled, specialist physiotherapy posts were in the process of being appointed.

In the Northern Ireland Assembly at Stormont in September, we worked with Members of the Legislative Assembly to launch the new All Party Group on Muscular Dystrophy. The Group then launched a major inquiry into access to specialist neuromuscular care, and this would become the vehicle to secure additional funding and support for people with muscular dystrophy and related neuromuscular conditions.

A group of 50 supporters, health professionals and MPs, took part in the formal launch of the report, Invest to Save: Improving services and reducing costs in Scotland in September at the Scottish Parliament.

Campaigners at the event called on the Scottish Government to build on existing specialist services which would result in savings in Scotland and improve lives. Jackie Baillie MSP, who has been leading the battle for improvements to services as Chair of the Cross Party Group on Muscular Dystrophy in the Scottish Parliament, hosted the event and tabled a motion in the Scottish Parliament to add weight to the campaign.

Edinburgh man, Mark Chapman, 41, who has Duchenne muscular dystrophy and is Chair of the Muscular Dystrophy Campaign’s Scotland Muscle Group, said that for people with the condition, every day counts:

“Time is just so precious for people with Duchenne muscular dystrophy. Your health can change so much in such a short time. Care advisor posts are so important; we simply cannot afford to wait around for these to happen.

“Two part-time care advisors are not enough to cover an entire country. When you are a child, the care in Scotland is pretty good. For me, I was put in touch with an expert care advisor, who was always on the end of the phone. However, as you get older the services become thinner. By the time I started having breathing difficulties and became increasingly vulnerable in my mid-twenties, all that care had dropped away.”

Following the elections in Wales, Scotland and Northern Ireland in May, more than 50 newly-elected parliamentarians from across all political parties pledged to lend their support to local people living with muscular dystrophy and related neuromuscular conditions. They all signed our Manifesto for Muscle and in so doing lent their weight to our campaign for better access to specialist neuromuscular care.

Dave Anderson MP, Chair of the All Party Parliamentary Group for Muscular Dystrophy, won the prestigious 2011 Dods Charity Champion Award in recognition of his work with the Muscular Dystrophy Campaign. His success made a substantial news piece in the Daily Mail.

‘Care advisors make a tremendous difference to peoples lives, making them more bearable and helping to avoid emergency medical intervention,’ he said.

“A survey of MPs revealed that the Muscular Dystrophy Campaign, alongside the Trailblazers, is making a strong impact among MPs in terms of awareness and support, and there was cross-party consensus that the general reputation and work of the charity is held in high regard.

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‘Care advisors make a tremendous difference to peoples lives, making them more bearable and helping to avoid emergency medical intervention,’ he said.
As a charity, we are committed to a vision where support, mobility aids and specialist equipment are available to ensure independence and where self-determination and a rich quality of life are achievable by each person living with one of the neuromuscular conditions.

Since the Joseph Patrick Trust (JPT) was established within the charity 26 years ago, it has donated more than 6,000 pieces of specialist equipment worth more than £6m. All of this has given thousands of people with muscular dystrophy and related neuromuscular conditions increased independence and enhanced quality of life.

The son of Joseph Patrick, a founding member of the then Muscular Dystrophy Group and donor through the family charitable Trust, Alexander Patrick founded our welfare fund, the Joseph Patrick Trust, in 1986 in memory of his father, and inspired by his brother who had Duchenne muscular dystrophy.

In April 2011, the JPT celebrated its 25th anniversary. Over the years, Alexander’s commitment to the Muscular Dystrophy Campaign has been expressed through his support of groundbreaking research projects and in his advice and guidance through serving as a trustee, Vice Chairman and currently as a Vice President. He has made a truly remarkable contribution to our fight against muscular dystrophy and related neuromuscular conditions, and to many other charitable causes. This support was recognised in the spring this year when he was awarded the title Commander of the Order of the British Empire (CBE) in the Queen’s birthday honours.

During the past year, the JPT awarded a total of 176 grants, worth £88,276.44, to part-fund equipment for adults (110) and children (66) in the following regions:

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<thead>
<tr>
<th>Region</th>
<th>Equipment</th>
<th>Percent</th>
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<tr>
<td>South West and South Wales</td>
<td>Wheelchair adaptations</td>
<td>5</td>
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<tr>
<td>London</td>
<td>Chairs</td>
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<td>Midlands and Anglia</td>
<td>Computer</td>
<td>11</td>
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<tr>
<td>North East and Yorkshire</td>
<td>Manual wheelchair</td>
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<tr>
<td>North West of England and North Wales</td>
<td>Electric wheelchair</td>
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<td>Northern Ireland</td>
<td>Discretionary grants</td>
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<td>Scotland</td>
<td>Vehicle adaptations</td>
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<td>South East</td>
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<td>Therapy equipment</td>
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<td>Scooter</td>
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<td></td>
<td>Portable aids</td>
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Promoting independence

Joseph Patrick Trust awarded 176 grants worth £88,276.44
Funds raised could help to change the lives of the next generation born with muscular dystrophy, Stevie said.

Stevie’s nan, Linda Harman, 61, (pictured above, centre) read the article and was so impressed to read about her inspiring grandson that she decided there and then to skydive. When she told her family, her son-in-law, Marco Hatfield, decided to join her too.

I’m so pleased I can now say ‘I did it’ and it was the most fantastic thing ever! Such a buzz, plus knowing I have raised well over £500 is even better, said Linda.

Two other local residents who noted the Watford Observer article were cricket coaches, Ian Sampson and Gulfraz Riaz, both 40. Inspired by Stevie’s story in the paper, Ian and Gulfraz decided to walk from Watford Town Cricket Club to Lord’s Cricket Ground in London, in full batting gear.

Not only that, but Stevie’s family decided they wanted to raise some money themselves too. During the February half-term, Stevie and his family group all donned the charity’s orange T-shirts and for three hours collected outside their local Sainsbury’s in Watford.

One local newspaper article led directly to a number of people doing fundraising challenges for us, around £2,300 being raised and a community newly engaged in a charity that supports – among the 70,000 adults and children affected by muscular dystrophy and related neuromuscular conditions – a lovely Watford family.
Trailblazers is a group of young campaigns from across the UK who tackle the social issues affecting young disabled people. The group, which grew by 26 percent to a total of 404 members in the past twelve months, also exists to provide Trailblazers with the opportunity to develop new skills, make friends and campaign on what is important to them, such as access to higher education, employment and social and leisure opportunities.

The charity campaigns vigorously for change and to raise awareness of muscular dystrophy and related neuromuscular conditions. The Trailblazers, who do just that for young disabled people, had a busy and successful year, they held six evidence sessions, launched two hard-hitting reports and one award-winning documentary; presented a petition to number 10 Downing Street, and were featured extensively in regional and national media.

Over the past 12 months, the All-Party Parliamentary Group (APPG) for Young Disabled People, which is run by the Trailblazers, held six evidence sessions as part of a parliamentary inquiry into the issues that affect young disabled people in the UK today. Eighty Trailblazers and MPs quizzed Ministers, and held transport providers, universities, employers, the tourism industry and the leisure industry to account for their services for disabled people. The APPG for Young Disabled People has consistently attracted positive media attention and 70 Trailblazers were featured on local or national TV and radio this year as a result of the inquiries.

The young campaigning group launched two incisive reports: The Big Picture, on the accessibility of cinemas, and Under Investigation, which revealed the very real issue of disability hate crime.

The cinema campaign involved more than 150 Trailblazers and launched in August 2011. It highlighted the fact that disabled movie-lovers, who represent 12 percent of the cinema-going public in the UK, receive a second-class service at major cinema venues throughout the country. Trailblazers produced a charter, laying out the standards of access and service that disabled cinema-goers should be able to expect and called on cinema operators to commit to meeting the benchmark requirements. The group delivered a petition, with more than 1,000 signatures, to number 10 Downing Street in December, calling on cinemas to sign up to the charter. They then held a summit in Parliament with cinema company executives, where national and regional broadcast and print media coverage was secured and cinema companies agreed to improve the service they provide to disabled cinema-goers.

Along with the report, the Trailblazers produced a documentary, Lights, camera, access, highlighting the experience of disabled people visiting their local cinemas, enlisting the support of Simon Pegg (right).

Under Investigation, the report which brought to light the damage disability hate crime causes to the lives of young disabled people, was launched in February 2012 and called on the government, the police and all relevant authorities to take decisive measures to ensure this behaviour is not tolerated. Six Trailblazers campaigners were featured on national and regional TV and radio news bulletins, including live interviews on ITV’s Daybreak and coverage in the national press. The report was also discussed in Parliament and the Minister for Disabled People described the Trailblazers’ report as an excellent piece of research.

Vivek Gohil (pictured below, centre) is an active and dedicated campaigner for the Trailblazers. The 22-year-old, who has Duchenne muscular dystrophy, was involved in all of last year’s APPG meetings in Parliament, and in both the cinema and the disability hate crime campaigns.

“At the launch of the cinema campaign, I opened the APPG meeting with a speech. It was the first time I had done anything like that and I was really nervous. I got great encouragement from other Trailblazers and the whole thing went well; I’m glad I got the chance to do it. This has all been new to me.

“I was interviewed on my local radio station and BBC East Midlands interviewed me for East Midlands Today outside number 10 Downing Street, where we went to present the cinema petition. I’m glad to be involved with Trailblazers because we can go to Parliament with all our ideas and we are taken seriously.

“Getting more involved with the Trailblazers has helped me to become more confident and to realise that what I am thinking, as a disabled person, is valid. We can speak out in a productive, constructive way; we’re taken seriously. It’s much more helpful than complaining,” said Vivek.

Hollywood legend Sigourney Weaver, who featured in the documentary, added her voice to the cinema campaign.

“It should be always universal access so I support everything you are doing to change that. Everyone has the right to go and see a good movie”

“I feel proud to be chairing this group, which has been set up to tackle the uphill struggle that young disabled people face to achieve goals in life taken for granted by non-disabled peers. We have come a long way in how we view disability in this country, but physical and social barriers are a harsh reality still. It is not right or fair that a person should face a constant daily battle on everything from accessing higher education and employment to using public transport and socialising with friends and family."

Paul Maynard MP, Chairman of the APPG for Young Disabled People
Terrie Bentley contacted the advocacy service when her partner for his son’s rights seemed to be getting nowhere.

“We do not sit here as a family and dwell on the fact that Jordan, my son, who has Duchenne muscular dystrophy, has a deteriorating and progressive condition, and that we will probably all out-live him.”

Jordan is 17, and until the end of July 2011 had managed to attend mainstream school thanks to the excellent support given to him during his time there. He was picked up from home on a daily basis and driven to school, had great Teaching Assistants, and was collected from school at the end of each day. This was all arranged and costs incurred by our local county council.

Jordan decided to study for a Diploma in IT at our local college after leaving secondary school. I assumed transport would be provided for him throughout his further education until he was 19. How wrong was I?

After applying for Post 16 Transport Assistance, I was shocked to receive a letter back stating Jordan was not entitled to transport because the local college was less than three miles away from our home. Jordan had to travel to and from the college in his electric wheelchair with the help of his sister for two months, before the county council finally agreed to supply transport until the end of February 2012 to cover the winter months!

A few letters back and forth to the county council, I decided to get in touch with the Muscular Dystrophy Campaign to see if they could advise me. The advocacy officer contacted me immediately; he wrote a fantastic letter to our county council in support of my MP and also advised me to write to my local MP, Mrs Eleanor Laing.

I was overwhelmed to receive not only a letter from my MP, but also a telephone call from her secretary to confirm that the county council would agree to continue to provide transport until the end of the summer. She said that she was shocked by their original decision.

“I honestly do not believe Jordan would have been granted the transport if I had not had the support from the Muscular Dystrophy Campaign and my local MP.”

I have supported the Muscular Dystrophy Campaign since Jordan was diagnosed just prior to his fifth birthday. I have run the London Marathon three times now, run the Great North Run and was one of the first to trek the Sahara Desert with them. I never expected them to pay me back but they certainly have.

“Thank you so much to the Muscular Dystrophy Campaign, and to my local MP, Mrs Eleanor Laing. I could not have done it without either of you.”

* The Joseph Patrick Trust provides grants towards the cost of vital equipment.

Terrie Bentley contacted the advocacy service when her partner for his son’s rights seemed to be getting nowhere.

“We do not sit here as a family and dwell on the fact that Jordan, my son, who has Duchenne muscular dystrophy, has a deteriorating and progressive condition, and that we will probably all out-live him.”

Jordan is 17, and until the end of July 2011 had managed to attend mainstream school thanks to the excellent support given to him during his time there. He was picked up from home on a daily basis and driven to school, had great Teaching Assistants, and was collected from school at the end of each day. This was all arranged and costs incurred by our local county council.

Jordan decided to study for a Diploma in IT at our local college after leaving secondary school. I assumed transport would be provided for him throughout his further education until he was 19. How wrong was I?

After applying for Post 16 Transport Assistance, I was shocked to receive a letter back stating Jordan was not entitled to transport because the local college was less than three miles away from our home. Jordan had to travel to and from the college in his electric wheelchair with the help of his sister for two months, before the county council finally agreed to supply transport until the end of February 2012 to cover the winter months!

A few letters back and forth to the county council, I decided to get in touch with the Muscular Dystrophy Campaign to see if they could advise me. The advocacy officer contacted me immediately; he wrote a fantastic letter to our county council in support of my MP and also advised me to write to my local MP, Mrs Eleanor Laing.

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Bringing people together

35 Muscle Group meetings, 600 members face-to-face

As a charity, we understand the value of a strong community. We bring together individuals and families affected by muscular dystrophy and related neuromuscular conditions, and also ensure that health professionals and clinicians are aware of these devastating conditions and the effects of living with them. Our work with health, social care and education professionals has meant that more families living with muscular dystrophy and related neuromuscular conditions have access to the information and vital services they need.

CONFERENCEs AND INFORMATION DAYS

During the past 12 months, we promoted our charity’s information and best practice guidelines to the Association of British Neurologists and the British Paediatric Neurology Association for inclusion within training curriculums. We also presented the guidelines at our National and Scottish conferences and at a Neuromuscular Care Conference for care advisors, physiotherapists, occupational therapists and those working in education.

Training and information days were held for community teams in Bolton, Surrey, Barnsley and North Yorkshire, while all of the newly-appointed neuromuscular care advisors were trained and inducted by us. We held two training events for neuromuscular care advisors and specialist nurses, and continued developing the UK Neuromuscular Database.

At our National and Scottish conferences, hundreds of people heard from the young scientists, who presented posters of their Muscular Dystrophy Campaign-funded research. They did this in lay language (ie straightforward, non-technical language), and their presentations were successful.

PUBLICATIONS AND FORUMS

In order to save on costs and ensure funds go directly into our core work, we brought the publishing of Target MD, the charity’s flagship lifestyle magazine entirely in-house. We also strengthened our communication of scientific results to our families and supporters, by increasing the annual number of editions of our research magazine Target Research from one to four. It was timely to revamp the magazines, and we consulted widely with our readership to do so. We continue to make sure we deliver fresh and relevant publications, in our charity’s house style and tone of voice, to our growing list of subscribers.

We established the professionals’ area on the website, and further development is planned. We published our new report Hospitals in Focus: Health care not health risk, which revealed that many people with neuromuscular conditions are not getting the right treatment when they are admitted to hospital. The report generated national media attention, and Health Minister Simon Burns MP had this to say:

“I am very pleased to support the Muscular Dystrophy Campaign in their drive to improve care for their members. Their report has shown just how crucial it can be for a patient’s care that clinicians have the right information at the right time, especially when treating conditions they may not see very often.”

In Wales, professionals came together through the Welsh Muscle Groups and at meetings in the Welsh Assembly. Over the past 12 months, we held 35 Muscle Group meetings, including our inaugural one in Northern Ireland, meeting around 600 of our members face-to-face, and bringing them together with local MPs, health professionals and NHS decision-makers.

Since the launch of our Parents Education Network (PEN) in February 2012, the number of schools known to the charity has increased by 40 percent. The forum, which is part of our online community TalkMD, gives parents vital emotional and practical support as well as the opportunity to discuss issues such as Special Educational Needs (SEN) statements and transition. Since it started, it has attracted more than 6,000 views from people seeking information and 103 posts from parents asking for support.

Forging worthwhile partnerships with schools is an initiative that has proven very successful. Last year we built partnerships with three schools in the South East and South Central regions that have a high number of students with muscular dystrophy or a related neuromuscular condition. By going into partnership with these schools, we have helped to ensure that we are offering vital support to these schools, as well as the students and their families.

“Just wanted to write and say how incredibly impressed I have been with my recent experience of getting in touch with the Muscular Dystrophy Campaign. You have been so helpful, and the information pack I requested yesterday (that arrived this morning!) is fantastic.”

Chartered Psychiatrist, King’s Lynn

“PEN is fabulous. Education is the biggest worry in my son’s life at the moment. It is great to have a space where I can speak to other parents about the issues that Joe is facing.”

Annette Rush, whose son, Joe, has Duchenne muscular dystrophy
A flagship fundraiser from the property industry

As a charity, we work with a range of supporters to generate voluntary income to fund our work in leading research and supporting people with muscle-wasting conditions. The Microscope Ball Committee is one such group of supporters.

In October 2011, 700 of the country’s leading property industry executives joined us at the Hilton on Park Lane for a fun-filled Bollywood-themed Microscope Ball. The event was a resounding success, and raised a dazzling £280,000 for the charity: this makes the 2011 Microscope Ball one of the most profitable in the event’s 28-year history. Since it began, the Microscope Ball has raised more than £2m for the Muscular Dystrophy Campaign.

David Hanrahan has been involved for 15 years in organising the Ball, which started 28 years ago as a breakfast fundraiser.

“Around 30 people attended those first events but eventually demand transformed the breakfasts into a ball, which today attracts more than 800 of the most influential people from the most prestigious commercial property companies in the country.

“It’s a perfect example of how a modest fundraising initiative can grow over time into something major.

Thank you

Our individual, charitable trust and corporate partners make it possible for us to carry out our vital work. A full list of donors is available in our financial statements.

We would like to say a big thank you to the following organisations who, over the last year, have supported the Muscular Dystrophy Campaign.

We are extremely grateful to receive the continued support of Genzyme, a most valued strategic partner.

Matalan employees and customers chose to support the Muscular Dystrophy Campaign with store collections held across Scotland and the North West, fundraising to help people living with muscular dystrophy and related neuromuscular conditions. We are extremely grateful to this leading retailer for their wonderful support of our charity.

Thanks to the annual Big Give Christmas Challenge in December 2011, £233,100 was raised for the Muscular Dystrophy Campaign. The Big Give is a non-profit organisation dedicated to helping charities attract new supporters and increase donation levels. During one week in December, supporters donated to the charity and those donations were matched by the Big Give and, together with the Gift Aid claimed on them, this fantastic sum was raised for us.

Our partnership with CeX continues to grow, currently raising more than £10,000 from in-store donations each year.

We’d like to thank Foster Denovo for their ongoing commitment to support the charity, with special thanks to David Brosch and David Stockdale, who raised more than £12,500 climbing Mont Blanc.

Setting standards in analytical science

We had a fantastic Charity of the Year partnership with LGC, the analytical science company whose vision is to use science to make the world a better place. They raised more than £22,000 for us, through a range of fundraising activities, from cake sales to a Christmas fair.

www.muscular-dystrophy.org
The campaigns team launched the Northern Ireland inquiry into the gaps in care and specialist services for people with muscular dystrophy and related neuromuscular conditions.

We continued to provide support for three clinical fellows in Newcastle, London and Oxford to train neuromuscular clinicians of the future. The clinical fellows receive training in all aspects of neuromuscular disease, at the same time as undertaking cutting-edge research, under the guidance of leading experts.

In December 2011 the Muscular Dystrophy Campaign’s information service was certified by the Information Standard, the Department of Health quality mark that identifies reliable sources of quality, evidence-based health information.

In 2011/12 we were delighted to welcome 178 new individual volunteers who filled a variety of specific opportunities in our office, in the community and at home to help in the fight against muscle-wasting conditions. We also benefited from the support of more than 800 individuals who participated in runs and organised a range of weird, wacky and wonderful fundraising events for us.

In 2011/12 we welcomed a further 27 new fundraising groups and hope to continue to welcome many more in the year ahead. Our network of 48 branches raised almost £250,000 and our new fundraising groups almost £100,000.

In partnership with the MRC Centre for Neuromuscular Diseases, we organised the fifth UK Neuromuscular Translational Research Conference, in March 2011. The focus of this year’s conference was the development of treatments for neuromuscular diseases and new techniques to improve diagnosis, such as next generation sequencing.

Our network of 48 branches raised almost £250,000 and our new fundraising groups almost £100,000.

The information service received 10,448 requests for literature and 4,138 requests for advice and support, an increase of 22 percent from last year.

The charity continues to invest in infrastructure that promotes the bench-to-bedside transition of promising technology. We continued funding two clinical trial co-ordinators at the Muscle Centres in London and Newcastle to help with the development of clinical trials.

The impact and effectiveness of the Muscular Dystrophy Campaign was recognised when we won the 2011 Charity Times Campaigning Team of the Year award.

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In November Trailblazers won the UK Youth Hearing Unheard Voices Outstanding Contribution award at a gala event held at St James’ Palace, hosted by HRH the Princess Royal.

In December 2011 the Muscular Dystrophy Campaign’s information service was certified by the Information Standard, the Department of Health quality mark that identifies reliable sources of quality, evidence-based health information.

The total income for the year was £6.3m, which included additional sums of £641,000 through our Tesco Charity of the Year partnership in 2009-10. Our overall income (excluding Tesco Charity of the Year) grew by £176,000, an encouraging increase of three percent over the previous year, despite the very difficult economic circumstances.

Our overall expenditure for the year was £5.9m. Over the year we generated a surplus on restricted funds of £483,000 and saw a small deficit on unrestricted funds of £38,000. The surplus on restricted funds will be used to finance charitable activities in the forthcoming year.

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(Summary of results is taken from the Group Statement of Financial Activities for the year ended 31 March 2012. Full accounts are available on our website at www.muscular-dystrophy.org)
Our 2011/12 Financial Statements are available upon request. Download a copy from our website, or call the office and we’ll send you a hard copy.

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Registered Charity No. 205395 and Registered Scottish Charity No. SC039445

Printed on PEFC paper, produced at a mill that is certified with the ISO14001 environmental management standard

Thank you for your support