Muscular Dystrophy Campaign

Making an impact

Annual review 2012/13
About us

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 improving the lives of everyone affected by them.

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

Leading research. Supporting people.
We are delighted to report the hugely positive progress the charity has made in the last year in leading the fight against muscular dystrophy and related neuromuscular conditions. Research has brought us to an exciting stage in the development of therapeutic approaches and we are really pleased that clinical trials are now underway covering more than 30 conditions.

The early results from the trials in Duchenne muscular dystrophy appear to show encouraging promise but we must await the formal results from larger, late stage trials. Determined to remove barriers to accessing emerging treatments, we are working with the All Party Parliamentary Group for Muscular Dystrophy in launching an Inquiry into high-cost treatments for rare diseases. Neuromuscular conditions are a group of rare and very rare conditions which have not generally been given the same priority in research funding or in investment in clinical care as the more common acute conditions. By influencing decision makers with NHS, NICE (and the Scottish Medicines Consortium) and the MHRA, we want to ensure potential treatments can reach individuals as quickly as possible.

Through our work to improve the provision of specialist neuromuscular services across the UK, the NHS is now investing in a national network of 39 care advisors and specialist nurses, a huge increase from the 13 in post only five years ago. We also secured this year the first-ever set of national guidelines from the Department of Health setting out the services people with muscle-wasting conditions can expect to receive; this was achieved at a time when the NHS faces huge budgetary pressures and major reform. In the Scottish Parliament and the Northern Ireland Assembly, we led major initiatives which secured vital support for much needed service improvements and in Wales we have also continued to drive service developments.

In a difficult financial climate, and thanks to the generosity of supporters together with the determination of our fundraising volunteers, the charity has achieved a positive surplus of £650k in 2012/13, placing us in a secure position from which to invest more funds in groundbreaking research and services in the future.

Our warmest thanks go to all our amazing supporters and volunteers, to our hard working staff team and to our very dedicated trustees.
In our fight against muscle-wasting conditions, we fund world-class research to find effective treatments and cures. There is currently no cure.

Having funded vital, basic research over the past 54 years into treatments and cures for muscular dystrophy and related neuromuscular conditions, it is important to keep the momentum going where great progress is being made.

This year, we continued our investment into exon skipping technology. The Muscular Dystrophy Campaign has invested more than £1m into the development of this technology over the past 20 years and although first generation drugs are now in clinical trials in boys with Duchenne muscular dystrophy, it is likely that they will need to be further improved. Our research portfolio includes grants to Professors George Dickson, Dominic Wells, and Matthew Wood who are working towards this goal. For more details see page 20.

In 2012, Professor Francesco Muntoni and the MDEX consortium received a further boost when they were awarded an EU Health Innovation grant of €5.5m to develop a molecular patch for exon 53 of the dystrophin gene and to test the molecular patch in clinical trial. The Muscular Dystrophy Campaign was instrumental in setting up the MDEX consortium and we continue to represent the patients’ voice as one of the three charities on the MDEX consortium panel.

With potential treatments on the horizon, the charity is determined to pave the way for treatments to reach the market as quickly as possible. Through the All Party Parliamentary Group for Muscular Dystrophy, we launched an inquiry into access to rare disease drugs for muscle-wasting conditions such as Duchenne muscular dystrophy, with pharmaceutical companies and leading researchers in the field of neuromuscular science the first to give evidence. We started working on influencing the NHS and began to work with drug regulatory bodies and the biopharmaceutical industry to ensure that patients in the UK have swift access to any emerging treatments.

The Muscular Dystrophy Campaign launched its Duchenne Research Breakthrough Fund in mid-2012 with an ambitious target of £1.6m. Fund ambassadors have been promoting it through local news, and through our Make Today Count initiative (see more on page 18 and 19).

"The Muscular Dystrophy Campaign has been very supportive of us as a family since Brandon was diagnosed with Duchenne muscular dystrophy in November 2011. Over the years, they have been at the forefront of funding researchers who are looking for treatments and a cure for this condition. Their excellent peer review system gave us peace of mind when donating money towards their Duchenne Research Breakthrough Fund."

Chris and Joanne Govender
Kilmarnock, Scotland
Next year we will... continue to invest in research leading to potential treatments, and we will influence parliamentarians and governments in Westminster, Cardiff, Edinburgh and Belfast to ensure that UK patients have timely access to emerging treatments.
As the leading charity fighting muscle-wasting conditions, we are dedicated to improving the lives of everyone affected by them. We work with families affected by these conditions to put pressure on the NHS to continue to invest in specialist neuromuscular services. As a result, over the past four years we have seen a 300 percent increase in the number of neuromuscular care advisor and specialist nurse posts from 13 to 39.

Together with Treat-NMD we launched the first-ever nationwide audit of Muscle Centres and clinics, leading to a growth in the number of Centres of Excellence. This builds on the publication of new national standards for neuromuscular services by the Department of Health, intended to lead to a more consistent level of service provision across the country.

In July 2012, we launched The McCollum Report into access to specialist neuromuscular care, following an eight-month inquiry by the All Party Group on Muscular Dystrophy in the Northern Ireland Assembly. We also alerted the Welsh Assembly and the Scottish Parliament in our continuing campaign to improve specialist care.

We worked with leading media outlets, including the Belfast Telegraph, The Irish Times, and BBC Radio Ulster to ensure the news reached people affected by neuromuscular conditions across Northern Ireland. The report’s top recommendation of the urgent need to appoint a neuromuscular lead in February achieved a landmark campaigning success with the appointment of a Northern Ireland lead for muscular dystrophy and related neuromuscular conditions.

Following persistent pressure from the charity and our supporters in Wales, the NHS in Wales has created the Wales Neuromuscular Network and in October published a landmark document outlining the vision for improving neuromuscular services in Wales. The vision has constantly evolved throughout the year, and we will continue to put pressure on the NHS to ensure the best services are available to families in Wales affected by muscle-wasting conditions.

Last year we said we would... extend NHS investment in neuromuscular services, increasing the number of neuromuscular healthcare professionals in post, and we achieved it.

Next year we will... protect and extend NHS investment in neuromuscular services, establishing ten neuromuscular forums across England to bring people with muscle-wasting conditions together with decision-makers from the new NHS structures, as well as with clinicians and health professionals.
In pursuing our vision of a world where muscular dystrophy and related neuromuscular conditions are not a barrier to length or quality of life, our welfare arm – the Joseph Patrick Trust (JPT) – awards grants towards specialist equipment. Since the JPT was established in 1986, it has awarded grants worth more than £6m to thousands of people requiring specialist equipment. Here is what the JPT awarded in 2012/13.

We are hugely grateful to Alexander and all the Patrick family for their valued, generous and ongoing support of the JPT and our work.
The meeting was an encouraging first step towards the next stage in our campaign. We can achieve really significant service improvements over the next few years by keeping up pressure for change on the new Commissioners. If we work with them at regional and national level and convince them of the fierce urgency of now, then we can together succeed.

Brian Deehan

70,000 adults and children in the UK affected by muscle-wasting conditions
We are determined to improve the lives of all adults and children affected by muscle-wasting conditions, and to ensure that everyone has access to the specialist healthcare services they require. We also work hard to ensure that the voice of the patient is heard.

As the NHS undergoes a period of major reform, we are committed to ensuring that the needs of people with rare conditions are not overlooked. With a £10k grant from the pharmaceutical firm, Sanofi, the charity has been able to pilot regional ‘patient advisory panels’. The purpose of these panels, comprised of people affected by muscle-wasting conditions, is to give advice and feedback to commissioners. The patient-panellists, with their first-hand knowledge of what it means to live with rare and very rare conditions and their need for access to high-quality specialist multi-disciplinary services such as physiotherapy and hydrotherapy, will give expert advice and guidance to those with the power to commission services.

To build on this foundation, we were successful in a grant application to the Department of Health for an amount of £583,000 over the next three years. This will mean people across England, affected by muscle-wasting conditions, can access health services that meet their needs and are informed by their voices, thanks to the pilot project of these patient-commissioner panels.

Patient survey

In 2012, we conducted a nationwide survey of people living with muscle-wasting conditions. Around 600 people responded to the survey, which revealed a continuation of the ‘postcode lottery’ of available care and support, with reports of adults and children at high risk of death from heart and lung problems not receiving regular checks. Many reported misdiagnoses or lengthy waits for diagnoses, while others had received inaccurate advice from their GPs. Nearly half of the patients surveyed said their GP did not understand their condition well enough to plan local care.

In calling for this unacceptable situation to change, the Muscular Dystrophy Campaign called on the Government to ensure newly established GP-led Clinical Commissioning Groups work with specialist neuromuscular clinicians, regional NHS leaders and people affected by muscle-wasting conditions, to ensure warning signs are picked up sooner and appropriate care and support services are put in place locally. These would complement the patient-led commissioning groups being established across England.

The findings of our 2012 patient survey received media attention across the UK, with people affected by muscle-wasting conditions taking to the airwaves to share their experiences of local NHS services.
Our advocacy service, introduced in April 2011, has helped hundreds of people to access services, benefits and equipment to which they are entitled and thus maintain their independence and improve their quality of life.

The valuable support provided by the charity’s pro bono partnership with law firm, Hogan Lovells, was recognised by the Charity Times in 2012 when the partnership was shortlisted for a national award.

Grants from the Henry Smith Charity (£90k over three years) and from BIG Lottery Fund’s Reaching Communities programme (£162k over three years), will help us to support more people in urgent need of help. The grants will also enable us – in a new project – to train Muscle Group members across the country to act as advocates to meet their own and others’ needs.

Muscle Groups

In giving people affected by muscle-wasting conditions a voice to bring about change, and an opportunity to meet other people in their local area, the charity runs local Muscle Group meetings.

During 2012/13, the charity held 45 Muscle Group meetings across England, Wales, Scotland and Northern Ireland. A key focus of these meetings was the new Personal Independence Payments scheme, and 1,100 people had the opportunity to learn how the changes will affect their disability benefits.

People with muscle-wasting conditions, along with their families and carers, are at the heart of everything the Muscular Dystrophy Campaign does.

Last year we said we would... help more people to get the services and equipment they need, while increasing the number of advocacy cases supported by our pro bono partner law firm, Hogan Lovells, and we achieved it.

Next year we will... continue to meet the growing demand by expanding the information and advocacy service, while extending our reach to people affected by muscle-wasting conditions through new initiatives, such as a network of 20 local, volunteer advocacy ambassadors. We will also expand our network of patient-led Muscle Groups by at least 10.

Fighting your corner

...and we achieved it.

“...had been told that the DLA (Disability Living Allowance) wasn’t there for people like me. I am grateful for people like you who offer support and advice – thank you.”

Stephen

who contacted the advocacy service for benefits advice

People with muscle-wasting conditions, along with their families and carers, are at the heart of everything the Muscular Dystrophy Campaign does.
We supported 123 people to secure £853,998 worth of support including 11 housing, 12 adaptations, 40 benefits, 25 care packages, 10 wheelchairs.
Some highlights

We promoted our charity’s information and best practice guidelines at the Neuromuscular Centre Conference for care advisors, physiotherapists, occupational therapists and those working in education. We also held training and information days for community teams in Bolton, Surrey, Barnsley and North Yorkshire.

Thanks again to Candis Magazine, the charity benefited from their Big Give 2012. During one week in December, all donations to the charity through the Big Give were doubled, raising an impressive £120k.

The charity continued to work in partnership with the Medical Research Council (MRC) Centre for Neuromuscular Diseases by bringing together leading researchers and clinicians for the sixth annual UK Neuromuscular Translational Research Conference in March 2013 in Oxford. It was attended by more than 200 scientists, clinicians and representatives from patient groups and pharmaceutical companies.

In addition to bringing together hundreds of people at our annual National and Scottish conferences, we presented our work at partner charities’ annual conferences, such as the Myotonic Dystrophy Support Group, the FSH (facioscapulohumeral muscular dystrophy) Support Group, the Duchenne Family Support Group and the Jennifer Trust for SMA (spinal muscular atrophy). We also established a monthly drop-in advocacy surgery at the new NeuroMuscular Centre in Coventry.

We received generous support for continuing research into treatment and cures for spinal muscular atrophy (SMA) when the Gwyneth Forrester Trust awarded us £50k, and for myotonic dystrophy with a £50k grant from the Cranbury Foundation. A grant of £30k from the Eranda Foundation helped the charity launch the Richard Attenborough Fellowship Fund to encourage gifted young scientists to pursue careers in the neuromuscular field.

Funding from the Health and Social Care Alliance in Scotland – an amount of £39k over two years – meant we could support young people in Scotland affected by muscle-wasting conditions to make an easier transition to adult services, and thereby to lead healthier, more active and fulfilling lives.

Through the generosity of 71 of our individual supporters who left gifts in Wills to the Muscular Dystrophy Campaign, the charity received just over £950k in 2012/13 in legacy income. Legacies, large and small, send out a very strong and personal message of hope for the future, and without people remembering the charity in this way, we would be unable to continue about a quarter of the research projects and services we provide.

With £500k funding from the charity, Professors Doug Turnbull and Mary Herbert at Newcastle University developed a technique called cell battery transplant that could allow women affected by mitochondrial disease to bear their own, unaffected children. For this technique to be brought into clinical practice, a change in the law is required and so the HFEA (Human Fertilisation and Embryology Authority) held a public consultation. Working closely with the HFEA and the Wellcome Trust, the charity assisted in explaining the consultation process to the public, with our Director of Research, Dr Marita Pohlschmidt, being featured in The Times, Daily Telegraph, Huffington Post, ITN News, BBC World Service and Sky News, and in live debates on BBC Radio Five Live and BBC London. In March, the HFEA announced that people in the UK were broadly in support of the further development of this procedure.

The charity was shortlisted for four awards at the Charity Times Awards 2012 in recognition of the dedication and commitment of our supporters in campaigning and fundraising. Lord Walton of Detchant, our Honorary Life President, was awarded the Outstanding Individual Achievement for his distinguished contribution to the charity over 50 years, in particular his ongoing work with the APPG for Muscular Dystrophy and the Walton Report.
Some highlights

Matalan continues an extremely successful partnership programme with us. Through innovative fundraising in-store, and the support and enthusiasm of their staff members, Matalan has raised more than £130k for the charity.

We held our third annual Celebrity Sports Quiz in the Long Room at Lord’s Cricket Ground in March 2013. Big name sports stars, such as Phil Vickery, Darren Gough and Jimmy White, put their sporting knowledge to the test in support of the charity. With BBC’s Chris Hollins as quizmaster, and former Lions’ rugby lock, Martin Bayfield as host and auctioneer, the event raised a fantastic £110k for the charity.

The Friends of Muscular Dystrophy had a tremendously successful fundraising year for the charity. They hosted ‘An Evening with Sir Alex’ in September at the Mercure Hotel in Manchester, where 500 guests got a unique peek into the life of the UK’s most successful football manager as he answered questions put to him. The evening raised a whopping £100k to provide equipment to those who need it via the Joseph Patrick Trust.

Our network of 40 volunteer branches raised £186k and provided welfare grants totalling over £63k to families in their communities affected by muscle-wasting conditions. We were delighted that our 57 fundraising groups and family funds raised almost £100k.

With joint funding from the Muscular Dystrophy Campaign and the Myotonic Dystrophy Support Group, a new patient registry was launched in May 2012 for individuals with myotonic dystrophy type 1. The new registry allows clinicians and researchers to speed up the transition of treatments from laboratory to clinic by speeding up the recruitment process of people to take part in clinical trials. In addition, the Muscular Dystrophy Campaign’s awarded a clinical fellowship to Dr Saam Sedehizadeh’s at the University of Nottingham whose work aims to bring us closer to clinical trial readiness for myotonic dystrophy type 1.
This group of young disabled campaigners from across the UK has grown to a membership of around 500 – an increase of 25 percent over the past year. In bringing to public and government attention the social issues that affect young disabled people, they have taken on the airline and housing industries in the past year – and won significant victories.

In continuing their work towards removing barriers and promoting independence, the Trailblazers held five meetings of the All Party Parliamentary Group (APPG) for Young Disabled People, published three reports on housing, airlines and led the inquiry and report launch for the APPG for Young Disabled People – Removing barriers, promoting independence. Their report on air travel – Up in the air – led to the launch of a working group by the Civil Aviation Authority and the airline industry to remove the barriers to air travel that many disabled people face. Similar groups, through the hard work of the Trailblazers have been established by the cinema and property industries. As a direct result of their campaigning, London Underground has introduced manual boarding ramps for the first time ever.

Seventeen young disabled people increased their skills and developed their CVs by undertaking work experience in the Muscular Dystrophy Campaign office during the past year.

The Trailblazers had their most successful media coverage year to date, owing to media interest in campaigns on disability hate crime, the need for accessible accommodation to rent or buy, air travel issues for disabled passengers and access to grassroots sport for young disabled people. This important campaigning work was covered by Channel 4 News, The Guardian, Daily Telegraph, Daily Mirror, Mail Online, Express Online, Huffington Post, The Independent, ITV’s Daybreak, Sky News online, BBC News online, BBC Radio Five Live and BBC Radio 4 You & Yours. We also targeted decision-makers through leading trade titles, such as Police Professional, Inside Housing, Building Design and UK Landlord magazine. All of the media coverage was led by Trailblazers.

Michaela lights up Olympic torch relay

Founder member of the Trailblazers, Michaela Hollywood (pictured opposite), who has spinal muscular atrophy, had an unforgettable experience last June as an Olympic torchbearer in Dromore in Northern Ireland. With so much excitement around the Olympic torch relay and crowds lining the route, she put muscular dystrophy in the spotlight as the torch continued its journey around the UK.

Next year we will...

Grow the Trailblazers network by 20 percent, with a focus on developing employment opportunities for 30 young disabled people through a new work experience programme.
Our congratulations go to all of those supporters of the Muscular Dystrophy Campaign who were among the 8,000 people to carry the Olympic Flame some 8,000 miles around the country, and the Paralympic Flame, ahead of the London 2012 Olympics and Paralympics.

“...will probably never happen again in my lifetime and I am privileged to be a part of it. I am not doing it just for me, but for people with muscular dystrophy. I hope it will inspire and motivate them and make more able-bodied people see past the wheelchair.”

Michaela Hollywood
Building our community

Through our website, social media and printed publications, the Muscular Dystrophy Campaign shares news and information not only with our supporters but with the wider community at large.

Responding to the findings of our comprehensive user-experience research, we gave our website a significant overhaul. Thanks to a grant from the Clothworkers’ Foundation, the website now has improved navigation, provided key information about the 60 conditions that we cover, and highlights our support services. The results have been significant. Visitors to the website came from 197 countries – the UK, the USA, India, Canada and Australia being the top five. Our Twitter and Facebook communities have also continued to grow apace.

In providing expert advice and assistance to individuals and families affected by muscle-wasting conditions, as well as to health professionals, we received 22,118 requests for information via email, our website and our Freephone helpline – up one-third compared to last year. Our information service has been awarded the Information Standard - a Department of Health quality mark that identifies reliable sources of quality, evidence-based health information. With more than 100 free publications which offer expert medical and social information, since April 2012, 18,270 publications have been downloaded from the charity’s online resource library.

Our valuable and popular online forum, TalkMD, has been improved to provide a more effective, safe and lively meeting place for people affected by muscular dystrophy and related neuromuscular conditions, as well as their friends, families and carers across the UK. The forum is moderated by three volunteers, all of whom are affected by a muscle-wasting condition, and who offer all new visitors a warm, sincere and friendly welcome on behalf of the Muscular Dystrophy Campaign.

The charity takes seriously our role to communicate progress on key charity projects, and to promote opportunities for people affected by muscle-wasting conditions to live independent lives and enjoy a good quality of life. Our flagship publications, Target MD and Target Research offer a quarterly opportunity – as requested by readers – for news, views, research progress and aspirational lifestyle stories and profiles. Our Campaign newsletter comes out three times a year, keeping supporters up-to-date with latest fundraising events and forthcoming opportunities.

Through our media work, we have consistently secured excellent regional and national press coverage, not only building on developments in research, campaigns, care and fundraising, but also providing a vital platform for individuals affected by muscle-wasting conditions to have their voices heard.
Next year we will...

continue to develop our website, social media presence and tailored e-communications to ensure all those affected by muscle-wasting conditions have the information and advice they seek, and communicate effectively with all our supporters and the wider community.
In April 2012, 109 runners took to the capital’s streets in orange and together raised £240k towards our vital work. Tim Northam, who took on the challenge on behalf of his wife and daughter who both have facioscapuloumeral (FSH) muscular dystrophy, had this to say:

“My daughter, Bella, was diagnosed with FSH about five years ago, and is now in a wheelchair and completely dependent upon others for her care. We spent the early years after her diagnosis worrying about what the future would hold and basically getting depressed about it. However, Bella’s infectious enjoyment of life has spread to us all and we resolved to start enjoying life again. I resolved to lose weight and get fitter and, after running 5k, 10k, a half marathon, I signed up for the 2012 Virgin London Marathon. I decided to run for the Muscular Dystrophy Campaign because of the great support we’ve had from them in the past and no doubt will need in the future. With wonderful generosity from family, friends and colleagues at Morgan Stanley, I raised over £10k for the charity.”

Building on the success of the Muscular Dystrophy Campaign Town and Gown 10k in Oxford, we expanded our series to other historic university cities. On a very wet and windy day in April 2012, we held our inaugural Town and Gown 10k in Cambridge and, despite the torrential rain, around 500 runners ran the scenic, multi-terrain route and raised close to £20k for the charity. The press team secured an eight-week media partnership with the Cambridge News, which featured a series of news articles raising awareness of muscle-wasting conditions, showcasing the charity’s work and sharing information about the race.

Team Jed, led by the Thirkettle family for their son, Jed, who has Ullrich congenital muscular dystrophy, has become a formidable fundraising group for research into Ullrich/congenital muscular dystrophy. Their team of 31 ran in the 31st Great North Run in 2012 and raised £33k.

“Tearful, physically, mentally and emotionally exhausted, I crossed the finish line. Never have I felt such achievement – individually and collectively – having given everything by running for those who cannot.”

Michael Thirkettle

On our Make Today Count weekend, the Bristol and Bath fundraising team’s third annual Authentic Indian Banquet raised a fantastic £10k towards Dr Matthew Wood’s Duchenne muscular dystrophy research at the University of Oxford. And in Glasgow, the Soundstational choir gathered in a flashmob to raise awareness and funds by belting out ‘Lean on me’ to passers-by.
Make Today Count, four days, 130 skydivers, 34 flashmobbers, six collections and a banquet raised over £100k for our Duchenne Research Breakthrough Fund

Building family funds

The family of five-year-old Abbi Bennett (pictured below with ambassador Kelly-Marie Stewart) set up the ‘Abbi One in a million’ fund to help fund research into Ullrich congenital muscular dystrophy and improve the lives of those affected by these and other muscle-wasting conditions. After winning over locals in her home town through a piece in the Birmingham Mail, Abbi’s story was snapped up and featured by the Daily Mail and Daily Mirror. Setting up a family fund is a great way to fundraise for the charity, as a family group. Families can raise funds for their areas of interest with administrative support from the charity.

Next year we will...

continue to generate sustainable voluntary income and associated Gift Aid to meet 2013-14 targets, and to continue to expand our support networks UK-wide with individual, group and Family Fund opportunities for involvement.
Improving exon skipping

Exon skipping technology is currently in clinical trials in boys with Duchenne muscular dystrophy, using molecular patches to mask the mutation and restore dystrophin production. Although the approach is showing promising results, research is required to optimise the technology and adapt it for different conditions.

Muscular Dystrophy Campaign-funded research in Professor Dominic Wells’ laboratory at the Royal Veterinary College aims to improve exon skipping technology by addressing the challenge of getting the molecular patches to travel from the bloodstream where they are injected, into all the muscles of the body, particularly the heart. The project will investigate ways to make blood vessels more ‘leaky’ so more molecular patch can reach the muscles. This will vastly improve the effectiveness of exon skipping and may also allow the use of lower doses.

Professor George Dickson at Royal Holloway – University of London – is working to combine exon skipping with another approach – molecular patches to block the action of a hormone called myostatin – to boost its effectiveness. This combination therapy may prove to be more effective than each potential treatment on its own; blocking myostatin on its own may offer potential to treat other types of muscular dystrophy.
Financial year

Summary of accounts

The charity had a successful year financially and ended the year with net incoming surplus resources of £650,000. This was achieved while maintaining our level of charitable activity. Reductions in costs of charitable activity compared to 2011/12 arose from the de-merger of the NeuroMuscular Centre at the start of 2012/13, the conclusion of the Tesco 2010 Charity of the Year partnership in 2011/12 and cost savings in 2012/13. At 31 March 2013, the free unrestricted funds were £969,000 providing a sound level of reserves for development of charitable activity in the forthcoming year.

A surplus of £650,000 for the year has considerably strengthened the financial position of the charity.

The total income for 2012/2013 was £4,544,000. Income from donations, gifts, grants and fundraising activities totalled £3,412,000. £952,000 was received from legacies and other incoming resources amounted to £180,000.

The outgoing resources were split between research projects seeking cures and treatments for muscular dystrophy and related neuromuscular conditions, which comprised 56 percent of charitable activities. The expenditure on medical research in the year was offset by an amount written back of £65,000 on research projects completing, where costs incurred were lower than anticipated. Care and support comprised 28 percent and communication and campaigning comprised 16 percent of our charitable activity.

Income

- Events and volunteer fundraising 44%
- Major donors 4%
- Regular giving and appeals 14%
- Corporate giving and sponsorship 7%
- Trusts 7%
- Legacies 21%
- Other income 3%

Spending on charitable activities

- Research 56%
- Care, support and advocacy 28%
- Communication and campaigning 16%

Summary of results is taken from the Group Statement of Financial Activities for the year ended 31 March 2013
We cover more than 60 neuromuscular conditions

Muscular dystrophies:
- Duchenne muscular dystrophy (DMD)
- Becker muscular dystrophy (BMD)
- Emery-Dreifuss syndrome
- facioscapulohumeral muscular dystrophy (FSH)
- oculopharyngeal muscular dystrophy (OPMD)
- congenital muscular dystrophies
- limb girdle muscular dystrophies

Myotonic disorders:
- myotonic dystrophy type 1 and 2
- congenital myotonic dystrophy
- myotonia congenita
  (dominant type – Thomsen, recessive type – Becker)
- Schwartz-Jampel syndrome
- pseudomyotonia
- neuromyotonia (continuous muscle fibre activity – Isaac’s syndrome)

Congenital myopathies:
- central core disease
- multifilmy core disease
- nemaline myopathy
- myotubular (centronuclear) myopathy
- fibre-type disproportion

Non-specific myopathy

Mitochondrial myopathies

Lipid storage myopathies (metabolic disorders):
- carnitine deficiency
- carnitine palmityl transferase deficiency
- myoadenylate deaminase deficiency

Inherited metabolic disorders:
- glycogen storage disease of muscle
- Type II (Pompe’s disease – acid maltase deficiency)

Type III (Cori-Forbes debrancher enzyme deficiency)
Type IV (Anderson – brancher enzyme deficiency)
Type V (McArdle disease – phosphorylase deficiency)
Type VI (Tarui – phosphofructokinase deficiency)

Periodic paralysis (muscle channelopathies)

Myositis:
- dermatomyositis
- juvenile dermatomyositis
- polymyositis
- inclusion body myositis (IBM)

Spinal muscular atrophies:
- severe SMA (Werdhig Hoffman disease – type I)
- intermediate SMA (Type II)
- mild SMA (Kugelberg Welander disease – type III)
- adult spinal muscular atrophy
- X-linked bulbospinal neuropathy (Kennedy’s syndrome)
- dominant SMA variants

Hereditary neuropathies:
- Charcot-Marie-Tooth disease
- peroneal muscular atrophy

Inflammatory and autoimmune neuropathies:
- Guillain-Barré syndrome (GBS)
- chronic inflammatory demyelinating polyradiculoneuropathy
- multifocal motor neuropathy
- paraproteinaemic demyelinating neuropathy

Disorders of the neuromuscular junction:
- myasthenia gravis
- congenital myasthenic syndromes

Myositis ossificans progressiva (MOP)

Myofibrillar myopathies

Illustration: turovsky/istock

There are over 639 skeletal muscles in the body.

A muscle can support more than 1,000 times its own weight.

About 40 percent of body mass is skeletal muscle.

A muscle can support more than 1,000 times its own weight.

Illustration: turovsky/istock
We are extremely grateful to individuals, charitable trusts and corporate supporters for their significant support of our activities this year:

Academy of Medical Sciences
ACCOR UK
Allergan International Foundation
Awards for all Scotland
Miss Agnes H Hunter’s Trust
Miss Sandra Bailey
Mr John D S Booth
Miss Marion Broughton’s Charitable Trust
The Albert Hunt Trust
The Annandale Charitable Trust
The Austin & Hope Pilkington Trust
B Baggins Foundation
Mrs Diana Barber
The Barbour Foundation
Professor Martin Bobrow CBE FRS FMed Sci
Ms Cornelia Bower
Brandon’s Fund
Mr Mike Challands
Mr Jeremy Champion
Ms Sinead Chapman
The Clothworkers’ Foundation
Mr Robert Clough
The Constance Travis Charitable Trust
Mr Ian Corner
The Cranbury Foundation
The Cumber Family Charitable Trust
Mr Peter Done
The Elizabeth Ferguson Charitable Trust Fund
The Eranda Foundation
Mr Max Essayan
The Eveson Charitable Trust
The Joseph and Annie Cattle Trust
Dr Andrew Cattenstro
Sir Alex Ferguson CBE
The Fowler Smith and Jones Trust
The G&E Pollitzer Charitable Settlement
The Gamma Trust
The Garfield Weston Foundation
GE Healthcare
Genzyme
The Goldsmiths’ Company Charity
Guoman Hotel Management (UK) Ltd
The Gwyneth Forrester Trust
Haines Watts
The Hamilton Wallace Trust
Mr Lawrence B Harper
The Headley Trust
The Henry Smith Charity
The Holbeck Charitable Trust
The Hugh Fraser Foundation
The Hull and East Riding Charitable Trust
The I.B.B Trust
The James Weir Foundation
The Joseph and Annie Cattle Trust
The Joseph Strong Frazer Trust
Kidlington and Gosford Leisure Centre
The Liz and Terry Bramall Foundation
The London Legal Support Trust
The Lord Belstead Charitable Trust
Mr Charles Manby
Mrs Nicola Manby
Matalan
Mr Mayo L Marriott
The Martin Connell Charitable Trust
Mrs Justine McAlister
The Millennium Stadium charitable Trust
The Montague Thompson Coon Charitable Trust
Mr David W Moyes
The N Smith Charitable Settlement
Nexen Petroleum UK Ltd
Next

The Northwood Charitable Trust
The Oakdalle Trust
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Our thanks to all those who tirelessly raise funds for the charity’s work through branches, groups and family funds. We highly value this ongoing support.

We rely almost entirely on voluntary donations and legacies to fund our vital work. We are not able to list every individual here, but our sincere thanks go to everyone who has donated and fundraised for the charity this year.

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Muscular Dystrophy Campaign is an operating name of the
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Our 2012/13 Financial Statements are available upon request. Download a copy from our website, or call the office and we’ll send you a hard copy.

Thank you for your support