Muscular Dystrophy Campaign

# Making an impact

Annual review 2013/14

# Welcome

Our warmest thanks must go to our generous supporters and donors who have enabled us to make striking progress towards our goal of beating muscular dystrophy and indeed all muscle-wasting conditions.

You will read about the impact the charity has made over the last year through maintaining our focus on funding groundbreaking research leading to potential treatments, and we are very encouraged by the growing number of potential drug therapies being tested in clinical trials today. We have also been successful in driving forward improved access to specialist NHS care and developing services and support so people can live independent and full lives. We remain determined to accelerate progress in each of these areas.

We were deeply saddened by the death of our former President and long-term supporter, Lord Richard Attenborough, in August. He was an extraordinary man, who supported us for more than 50 years and raised hundreds of thousands of pounds towards our research. In his memory, and with eyes firmly placed on the future, we have established the Richard Attenborough Fellowship Fund, so young researchers can maintain and indeed accelerate the search for treatments.

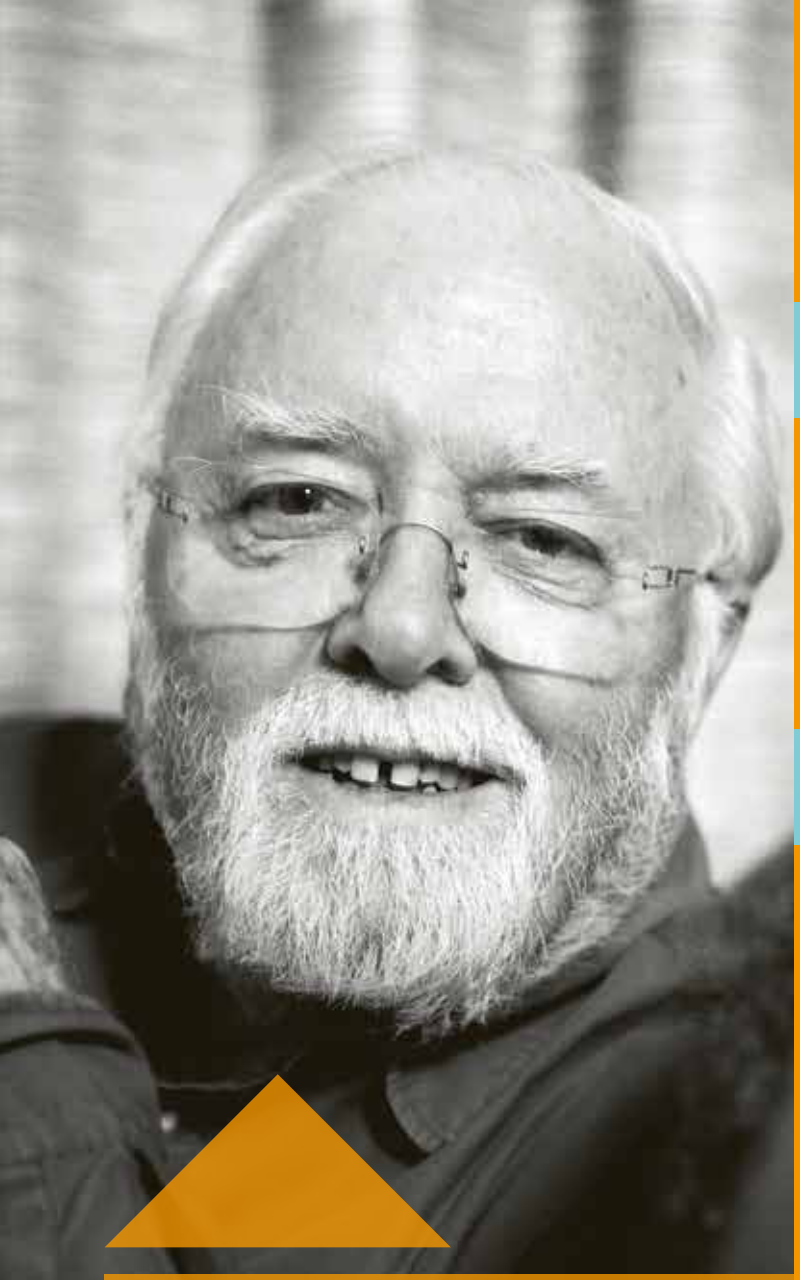
We are delighted to have brought together charities and organisations in the neuromuscular field, both in this country and internationally, to work with us to improve the lives of everyone affected by muscle-wasting conditions. We also link closely with clinicians and health professionals to improve specialist healthcare.

We are pleased to note the important legal advice provided on a pro bono basis by Hogan Lovells, a prestigious law firm, to underpin our advocacy service and have recently established a partnership with Anderson Strathern to extend this service to Scotland. We have worked effectively with parliamentarians, ministers and regulatory bodies to drive forward fast access to emerging treatments; for those with muscle-wasting conditions, every day counts. Further, we have secured £400k of new NHS investment in Wales towards equipment, additional support through NHS Scotland and a commitment in Northern Ireland for additional specialist care.

Of course, these advances would not have been possible without the support of many people. Our warmest thanks go to our dedicated supporters and fundraisers, expert scientists and clinicians, our trustees for their valued advice and guidance and to the charity's staff team. Together they have made this a year of impressive achievements and progress. There is much more to be done and we are determined to step up our fight to beat muscle-wasting conditions and improve the lives of everyone affected by them.

**Robert Meadowcroft**
Chief Executive

**Bill Ronald**
Chairman



# Lord Attenborough 1923 – 2014

**After visiting a local fete in 1962 and meeting some boys who had Duchenne muscular dystrophy, Lord Attenborough offered his support to us, contributing greatly to fundraising and raising the profile of the charity while still pursuing his film career. He served as President from 1972 until 2002, when he became an Honorary Life President.**

**"I've received far more than I have given as far as the charity is concerned. The privilege of knowing the parents and of coming to understand the depths of what their utterly unselfish love can amount to, is a gift that perhaps I will never witness anywhere else. And I shall be ever grateful to the Muscular Dystrophy Campaign for that."**

**We will always be grateful to Lord Attenborough (Dickie as he was known) and our thoughts are with his family.**

# Our vision

A world with effective treatments and cures for all muscle-wasting conditions so there are no limits in life for individuals and families affected.

# Our mission

We are the UK charity for people affected by more than 60 different muscle-wasting conditions.

- We support research to drive the development of effective treatments and cures for all conditions
- We ensure access to specialist NHS care
- We provide services and opportunities that enable individuals and their families to live as independently as possible.

We know we can beat muscle-wasting conditions more quickly if we work together. We are uniting skills, knowledge and resources in the UK and working with others around the world so we can improve the quality of life for the people affected, and to bring cures closer to reality.

# How we're doing ...

... to improve the quality of life for people affected by muscle-wasting conditions and bring cures closer to reality

## Last year we said we'd...

support research with the goal of effective treatments being introduced for all conditions

- We invested in seven new research projects focusing on Duchenne muscular dystrophy.
- We awarded a Clinical Training and Research Fellowship for a project to improve diagnosis for people with limb girdle muscular dystrophy.
- We supported the launch of the facioscapulohumeral muscular dystrophy (FSH) registry, which now has more than 400 people on it.
- We drew together the Duchenne Forum – a funding partnership between six UK charities dedicated to beating Duchenne muscular dystrophy.

## Next year we'll...

- continue to invest in research to develop effective treatments
- invest in clinical infrastructure, such as clinical fellowships, patient registries and natural history databases
- work more closely with other charities in the UK and internationally to fund a greater number of high-quality research projects
- promote the involvement of more people affected by muscle-wasting conditions in decisions about research funding
- keep families up-to-date with our research by developing our excellent research communications.

## Last year we said we'd...

improve access to specialist care

- We created neuromuscular forums across England to look at what specialist services are available, so we can press for specialist services where they're needed and tell people what local services exist.
- We secured funding for a total of 45 care advisor and neuromuscular nurse posts, an increase of six in the past year, and 32 since 2009.
- We campaigned on access to rare disease drugs, and this led to the government's launch of an Early Access to Medicines scheme.
- We campaigned in Wales for specialist equipment, which led to an investment of £400k, and we continue to campaign in Scotland for provision of hospice facilities for young adults.
- We campaigned in Northern Ireland for improved care, and the Health and Care Services have committed to recruiting two new care advisor posts.

## Next year we'll...

- protect and extend NHS investment in neuromuscular services, and bring people with muscle-wasting conditions together with decision-makers from the new NHS structures
- continue to influence parliamentarians and governments in Westminster, Cardiff, Edinburgh and Belfast, to ensure UK patients have timely access to emerging treatments and specialist care
- give a greater voice to people with muscle-wasting conditions to influence change and improve healthcare services.

## Last year we said we'd...

provide direct essential support and promote independent living

- We responded to 25,000 requests for information.
- We ran information days for specific conditions.
- We visited clinics across London to tell patients about our services.
- We helped in 200 cases where people were struggling to get the services, benefits and equipment they're entitled to (a total of about £500k).
- We started a network of Advocacy Ambassadors, to give local peer-to-peer advice and support.
- We grew our Muscle Group membership by 25 percent, meaning about 1,500 people come to these information and support meetings across the UK.
- We saw the airline industry make top-level service improvements through the work of the young campaigning network, the *Trailblazers*.

## Next year we'll...

- expand our information and advocacy service to meet growing demand
- grow our network of Muscle Groups across the UK
- launch a new online map of neuromuscular services
- grow the *Trailblazers* network and develop employment opportunities for young disabled people through our work experience programme
- launch a new online training resource for GPs and begin work on a similar tool for physiotherapists.

## Last year we said we'd...

generate sustainable income to fund charitable activities

- We exceeded our overall voluntary income target, with £2,193k net fundraised income including associated Gift Aid, legacy income of net £2,148k, including one individual gift of shares valued at £500k.
- We expanded our support networks with a total of 101 branches, regional and event groups fundraising UK-wide, and through new Family Funds.
- We ran specific appeals for various conditions (the Duchenne Breakthrough Fund, two Clinical Training and Research Fellowships – Richard Attenborough and Q Trust, the Action on FSH Appeal and the Ullrich/CMD research fund) and raised a total net £858k, restricted to specific research programmes as requested by donors.

## Next year we'll...

- raise the £2m net fundraised income needed to meet charitable commitments for the year, plus £800k anticipated in net legacy income
- expand our fundraising networks UK-wide
- enable greater investment in research by raising funds for the Duchenne Research Breakthrough Fund and Clinical Training and Research Fellowships, and the establishment of a new Lectureship.

**400**
people in new FSH registry

**27**
live projects

# Moving closer to effective treatments

With our eye on the goal of developing effective treatments for all the conditions we support, the past year brought both excellent and challenging results. In light of this changing environment, we reviewed and published our new research strategy. Paving the way to treatments sets out eight strategic goals we'll be working towards over the next five years.

With the successful launch in 2013 of the Duchenne Forum, we not only invested in seven pioneering research projects focusing on this devastating condition, but five other charities joined us in doing so. The projects cover a broad range of approaches, to increase our understanding of the biological mechanisms that lead to Duchenne muscular dystrophy, and develop treatments for it.

In focusing on international collaboration, our Director of Research, Dr Marita Pohlschmidt, was elected Chair of the Executive Committee of the ENMC (European Neuromuscular Centre). The ENMC, of which we are a foundin g member, facilitates collaboration and communication within the scientific community through the funding and organisation of workshops.

Together with TREAT-NMD, we brought together scientists, clinicians, pharmaceutical companies and regulators to bring treatments for Duchenne muscular dystrophy to the market more quickly. Again with TREAT-NMD, we set up and launched the facioscapulohumeral muscular dystrophy (FSH) patient registry, and continued our support for the myotonic dystrophy registry.

In 2013, a public consultation found general support for mitochondrial transfer IVF. The technique, which could prevent mitochondrial myopathy being passed on to future generations, was developed from research we funded in Professor Doug Turnbull's laboratory. We are now calling for swift action to change the regulations required to move the technique into clinical practice.

"I feel very fortunate to have worked in the early development of tests for Duchenne muscular dystrophy and to have contributed to the understanding of the pathology. It's an even greater pleasure now to make a difference to the lives of patients through the development of a treatment."

*Professor Davies' current, two-year research project looks at: 'The development of small molecule upregulators of utrophin for the treatment of Duchenne muscular dystrophy.'*

**9**

universities where our research is taking place

# Professor Dame Kay Davies

**DBE FRS FMed Sci, University of Oxford**

**"After collaborating on the first prenatal diagnosis of Duchenne muscular dystrophy in the early 1980s (my group established the large size of the gene once the Kunkel and Worton groups had identified it), we discovered utrophin in 1989 and postulated that it might compensate for dystrophin deficiency in patients with Duchenne muscular dystrophy. It's a long and hard programme to bring a drug to clinic; the Muscular Dystrophy Campaign recognised the importance of utrophin early on and has consistently funded a researcher in my group. We've valued both the research support and the contact with patients and families."**

# Khurm Arshad

**Auzair's Fast Track Research Fund, Bristol**

**"Specialist healthcare services have a huge impact on everyone affected by severe and devastating muscle-wasting conditions; there's no time to waste as conditions change daily and so do healthcare needs. Without the charity's campaigning work, my 17-year-old brother Auzair, who has Duchenne muscular dystrophy, would be going into adult services with no care pathway, and no specialist healthcare services. I appreciate how the charity holds the local NHS in check, and how it's now pressing to ensure the NHS delivers cutting-edge medicines as soon as they become available."**

**Pictured l to r: Usmaan, Auzair and Khurm Arshad**

**45**

care advisors and neuromuscular nurses in post across the UK

# Improving access to specialist healthcare

People affected by muscle-wasting conditions need to have access to specialist NHS care from a multi-disciplinary team. We work across the UK to ensure they do.

Our Department of Health-funded Bridging the Gap team has set up regional neuromuscular forums across England, bringing together people affected by muscle-wasting conditions, clinicians and commissioners to identify gaps in specialist neuromuscular services and the most urgently-needed roles. By the end of March 2014, we were delighted to see funding for 11 new NHS roles secured through the forums' work.

The team has also organised training days for physiotherapists and occupational therapists, and is developing an online training module for GPs, to increase the number of health professionals who understand the needs of people with muscle-wasting conditions. We expect to launch our new online map of services – enabling people to find services in their area – in late summer 2014.

We work with parliamentarians and governments in Westminster, Cardiff, Edinburgh and Belfast to ensure patients have timely access to emerging treatments. Our campaign on access to rare disease drugs led to the government's launching the Early Access to Medicines scheme. Our campaigning in Wales has led to an investment of £400k towards specialist equipment, and in Northern Ireland to a commitment by the Health and Care Services to recruit two new care advisor posts. In Scotland we've been pressing for provision of hospice facilities for young adults.

Following our ongoing campaigning and constructive dialogue with NICE (National Institute for Health and Care Excellence), we heard in late 2013 of their plans to develop the first-ever clinical guidelines for 'uncommon neuromuscular conditions'. There are now 45 care advisor and neuromuscular nurses in post providing vital support across the UK, an increase of six in the past year, and 32 since 2009.

"Auzair is positive and ambitious and dreams of being an entrepreneur. We can't change the pace of medical progress – but we can plan ahead so we don't waste a moment if a therapy is shown to work."


# Michaela Hollywood

***Trailblazer,* County Down**

**"For too long, non-disabled adults have spoken for young disabled people. *Trailblazers* gives us a fantastic platform, with support and guidance, from which to speak out about what needs to change so we can live full, active lives and contribute to the world. Although medical research is needed, it shouldn't be the sole focus and we must contribute to society while scientists work to fix our bodies. The simple act of having a voice has transformed the world many times before, and I genuinely believe history will show *Trailblazers* to be the next revolutionary voice."**

**600**

*Trailblazers* working to change the social landscape for young disabled people

**30**

young disabled people have taken up *Trailblazers* work experience opportunities

# Promoting independent living

We are committed to making sure everyone affected by a muscle-wasting condition has what they need to live as independent a life as they wish. We do this by providing helpful, relevant information and advice, and by drawing people together in their local areas.

Last year we introduced a new way of offering local support. Supported by the Big Lottery Fund's Reaching Communities programme, we recruited and trained 20 volunteer Advocacy Ambassadors, all of whom know what it's like to live with a muscle-wasting condition, to offer local advice and support. This is in addition to our in-house advocacy service, which helps people with muscle-wasting conditions get the benefits, services or equipment they are entitled to. Prestigious legal firm, Hogan Lovells, offers pro bono legal consultancy, and we have recently partnered with a notable law firm in Scotland, Anderson Strathern.

Our supporters tell us how helpful it is to meet other people affected by the same condition, so we held information days for facioscapulohumeral muscular dystrophy (FSH), Becker muscular dystrophy and congenital muscular dystrophy across the UK last year. We also attended clinics in London, to tell people affected by muscle-wasting conditions how we can support them. Our UK-wide Muscle Groups bring people affected by muscle-wasting conditions together with clinicians and local MPs. Last year, we grew these Groups by 25 percent, with more than 1,500 people going to these meetings regularly.

Our network of young disabled campaigners – *Trailblazers* – launched campaigns on access to high streets, disability and relationships, and access to live music, and brought about top-level service improvements in the airline industry. They introduced a *Link-Up* mentoring programme in Scotland, putting younger people in touch with older *Trailblazers* for guidance and support.

**200**

advocacy cases

**25,000**

requests for information responded to

**£1.45m**

secured for individuals and families since advocacy service began in 2011

"Our spirit is most certainly not affected. Without *Trailblazers* and the backing of the charity, a lot of disabled people would simply have no voice."

## WE AWARDED 131 GRANTS WORTH A TOTAL OF £158,051

As the leading UK charity fighting muscle-wasting conditions, we are committed to enabling each individual to live as independent a life as they wish. Our welfare arm – the Joseph Patrick Trust (JPT) – awards grants towards specialist equipment such as powered wheelchairs, electric beds and assistive technology and since it was established in 1986, it has awarded 6,600 grants worth more than £6.4m to thousands of people requiring specialist equipment.

**£6,660k**

overall voluntary income

# Our financial year

## Summary of accounts

Thanks to the individual, company and trust supporters of the charity's work, we ended the year with a net surplus of £1,885k. This was achieved while increasing our level of charitable activity by over 25 percent. A significant part of this achievement was thanks to people remembering the charity in their Wills, and this has led to a fund of £850k, designated for research and other charitable activity in future years.

At 31 March 2014, the free unrestricted funds were £1,480k, providing a sound level of reserves for development of charitable activity in the forthcoming year.

The total income for 2013-14 was £6,660k. Income from donations, gifts, grants and fundraising activities totalled £4,139k. In addition, £2,148k was received from legacies. Investment income and other incoming resources amounted to £268k, of which £50k is ring-fenced Duchenne Forum charity funding for research into Duchenne muscular dystrophy.

The expenditure on charitable activities was in respect of medical research, care and support, communications and campaigning. Medical research in the search for cures and treatments for muscular dystrophy and related neuromuscular conditions comprised 45 percent of the total expenditure on charitable activities. Care and support comprised 41 percent, and communication and campaigning comprised 15 percent of our charitable activity.

The full accounts are available on our website at: www.muscular-dystrophy.org or upon request.

*Thank you for your support*


| | |
|---|---|
| Events and volunteer fundraising | 37% |
| Regular giving and appeals | 10% |
| Corporate giving and sponsorship | 6% |
| Trusts | 10% |
| Legacies | 33% |
| Other income | 4% |


| | |
|---|---|
| Research | 45% |
| Care, support and advocacy | 41% |
| Communication and campaigning | 15% |

Summary of results is taken from the Group Statement of Financial Activities for the year ended 31 March 2014

# £250k

raised for us at the 2013
Virgin London Marathon

# Supporting our work across the UK

Kyle's Fund is one of 27 Family Funds created this year. This support is vital to the sustainability of our charitable work, as we don't receive government funding. Without family fundraising, individual donations, branches and other community, corporate and trust support, we would be unable to achieve the major strides forward you're reading about in this report.

Last year, we continued to expand our support networks with a total of 101 groups fundraising UK-wide by the end of March 2014, comprising branches, local groups and event committees, and through the establishment of new Family Funds. With national initiatives such as Make Today Count, and the brand new and accessible Move a Mile for Muscles event, we involved 776 supporters and raised around £792k. We also added a third Town and Gown 10k to our series; the Durham event, together with those in Oxford and Cambridge, raised nearly £200k for the charity.

Thanks to all their active fundraising, Family Funds 'Team Jed', 'Dan's Hope', 'Abbi one in a Million' and the McAllister family, have enabled our investment into Ullrich congenital muscular dystrophy. In addition, we ran specific appeals for the Duchenne Research Breakthrough Fund, two Clinical and Research Training Fellowships (Richard Attenborough and Q Trust), and the Action on FSH Appeal. Together these raised a total of £858k in the year, restricted to specific research programmes as requested by donors.

We also provided opportunities for supporters to visit laboratories and meet scientists in Newcastle, Oxford and London during the year; with positive feedback from all who attended.

"When we first heard about the charity we decided to fundraise for research into a cure and for better treatments for all young boys with Duchenne muscular dystrophy."

**7,611**
people took on fundraising challenges and raised
**£1,670k**
for the charity

# Jenna Glass

**Kyle's Fund, Bellshill**

**Kyle is mad about action men. He can't decide whether to be Spiderman, Batman or the Hulk. While he's a typical five-year-old, Kyle was diagnosed with Duchenne muscular dystrophy in 2013. His daily steroid regimen maintains sufficient muscle strength so he can bounce on his trampoline with both legs. Mum and dad – Jenna and Kevin – started Kyle's Fund to support our groundbreaking research and, with fantastic support from family and friends, have organised a sponsored walk, a bungee jump, a charity race night, joined our Make Today Count skydive, entered a team of 21 into the Edinburgh Marathon, and raised an incredible £20k.**

Photo credit: Warren Media

# Some highlights

Make Today Count 2014
147 participants raised over
**£116k**

## Advocacy service

Our advocacy service helps people affected by muscle-wasting conditions fight for the services, benefits and equipment they are entitled to, so they can live full and independent lives. We have a pro bono partnership with prestigious law firm, Hogan Lovells, whose legal expertise helped us to secure £505k worth of assistance for 222 people during the past year.

"You were such a great help and have helped me get to a much happier stage in my life. Thank you."

Eilean Stewart, Glasgow

## Remembering Peter

**Peter Hooker (pictured above) loved reading our *Target* magazines. He would sit and read the magazine and keep up-to-date with the work of the charity. According to his dad, Owen, this was on his mind when he wrote his Will, and chose to leave half of his estate to the Muscular Dystrophy Campaign.**

Peter was born in Weybourne in 1968 to Owen and Ann, and soon after birth was diagnosed with myotonic dystrophy, a condition his older brother, Paul, and mum, Ann, were subsequently diagnosed with too. The family made contact with the Muscular Dystrophy Campaign when their sons were older, and valued the opportunity to find out more about latest developments in research and care for their condition.

A former pupil at Treloars College in Hampshire, Peter moved into the Leonard Cheshire care home in Hydon Hill when he was in his 30s. After falling gravely ill, he passed away in January 2013, a month short of his 45th birthday. With a generosity of spirit and a genuine interest in the work of the Muscular Dystrophy Campaign, he left a gift of £7,628 to our charity. Gifts such as these make a significant difference to our work, and we are extremely grateful for being remembered in this way.

We received £2,148k in legacy income over the past year, including one individual gift of shares valued at £500k.

**£505k**

worth of services secured for 222 people through our advocacy service in 2013/14

**Thanks** to generous funding from the Cranbury Foundation, we were able to support Dr Saam Sedehizadeh in his three-year research project to bring us closer to clinical trial readiness for myotonic dystrophy type 1 (DM1). A Clinical Fellow at the University of Nottingham, Dr Sedehizadeh will test around 5,000 drug-like chemicals for their potential to treat myotonic dystrophy. He will also follow a group of patients to help define outcome measures and find biomarkers that could be used in future clinical trials for DM1.

We involved volunteers in over
**100**
different roles

"I think the Muscular Dystrophy Campaign has done and is doing more than anyone in the UK to really try to pull the neuromuscular charities together, and I think this is admirable."

Professor Mary M Reilly MD FRCP FRCPI

**£1m** invested over the last 10 years in myotonic dystrophy research

**Our Lay Research Panel,** a group of supporters affected by neuromuscular conditions, considered more than 30 applications for research grants for the 2013/14 grant round. Feedback from the panel plays a key role in deciding which grants are awarded funding.

**Our research strategy** – *Paving the way to treatments* – was launched in early 2014, and outlines eight strategic goals to form the charity's research focus over the next five years. It focuses on developing therapeutic approaches, promoting clinical trial readiness and building key partnerships.

**We have established a place on three national clinical reference groups, ensuring the patient's voice is heard by NHS England.**

**The charity recognises centres that provide a 'one stop shop' of neuromuscular services for children and adults, as clinical centres of excellence. Three of these centres were recognised in 2013, bringing the total to seven.**

We awarded a *Clinical Training and Research Fellowship* to Dr Elizabeth Harris at Newcastle University, whose project aims to improve diagnosis for people with limb girdle muscular dystrophy.

With consistent national and regional media coverage – including *BBC Breakfast*, the *Today* programme and *The Sunday Times* – we achieved 75 pieces of media coverage each month.

## Sports Quiz

**In March,** 160 guests enjoyed a black tie evening with us in the world-famous Long Room at Lord's. This was our fourth Celebrity Sports Quiz, and we enjoyed the support of Martin Bayfield, Vassos Alexander and our own charity President, Sue Barker MBE. Thanks to everyone's generous support, the evening raised more than £120k towards our vital research.

## Microscope Ball

**In October,** over 700 people from the property industry gathered and raised a whopping £250k for the charity. The alpine ski-themed Microscope Ball, now in its 30th year and held at Westminster Park Plaza in Waterloo, is one of the industry's most prestigious and highly-anticipated events. Our sincere thanks to the Microscope Ball Committee for another successful Ball.

We grew our community of supporters through our social media presence on Facebook (by 3,200), Twitter (by 1,700) and YouTube (by 3,854 views).

2013 charitytimes Awards
Recognising leadership and professionalism
Winner

Our PR team was recognised for its media campaigning of the *Trailblazers* when it won PR Team of the Year at the 2013 Charity Times Awards.

# We cover more than 60 neuromuscular conditions

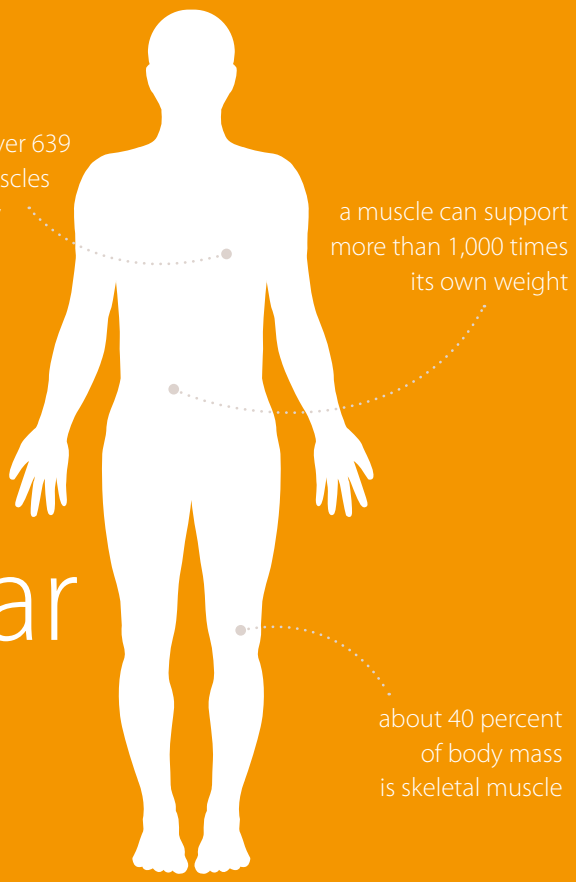



Illustration: turovsky/istock

### 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)
paramyotonia congenita
Schwartz-Jampel syndrome
pseudomyotonia
neuromyotonia (continuous muscle fibre activity – Isaac's syndrome)

### Congenital myopathies:
central core disease
multimini 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 – phosporylase deficiency)
Type VI (Tarui – phosphofructokinase deficiency)

### Periodic paralysis (muscle channelopathies)

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

### Spinal muscular atrophies:
severe SMA (Werdnig 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

# Thank you

We are extremely grateful to individuals, families, branches and groups, charitable trusts and corporate supporters for their significant support of our activities this year:

Alan Nash
Alison J Hampton
Allergan International Foundation
Anderson Strathern
Berkeley Foundation
Big Lottery Fund – Reaching Communities
Bruce Wake Charitable Trust
Campden BRI
Candidus Lodge
CeX
Chapman Charitable Trust
Charles S French Charitable Trust
City Bridge Trust
Clapp Family Charitable Trust
Daniel M Parker
Danny Desmond
David Daly
Department of Health Innovation, Excellence and Strategic Development Fund
Dipa Patel
Edward Rees
Ely Lilly
Eveson Charitable Trust
Fowler Smith and Jones Trust
Friends of Muscular Dystrophy
Genzyme
Hayward Sanderson Trust
Health and Social Care Alliance Scotland
Hogan Lovells
IBB Trust
J K Young Endowment Fund
Jeremy Champion
John P Harper
Larchwood Charitable Trust
Larry Till
London Classified
Lord Belstead Charitable Trust
Marc Lebe Trust
Martin R Moore
Masonic Samaritan Fund
Matalan
Mayo L Marriott
Michael Marsh Charitable Trust
Michele Pucci
Miss Elizabeth T Robertson's Charitable Trust
Miss Marion Broughton's Charitable Trust
Tony Moorwood
Next Plc
P F Charitable Trust
PTC Therapeutics
Roche
Rosetrees Trust
Sainsbury's Local
Sarepta Therapeutics
Simone Verri
Simplyhealth
Sir Edward Lewis Foundation
Sir Samuel Scott of Yews Trust
Sovereign Healthcare Trust
St George
Stuart K Ferguson
Sylvia Aitken Charitable Trust
The Albert Hunt Trust
The Annandale Charitable Trust
The Annet Charitable Trust
The Barbour Foundation
The Catherine Cookson Charitable Trust
The Constance Green Foundation (now the Green Hall Foundation)
The Cranbury Foundation
The Garfield Weston Foundation
The Greendale Charitable Foundation
The Henry Smith Charity
The Hospital Saturday Fund
The Inman Charity
The Joseph and Annie Cattle Trust
The Joseph Patrick Trust
The Joseph Strong Frazer Trust
The Kirkby Foundation
The Light Fund
The Liz and Terry Bramall Foundation
The M E B Charitable Trust
The Mason Le Page Charitable Trust
The Montague Thompson Coon Charitable Trust
The Paul Bassham Trust
The Pixel Fund
The Q Trust
The Rayne Foundation
The Row Fogo Charitable Trust
The Sir John Eastwood Foundation
The Young Q Trust
The Templeton Goodwill Trust
Tim Northam
Tony A Carey

With thanks to members of the following committees, whose enthusiasm and generosity make our events possible: the Microscope Ball Committee, Sports Quiz Committee, Oxford Spirit of Christmas Committee, Q Trust Quiz Committee, Pledge Dinner Committee and the Town and Gown Committee.

Our thanks to all those who tirelessly raise funds for the charity's work through branches, groups and Family Funds. We highly value your 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. Thank you.

"St George and the Berkeley Foundation are long term supporters of the Muscular Dystrophy Campaign and we've been delighted to continue our support into 2014. This year our staff have taken part in the Virgin London Marathon, Bupa 10k and RideLondon, and we've raised money through Christmas campaigns and in-office fundraising activities. We're extremely proud to support such a worthy cause."

Ian Dobie, Managing Director, St George

Thank you for your support

## Patron

**HRH The Prince Philip,**
**Duke of Edinburgh**
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Our 2013/14 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*

Muscular Dystrophy Campaign
61A Great Suffolk Street
London SE1 0BU

**t: 020 7803 4800**
**e: info@muscular-dystrophy.org**
**w: www.muscular-dystrophy.org**

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