



Our vision

A world with effective treatments and cures for all musclewasting conditions and no limits in life for individuals and families affected.

Our mission

We are the UK charity for individuals and families living with muscle-wasting conditions.

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

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 70,000 people affected, and to bring cures closer to reality.

We know we can beat muscle-wasting conditions more quickly if we work together.

How we make a difference

Founded in 1959, we have been leading the fight against muscle-wasting conditions for 56 years.

- Every six minutes a family in need contacts us for advice, information and support.
- By investing more than £55m in research, over the years, we have helped lay the foundations for the first potential treatments now in clinical trials.
- By bringing families together to campaign with us, we have secured investment of over £4m, over the years, in specialist healthcare from the NHS.

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On the cover: Vicky de Bruin with her son Luke (3) who has

Welcome

A huge thanks to our generous donors and supporters who enable us to make progress in working to beat muscular dystrophy and indeed all muscle-wasting conditions.

This *Impact report* sets out the important progress we have made on many fronts this year. This progress has been achieved at the same time as we have established a firm financial foundation for the future. We adopted our new name – Muscular Dystrophy UK – to reflect our role as the national charity for everyone living with a muscle-wasting condition. We also warmly welcomed the charity's new Ambassador, Jack Wilshere, the Arsenal and England footballer.

Muscular Dystrophy UK continues to drive progress in research, access to improved care and support for independent living. We made a commitment of over £1m into new research covering nine conditions, set up UK research funding partnerships, and established our first international funding partnership with organisations in France, Switzerland, Ireland and the US.

There has been significant progress in the past vear towards treatments becoming available. For those families with a son with Duchenne muscular dystrophy, the EMA (European Medicines Agency) licence for Translarna as the first treatment to target an underlying cause of Duchenne muscular dystrophy was a very encouraging step forward. However, there have been several obstacles placed on the path to its availability for eligible boys in the UK and, together with many families, we continue to press NICE and NHS England for a fast and positive decision.

We were delighted that Parliament approved regulations to permit mitochondrial donation IVF, after detailed debates. Muscular Dystrophy UK is a long-term funder of the internationally-recognised research into mitochondrial disease, carried out by Professor Doug Turnbull and his team at the University of Newcastle, and we were delighted with this positive step.

(I to r) Bill Ronald and Robert Meadowcroft



We secured significant improvements in NHS support across the UK, working closely with NHS commissioners and health professionals as well as with Parliamentarians and Assembly Members. New information and care initiatives included the publication of alert cards for several conditions, online training for GPs and physiotherapists, and a new online map of services.

We have strengthened our support for individuals and families at diagnosis and indeed at all stages of living with a musclewasting condition. Our information and support services helped more families, with dedicated posts in Scotland and Northern Ireland and similar support planned in Wales. The Joseph Patrick Trust, our welfare arm, awarded 170 grants for specialist equipment for children and adults last year.

The launch of our Duchenne Network, the growing number of Family Funds and support groups, along with the launch of the Awaaz Forums and our Branches, reflect our roots across the whole of the country. We play a unique role in drawing on the support of all those living with muscle-wasting conditions to influence decision-makers UK-wide.

We must give our thanks to many people, including the scientists, health professionals and commissioners, funders and fundraisers, our determined staff team and our President Sue Barker MBE. We also wish to thank our Trustees for their advice and guidance during the year.

It has been a year of important achievements. We are determined to accelerate the rate of progress to win the fight, together, to beat muscle-wasting conditions and improve the lives of everyone living with them.

WILL Round Bill Ronald

Chairman

Robert Meadowcroft

Chief Executive

(I to r) Olivia, Barry, Luke and Vicky de Bruin, from Kent



Connecting with the charityThe first port of call

Vicky de Bruin lives in Kent with husband Barry and their children – Olivia (5) and Luke (3).

"I remember that day in August 2013 like it was yesterday. It was the worst day of my life.

"We were absolutely numb. We'd just been told that Luke, our beautiful little 18-month-old, had Duchenne muscular dystrophy. We'd never even heard of it. To try and understand that he probably wouldn't live much past his 20s, blew our whole lives apart.

"The diagnosis came completely out of the blue. We were concerned Luke wasn't reaching his milestones, so he was sent for routine blood tests. We got a call late one evening to say Luke needed more specialist tests, and 12 weeks later we got the diagnosis.

"That awful conversation plays over and over in my head.

"I met someone from Muscular Dystrophy UK's **care and support team** at the clinic after our first neurologist appointment. They were really helpful and gave me all the information I needed. They also put us in touch with another family – that really helped us not to feel so alone.

"Through the charity's **advocacy service**, they also helped us get on the housing register, and we're now in an accessible house and awaiting further adaptations. It's such a relief to have a house that can help us support Luke and not to have to worry about the practicalities. This gives us more time to focus on Luke.

"Muscular Dystrophy UK plays such an important part in the lives of families like ours. Now, two years on, I'm happy to be a **peer support volunteer**. I can listen to other families and say I understand. It's good to be able to share my experiences and encourage others in the same way."

Muscular Dystrophy UK is the first port of call for 4,000 individuals and families newly diagnosed each year.

 To find out more about our support services, visit www.musculardystrophyuk.org/ get-the-right-care-and-support





Byan Gould has oculopharyngeal muscular dystrophy



Getting the right care and support, wherever you live

Bryan Gould (55) from Stourbridge was diagnosed with oculopharyngeal muscular dystrophy (OPMD) at the age of 47.

Since then, he has started an OPMD support group, volunteers for the Black Country Neurological Alliance and is an integral voice on his local patient participation group.

"Muscular Dystrophy UK has given me a platform to speak directly to decision-makers. Not only do I get to highlight my concerns, but also those of others with musclewasting conditions, to ensure there is effective support.

"Since I got involved with the charity, I've been using my voice to **campaign** on behalf of people living with a muscle-wasting condition. In 2014, I even got to meet with the Care Minister to talk about the urgent need for cough assist equipment.

"Having access to an **online map of resources** applicable to your
postcode and area can be a lifeline
and beneficial to both health and
mental state.

"Through the charity's Bridging the Gap project, the West Midlands Forum is bringing together consultants, healthcare professionals, care advisors, Muscular Dystrophy UK representatives, NHS England, commissioners and patients. I take very seriously my role as patient representative, providing local healthcare knowledge, and a psychological perspective on care.

"This then allows the charity to campaign and support parliamentary debate and guide clinical best practice," said Bryan.

Thanks to funding from the Department of Health's Innovation, Excellence and Strategic Development grant programme, the charity's Bridging the Gap project brings people together to improve access to specialist healthcare and improve the quality of life of those living with musclewasting conditions. Through this project, we've created an online hub – a central resource outlining useful support services available UKwide – and launched the first-ever GP e-learning module on musclewasting conditions.







Jonathan Gilmour (28) has Duchenne muscular dystrophy



BBC One Lifeline Appeal

"With muscular dystrophy, the goalposts are always changing. Instead of getting better as you get older, you get worse.

"My condition causes my muscles to get weaker. I'm missing a chemical. Like a car without any petrol. My body struggles to get around. I can't adjust my glasses, wipe my face, brush my teeth or shave myself, reach things, feed myself, dress myself, get out of bed myself.

"But despite my condition, I can still do my PhD, enjoy music, enjoy going out with my friends. There are lot of things I can do. My condition poses me difficulties. But I'm not defined by it.

"The research Muscular Dystrophy UK funds is really important for the next generations, to stop them having to go through what I've gone through, to improve their quality of life and give them hope." Jonathan Gilmour

We were thrilled to have secured a BBC One Lifeline Appeal, which aired in March 2015 and raised more than £34k for the charity.

The BBC One Lifeline Appeal is a monthly programme, in which a well-known personality introduces the vital work of a particular charity they care about, and appeals for donations. Since its inception 25 years ago, the BBC One Lifeline Appeal has helped raise money and increase the profile of more than 300 charities across the UK and overseas.

Our President, Sue Barker MBE, did a superb job of hosting the programme. She met 28-year-old Cambridge PhD student, Jonathan Gilmour, who is living with Duchenne muscular dystrophy. Sue also met seven-yearold Abbi Bennett, who has Ullrich congenital muscular dystrophy and her family, and Oxford scientist, Professor Matthew Wood, whose work we fund.





Abbi Bennett (7) has Ullrich congenital muscular dystrophy



Sue Barker MBE, President of Muscular Dystrophy UK



6.3m reached on social media

Professor Matthew Wood

2 Awaaz Forums for South East Asian families 4 muscular dystrophy parliamentary cross party groups

43 Family Funds

161 pieces of media coverage every month, including BBC, ITV, Daily Mail and Huffington Post

Support across

38 Branches

Reached over 20k likes on Facebook, up from 9k across the UK

Reached 10k Twitter followers from 8k before

Advocacy officers in Scotland and Northern Ireland

Additional NHS investment in Wales

49 care advisors and specialist nurses

2 clinical trial co-ordinators

30 research projects

Free advertising space provided as a gift by London Classified in Metro and Evening Standard reaching almost 3m people

9 regional neuromuscular forums





Funding for world-class research

Cambridgeshire couple, Debra and James McLellan, set up a **Family Fund** – Dan's Hope – to raise funds for **research** and to make a difference for their younger son.

Dan (6) was diagnosed with Ullrich congenital muscular dystrophy (UCMD) – a genetic muscle-wasting condition – when he was two.

"Dan is the sweetest, funniest, most resilient, happy-go-lucky boy. He is a huge Arsenal fan and would love to be a footballer. At the moment, he spends as much time as he can playing football. If there were a treatment for his condition, perhaps he'd be able to play football for longer.

"With Dan's diagnosis, our world exploded around us. It was very isolating. When Muscular Dystrophy UK put us in touch with other families living with UCMD, we discovered they were all fundraising for research. We decided to do the same, and we've now got our whole community involved," said Debra.

"Through our fundraising events, we felt we could tell our friends and community about Dan's condition. Many people are now doing their own fundraising for us."

The four families together have raised over £175k to date. Working with the charity's research team, they set up the **Ullrich Appeal**, initially funding UCMD research at University College in London.

"We're a small group of parents working together to raise a very big sum of money specifically to fund UCMD research. Having Muscular Dystrophy UK put their weight behind this and involve other **international** charities is amazing and encouraging progress. Little did we know our first fundraising event would lead to this," said Debra.

Muscular Dystrophy UK established a new international **co-funding initiative** called the Collagen VI Alliance – our first-ever international funding collaboration with charities from four other countries for further investment in UCMD research.

To find out more about our research, visit www. musculardystrophyuk.org/ research





Our fantastic corporate partners contributed £400k, including London Classified, Simplyhealth, Matalan, Santander Consumer Finance, Berkeley Foundation, St George, CeX, Lloyds Community Fund and staff at Barclays.



Through the generosity of **82** people who remembered the charity's work in their Will, a further **£1.75m** was received in legacy income towards our future research and family support programmes.

Charitable trusts and other grant-making bodies contributed **OVET £500k**. This included a substantial gift from the Montague Thompson Coon Charitable Trust, making it possible to invest in a new and sustainable Lectureship to accelerate research.

We also received the final instalment from the Marc Lebe Trust of £120k funding over a decade for Duchenne research; for which we are incredibly grateful.

Our flagship special event the Microscope Ball in its 31st year raised over £250k thanks to the wonderful support of the property sector.

Muscular

Dystrophy

Fighting muscle-wasting Condition

We are hugely grateful to over 10,000 donors who support the charity via direct debit or cash appeals, through the raffle, online shop and Christmas catalogue.

> The BGC Trader's Day resulted in a £100k donation, thanks to Vice **President Sir Alex Ferguson and** Roy Hodgson representing the charity at the event.

Running proved to be extremely popular, with **over 5,000** participants in Virgin Money London Marathon, our own Town & Gown 10k in Oxford and Cambridge, and many other running events UK-wide - our thanks to them all.

Thanks to the tremendous ongoing support of the Attenborough family, the charity received £36k in gifts at the late Lord Richard Attenborough's memorial service, towards our Richard Attenborough Fellowship Fund.



Fundraising in the community

"When Callum was 19 months old, we got the news that he had Duchenne muscular dystrophy. It was absolutely heart-wrenching."

Paul and Laura Smith, from Limavady in Northern Ireland, felt helpless. They had no family history, and had never heard of the condition.

"There was literally nothing we could do to stop Duchenne attacking our son's muscles. When we got in touch with Muscular Dystrophy UK, we heard about researchers working hard to find a treatment or cure. As a family, we wanted to do some fundraising that was a bit more personal to us, so we set up a Muscular Dystrophy UK **Family Fund** and called it #TeamCallum," said Laura.

"All the funds we raise go to the charity's **Duchenne Research Breakthrough Fund**."

"#TeamCallum has had donations from strangers, and we've become quite popular in our community! Callum's school has been fantastic, donating the full £2.4k raised from a play and a Christmas jumper day.

"A local football club donated the proceeds from their annual memorial tournament to us, and we've also been chosen as a beneficiary of a local dance event.

"It's been great being part of Muscular Dystrophy UK. Not only do we fundraise but we are also involved in campaigning for faster access to treatments," said Laura.

Six-year-old Callum is eligible for Translarna (see p18), a new treatment that could potentially keep boys on their feet for longer.

The Duchenne Research Breakthrough Fund has a target of £3.26m by 2018 – over £1.66m spent to date and a further £1.6m target to meet three-year commitments – towards the development of treatments, and ensuring they reach people with Duchenne muscular dystrophy.

In the last 12 months, 19 new Family Funds were established UK-wide, raising more than £200k.

 To find out more about our Family Funds, visit www.musculardystrophyuk.org/ get-involved







Through our campaigning activity, we organised for families, along with their boys who have Duchenne muscular dystrophy, to take a massive petition to Downing Street. The charity has taken the campaign directly to decisionmakers: NHS England, senior Health Ministers, NICE (National Institute for Health and Care Excellence) and even a meeting with the Prime Minister.

powerful evidence on what it would mean if their child could walk for longer, and lobbied parliamentarians.

Working with families, with strong stories, our press team helped pile on the pressure, securing over 200 pieces of media coverage, including substantial features in the Guardian, the Daily Mail, as well as BBC and ITV News. Our social media campaign reached over

not to fund and approve the drug, and then passed the final recommendation over to NICE.

Translarna is already funded in European countries, including France, Germany, Italy and Spain, but is not available in any part of the UK. We are pushing hard for a fast and positive decision from NICE, and to ensure boys in Scotland, Wales and Northern Ireland also have access to the drug.

Joseph Patrick Trust

Muscular Dystrophy UK's welfare fund, the **Joseph** Patrick Trust (JPT), provides grants towards the costs of specialist equipment. These include powered wheelchairs, adapted computers and electric beds, for children, adults and families living with a musclewasting condition. As ever, we are very grateful for the support of Alexander Patrick CBE DL and the Patrick family.

£189,077

herapy equipment adaptations vehicle adaptations 7 discretionary portable aids grants

170 grants: 108 for children, 62 for adults



Trailblazers linking up

Hayleigh Barclay (27) has been involved with Muscular Dystrophy UK's network of young disabled people, **Trailblazers**, since 2008.

"As a young person with a disability, I've had the opportunity through the network to have my voice heard and the confidence to start campaigns, such as better access to air travel.

"Trailblazers have helped us realise we have the power to change society."

Hayleigh, from Ayrshire, took part in our **mentoring programme** in Scotland last year. The Link Up project, funded by the Long-term Conditions Alliance (Scotland), paired two young people living with muscle-wasting conditions, who have similar interests.

Hayleigh was paired with Karis Williamson (16) from Inverness.

"It's hard enough being a young person, thinking about your next step in life. Add in the extra complications of having a disability, and it can be very isolating," said Hayleigh. Karis said she felt honoured to be in touch with such an inspirational person as Hayleigh.

"It really helped knowing she understood what life with a disability was like, and that she'd already achieved more than most people ever do," said Karis.

Muscular Dystrophy UK is committed to supporting those with muscle-wasting conditions to live as **independently** as possible. Trailblazers campaign for change, and fight social injustices. Members come from across the UK, and they carry out (undercover) investigations to assess access on public transport, on the high street, in cinemas, at live music events, etc.

They use the evidence to produce reports calling for change, and present these directly to decision-makers through the All Party Parliamentary Group for Young Disabled People.

Trailblazers' work in 2014/15 was possible thanks to Simplyhealth, Berkeley Foundation, The Longterm Conditions Alliance (Scotland) and the City Bridge Trust.





Our financial year

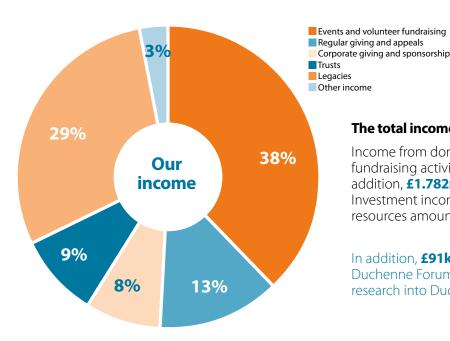
Overall income £6.112m

Thanks to individuals, families, Branches, companies and trust supporters, we ended the year with a surplus of £1.036m.

This was achieved while increasing our level of charitable activity by more than **15 percent**. A significant part of this was thanks to those remembering our charity in their Wills.

With this, we have been able to add a further £1m into our designated reserves for future years – half to be spent on scientific research and half on clinical studies. We have firm plans to expend this money over the next three years.

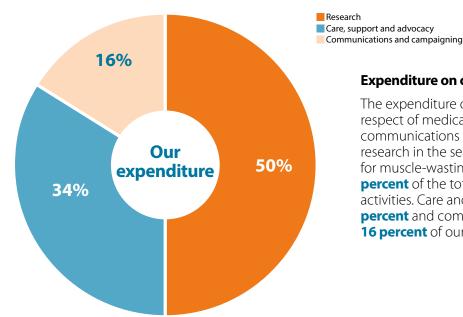
At 31 March 2015, the free unrestricted funds were £1.66m, providing a sound level of reserves for the development of charitable activity in the coming year.



The total income for 2014/15: £6.112m

Income from donations, gifts, grants and fundraising activities totalled £4.120m. In addition, £1.782m was received from legacies. Investment income and other incoming resources amounted to £210k.

In addition, £91k was received from the Duchenne Forum charities to joint-fund research into Duchenne muscular dystrophy.



Expenditure on charitable activities

The expenditure on charitable activities was in respect of medical research, care and support, communications and campaigning. Medical research in the search for treatments and cures for muscle-wasting conditions comprised 50 percent of the total expenditure on charitable activities. Care and support comprised 34 percent and communication and campaigning 16 percent of our charitable activity.

Thank you

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

The A B David Memorial Fund The Adint Charitable Trust The Albert Hunt Trust Anderson Strathern

The Annandale Charitable Trust The Annett Charitable Trust The Hon Michael Attenborough CBE

Karen Lewis-Attenborough
The Barbour Foundation
Barclays Investment Bank
Ian and Helen Barwell
BBC One Lifeline Appeal
Berkeley Foundation

BGC Partners Bio Marin

The Big Lottery Fund Marcus Brown

The Bruce Wake Charitable Trust

Tony Carey lan Carson

The Catherine Cookson Charitable Trust

Jeremy and Mary Champion
The Charles and Elsie Sykes Trust
The Christopher H R Reeves Charitable

The City Bridge Trust

Comic Relief Local Communities

Programme – Bradford Art and Leona Connolly

The Constance Travis Charitable Trust The Montague Thompson Coon

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The Scottish Property Festival Spirit of

Christmas (SPIFOX) The Shanly Foundation Simplyhealth

The Sir Edward Lewis Foundation
The Sir Samuel Scott of Yews Trust
The Sovereign Health Care Charitable

Trust

The Steel Charitable Trust

St George

The Templeton Goodwill Trust Michael and Donna Thirkettle

Ultragenyx David Watson The Weinstock Fund Andrew Weir Jack Wilshere

The Woodroffe Benton Foundation The Webb Family Charitable Trust

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

A special thanks goes to all those who tirelessly raise funds for the charity's work through Branches, groups and Family Funds. We highly value your support.

We are extremely grateful to so many people and organisations for their significant support this year.























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Muscular Dystrophy UK is the operating name of the 'Muscular Dystrophy Group of Great Britain and Northern Ireland' (a company limited by guarantee: 705357)

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Our 2014/15 Financial Statements are available upon request. Download a copy from our website or call the office and we'll send you a hard copy.