Muscular Dystrophy UK

Fighting muscle-wasting conditions

Impact report

2016/17

Accelerate research • Drive change for access • Empower independent living

Welcome

We are pleased to introduce the 2016/17 *Impact Report* setting out the highlights of the year and the progress we are making in the fight to defeat muscle-wasting conditions. With the huge commitment of supporters, donors and volunteers across the UK, we have stepped up our investment in research, secured much-needed improvements in NHS care and also reached more people affected by muscle-wasting conditions.

It has been a landmark year in which we worked with families, regulators and NHS officials to secure access to two emerging treatments which are now available through the NHS. Our effectiveness in campaigns led to the award of *Charity PR Team of the Year*.

Translarna is the first treatment to target an underlying cause of Duchenne muscular dystrophy and the early data suggest it can enable eligible boys to retain their ability to walk for longer. Further data will be gathered over the next five years.

Second, mitochondrial donation IVF is now approved for use with patients at specialist clinics in the UK. This groundbreaking technique will prevent eligible women from passing mitochondrial disease on to their children. We funded the vital early research into this technique carried out by Professor Sir Doug Turnbull and his team at Newcastle University.

Our increased support to accelerate the path to treatments includes major commitments to translational research at Oxford University, the UK arm of an international gene therapy study and the development of the NorthStar network for Duchenne. These commitments reflect a new investment of £4.5million and also embrace both our *Here for you: Mental health matters* initiative and support (with other charities) to extend clinical trial capacity.

In driving forward improvements in healthcare and quality of life for those affected by muscle-wasting conditions, we placed members of our Information and Advocacy Team in a number of larger muscle clinics to provide a seamless service alongside health professionals. We provided direct support to individuals and families securing over £1.1m worth of essential services and support. Our Trailblazers had several important campaign successes to improve access and inclusion.

We give our warm thanks to supporters, donors and all those who helped to raise the magnificent sum of £7.6m in income in 2016/17. In thanking our supporters, we also want to underline our appreciation of the remarkable 50 years of support as Patron by HRH The Duke of Edinburgh whom we thanked at a very special evening with many supporters present at St. James's Palace in June.

Our thanks also go to all our Trustees and committee members for their guidance and insight, especially Bill Ronald for his contribution as Chair, and to the staff team for all their hard work. We look forward to the year ahead with clear objectives and our determination to accelerate the steps to win the fight to beat muscle-wasting conditions.

Professor Mike Hanna
Chairman

Robert Meadowcroft
Chief Executive

Accelerating research to develop effective treatments and cures

We support research and build partnerships, with the goal of identifying effective treatments and cures for all muscle-wasting conditions.

We continued to invest in high-quality research during the past year, and saw much progress. It brought us closer not only to understanding the underlying causes of muscle-wasting conditions, but also to developing potential therapeutic approaches and improving quality of life.

Mitochondrial donation IVF gained approval for use in clinics throughout the UK. We funded early-stage research for this in Newcastle for more than 10 years. The groundbreaking technique will enable eligible women to have children who are not affected by mitochondrial disease.

We committed £4.15m into new strategic research projects*. We believe these investments will have a profound impact on lives, from the moment of diagnosis – not only improving quality of life but also seeking to extend lives.

Our Medical Research Committee (MRC) identifies and reviews strategic areas of promising research, with the aim to bring potential new treatments to clinics and to improve quality of life. During the past year, we strengthened the MRC further by recruiting seven new panel members, with a broad range of expertise.

Alongside the MRC review, our Lay Research Panel (LRP) played a key role in assessing the relevance and importance of research projects from the perspective of those living with muscle-wasting conditions.

We also boosted clinical trial capacity for UK patients, by investing in new posts in Newcastle, London and Liverpool.

We collaborated with national and international partners, and continued our support of UK registries for myotonic dystrophy and facioscapulohumeral muscular dystrophy (FSHD).

Highlights from 2016/17

£1.5m+ invested in **39** research grants

New and ongoing research into **11** muscle-wasting conditions

Research funding partnerships:

£65k – Duchenne Forum

£68k – Chief Scientist Office in Scotland

£94k – SMA Trust

£66k – Collagen VI Alliance

£10k – CMT UK

2 international grants awarded for nemaline myopathy research

£10,500 invested in a trial to improve quality of life

£4.15m invested in strategic research projects over five years

£122,346 invested in **3** clinical and research fellowships

55 Family Funds raised **£644,663** for research into 8 muscle-wasting conditions

Funding high-quality research • facilitating partnerships with the scientific community and industry • increasing clinical trial capacity for UK patients

*See p17 for more information about our strategic commitments

Driving change for access to specialist care and support

We are committed to improve and extend NHS investment in neuromuscular services, to ensure individuals and families have access to treatments and to specialist care, as close as possible to where they live.

Working with NHS commissioners and leading clinicians, we secured £510k investment in nine new NHS-funded roles, ensuring individuals and families across the UK get the specialist healthcare they need.

Over four years, the NHS has invested a total of £4.7m in 71 specialist neuromuscular posts nationally.

By building strong working relationships with key specialist neuromuscular groups across England, we have continued to be integrally involved in NHS decision-making.

Working with the London Ambulance Service, we launched an emergency alert system for priority support for those with muscle-wasting conditions. This means that ambulance crews will have vital information about patients before they get to them, in times of emergency.

Our *Right to breathe* campaign moved us closer towards achieving equitable access to cough assist machines for people with muscle-wasting conditions. Twenty-seven Clinical Commissioning Groups (CCGs) across England committed to commission and fund this vital equipment.

The past year also saw the launch of our work to expand the NorthStar network*, the world's largest natural history study for Duchenne muscular dystrophy, with additional support for the participating muscle clinics. Collecting information from adults will also help develop clinical trials and guidelines for best-practice care and support.

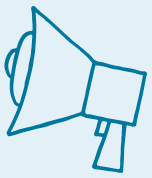
After the 2016 elections in Scotland, Wales and Northern Ireland, we secured the support of 35 newly-elected parliamentarians. They signed our *Manifesto for Muscle* and committed to supporting our work to improve access to specialist care and support for those with muscle-wasting conditions.

Highlights from 2016/17

Development of **neuromuscular forums and networks,** working with NHS officials, made possible by funding from Comic Relief and Sir James Knott Charitable Trust

1,750 alert cards for **11** muscle-wasting conditions given to clinics, individuals and families for use in emergency situations

170 Parliamentarians and Assembly Members, including the Prime Minister, backed our campaigns



£510k investment secured into **9** new NHS-funded neuromuscular roles

30k *Guardian* readers shared our article on access to housing for disabled people

120+ healthcare professionals trained each month to recognise symptoms of muscle-wasting conditions

Advocating for people's rights • equipping community healthcare professionals • securing specialist posts

*See p17 for more information about our strategic commitments

Improving quality of life by enabling independent living

We are focused on providing support to individuals and families to live as independently as they wish, and with improved quality of life.

During the past year, we received over 56,000 requests for support and information – two-thirds more than in the previous year. This also led to helping 298 individuals and families get a total of £1.2m in the services, benefits and equipment they were entitled to.

Over the past year, every two days we brought like-minded people together for peer support.

We also tackled the Government's reforms to Personal Independence Payments (PIP) to ensure they considered the needs of disabled people. We did this by bringing the findings of our *Focus on disability benefits* report to Parliament, highlighting these concerns to key decision-makers.

Training modules we have developed for PIP assessors will help them understand better the needs of those living with muscle-wasting conditions.

In the past 12 months, our new information resources have helped the individuals we support live more independently.

The launch of our *Here for you: mental health matters** project will help to press for increased access to psychological support. Our investment of £550k in *Here for you: clinic support* will also see our staff working alongside healthcare professionals in local clinics across the UK.

Trailblazers, the young disabled campaigners' network, continued to drive change for equal access. In their 2016 *Transport report* they called for the Government to make it unlawful for taxi drivers to refuse to carry wheelchair users or attempt to charge them higher fares. We are delighted this campaign met with success in early 2017, when the new law came into effect.

Highlights from 2016/17

£285k awarded in grants for specialist equipment, improving independence for **231 people**

Every 10 minutes we gave support and info to someone in need, an **increase of 66%**

81 families brought together to enjoy **4** new family fun and sport days across the UK

Made possible with funding from:
The 29th May 1961 Charitable Trust
The John Horniman Charitable Trust
The Eveson Charitable Trust
The Goodenough Charitable Trust

TRAILBLAZERS
Trailblazers network grew to **722 members** – a collective voice for change

17 young disabled people took part in work experience placements

Made possible with funding from the City Bridge Trust

Hear my Voice videos developed for and by young people with muscle-wasting conditions

Made possible by funding from The Evan Cornish Foundation and The Austin & Hope Pilkington Trust

2,466 Muscle Group members got together at meetings across the UK

£1.2m in welfare services secured, changing the lives of 298 people **100% increase**

Connecting people in communities • encouraging involvement • hearing the voice of young people • providing personal support and information

*See p17 for more information about our strategic commitments

Increases are based on 2015/16 figures

The best route to treatments and cures

"Shiv is a very caring, fun-loving and cheeky little boy. He's always smiling or laughing, loves cars and is our very own human navigation system. He has this ability to remember road names and routes."

Sejal and Manoj Thakrar live in London with their six-year-old son, Shiv. When they got the news that Shiv had Duchenne muscular dystrophy, they found themselves thrown into the world of Duchenne. They looked for the best route to effective treatments and a cure for the devastating condition.

"We spoke to charities, patient organisations, scientists and pharmaceutical companies, as well as other families. Then we realised there was hope for research to help Shiv and others with Duchenne.

"It was clear vital funds were needed to accelerate research so we set about fundraising for Muscular Dystrophy UK's Duchenne Research Breakthrough Fund. We launched our Family Fund so people could join us and help fund research."

With family, friends and colleagues supporting their Family Fund, Smile with Shiv, Manoj and Sejal have to date raised a massive £193k towards the work of Muscular Dystrophy UK.

With a keen interest in where the charity allocated funds in research, Manoj went to a Lay Research Panel (LRP) meeting last year. He then became a panel member.

"The LRP is an important feature in the charity's research funding process, giving people like us a say in the decisions made.

"Priorities for us are key research projects that have clinical benefit and a clear pipeline towards an effective treatment or cure for this generation of children living with Duchenne. We're also keen to fund work that boosts clinical trial capacity."

Alongside a robust peer review process, our research grant applications also go through a lay review. The LRP members, who have direct or indirect experience of living with a muscle-wasting condition, assess the relevance and importance of each project. The views of both the MRC and the LRP are considered in research funding decisions.

In accelerating research to develop effective treatments and cures, next year we will:

- invest in national infrastructure to prepare the UK for clinical trials and to ensure a swift bench-to-bedside transition of promising technology
- invest in high-quality research to understand the underlying cause of muscle-wasting conditions, develop potential therapeutic approaches and improve quality of life
- work closely with the scientific community to identify strategic research areas to bring potential new treatments to the clinic more quickly
- develop and support platforms to facilitate communication and collaboration within the scientific community nationally and internationally
- develop national and international partnerships to leverage our resources in particular for ultra-rare muscle-wasting conditions
- raise significant funds to help deliver our three strategic research projects (see p17).

photo credit: Kii Studios Photography

Driving change

When David Gale lost his Motability vehicle last year, the impact of the reforms to PIP struck home. He wanted to make sure this didn't happen to anyone else, so he started a petition. When it received close to 51,000 signatures, it was clear the impact was felt widely across the UK.

His petition, and the media campaign around it, forced the Government to review their policy. After nine months and much stress for David and his family, the Government announced they would allow disabled people to keep their vehicles for six months, pending appeal decisions.

"It was a great outcome and will help people through the appeal process. It will also avoid many getting into debt, panicking that their cars are going to be taken away from them. That was the most stressful thing for me."

The 33-year-old civil servant and football fan lives in Lochmaben with his fiancée and two-year-old son.

"Because I have Becker muscular dystrophy, my Disability Living Allowance (DLA) gave me life entitlement to a mobility vehicle. When DLA was replaced by PIP, I assumed this wouldn't change.

"Despite all the medical evidence I provided, the assessors put my mobility needs down as 'standard'. So I lost my car."

For David, his car is not only a means to independent living, but also his ability to commute the 30 miles to work every day. And as the family's sole breadwinner, David feared he could potentially have lost his job.

"I arranged a car loan, at huge cost. Eventually, after months of financial and emotional stress, I won my appeal case at a tribunal at Carlisle Magistrates Court.

"It's important to continue campaigning for the mobility component of PIP to be fairly assessed."

Our research showed that 900 people lost their Motability vehicles in this way every month. Over the past four years, 51,000 people lost access to their Motability vehicles during the switch from DLA to PIP.

Muscular Dystrophy UK supported David to start his petition. We also developed training modules for PIP assessors, to help them understand better the needs of those living with muscle-wasting conditions. By working with decision-makers at every level, we have continued to fight for those with muscle-wasting conditions to get what they need to live independently.

photo credit: Lenny Warren

In improving quality of life to enable independent living, next year we will:

- reach more people with muscle-wasting conditions, as well as their families, making sure they know about the range of support there for them
- develop more regular online Q&A opportunities with expert panellists, in line with needs of individuals and families
- expand the team of Information and Advocacy Officers in Northern Ireland, Scotland and Wales with posts in London, Newcastle and Oxford
- develop new resources to ensure individuals and families get the support they need at diagnosis
- grow the Trailblazers network and develop employment opportunities for young disabled people
- further support adults and families living with muscle-wasting conditions by training healthcare professionals and developing resources and guidance
- continue to provide an advocacy service, with pro bono support.


OMADIC

Paving the way for better psychological support

Suzanne Glover is half-way through her PhD at Ulster University, examining resilience in those who care for someone with Duchenne muscular dystrophy. For many years, the 24-year-old first-class honours graduate from Newtownards has supported families through diagnosis and has been fascinated by how strong people can be in challenging times.

She's brought her expertise to help shape the charity's new strategic commitment, started in early 2017 – *Here for you: mental health matters* (see p18). As a patient representative on the steering group, Suzanne hopes to highlight issues facing young people and their families. Living with spinal muscular atrophy (SMA), Suzanne is also a Trailblazer.

"Working as a team, the group will pave the way for better psychological support. I hope it will give those with muscle-wasting conditions the courage to speak out and ask for support when they need it. In turn, I hope that health professionals working with those with muscle-wasting conditions will have the knowledge and resources to provide appropriate support.

"Living with a muscle-wasting condition has a huge emphasis on physical needs. I know that the challenges of these conditions go far beyond the muscles.

"I feel valued when a health professional looks at me as a whole person, not just the physical symptoms they are treating. Our emotional, social and physical needs work together to give us a fulfilled and happy life."

Diagnosed with SMA at the age of two, Suzanne can't remember a time before SMA.

"It's simply life as I know it. My mum struggled to lose the image of the little girl running around in a party dress. But over time, we met more families with SMA and it soon became a new image. One where a little girl, with a wheelchair called 'whizzy' and a fearless attitude defied every challenge."

Through programmes such as Here for you: mental health matters, we are driving change for access to specialist care and support.

photo credit: cj photography

In driving change for access to specialist care and support, next year we will:

- enlist the support of parliamentarians and assembly members across the UK to improve access to emotional and psychological support
- protect and extend NHS investment in specialist services by increasing patient participation in regional neuromuscular forums and networks
- lead on the development of professional education for health professionals
- increase the number of parliamentarians and assembly members in all four nations supporting our work
- extend the series of condition-specific alert cards and build links with regional ambulance services to expand emergency support
- continue our Fast Forward campaign to improve the system for assessing and approving emerging treatments.

Michael and Michelle fight for access to Translarna

"The First Minister was so nice and listened when I told her about Duchenne and Translarna*. She asked me lots of questions and I told her how it helped me and would help other Scottish boys. She promised to help."

Michael Young is a determined young campaigner. Diagnosed with Duchenne muscular dystrophy at three, the nine-year-old took seriously the fight for access to Translarna. He's had two meetings with First Minister Nicola Sturgeon, and started a petition.

Michael participated for three years in the Translarna UK medical trial. When the trial ended, it looked like his access to Translarna might end too. With the charity's help, Michael started a petition, which secured a whopping 150,000 signatures!

"It was a devastating time for us. The lovely comments people made as they signed the petition gave us the strength to carry on. So did Michael," said Michelle.

"Don't worry Mum and Dad, lots and lots of people know that giving children medicine is the right thing to do. It is going to be all right," said Michael.

Michael had met with Nicola Sturgeon to ask if other boys like him in Scotland could also get Translarna. After his petition, he had a second meeting with the First Minister. He explained it wasn't right that children in Scotland couldn't get the medicine to keep them well and walking. The First Minister looked into it, and soon wrote to tell Michael he would be able to get Translarna on the NHS in Scotland.

"I'm probably the happiest boy in the world right now. It also means that other boys in Scotland, with Duchenne, could also get the medicine," said Michael.

"Time is so precious. Translarna has enabled Michael not only to continue doing things that many people take for granted – playing with friends, going to school – but he's also been able to hold his newborn baby cousins," said Michelle.

Translarna is the first drug to treat an underlying genetic cause of Duchenne muscular dystrophy. Children whose Duchenne is caused by a nonsense mutation, and who are aged five years or over and still able to walk, are eligible for this treatment.

photo credit: Lenny Warren

Translarna campaign

Along with boys like Michael and his family, we're fighting to get access to emerging treatments for all muscle-wasting conditions to families across the UK as quickly as possible.

Thanks to campaigning efforts of families across England, National Institute for Health and Care Excellence (NICE) announced in April 2016 that they were recommending Translarna for funding on the NHS in England. The treatment is now available to eligible boys right across the UK.

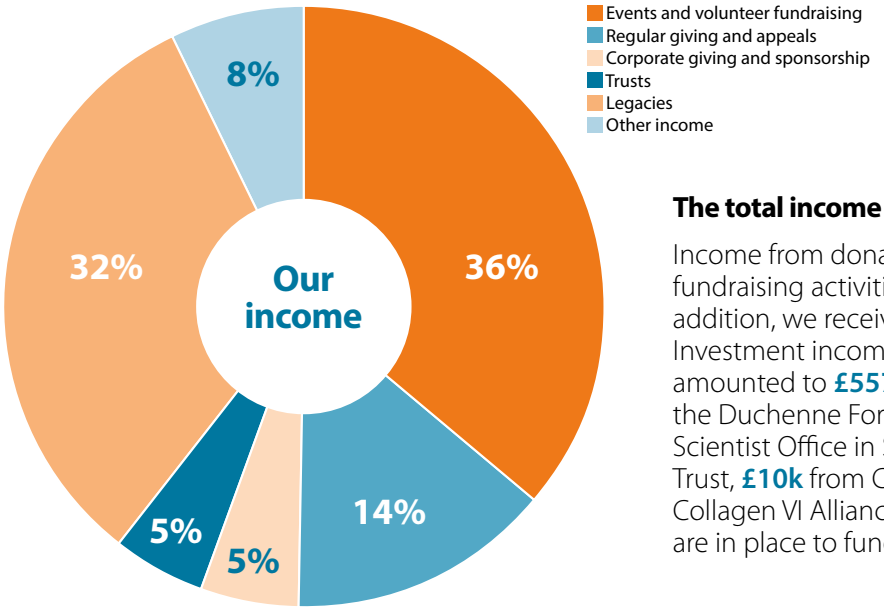
Together with the support of families, our media campaign for access to treatments was covered 1,500 times in media outlets across the UK: *Sky*, *BBC Breakfast*, *ITV*, *5Live*, *The Times*, *The Independent*, *The Evening Standard*, *The Herald*, *BBC Scotland*, *The Scotsman*.

Our financial year

Overall income £7.6m

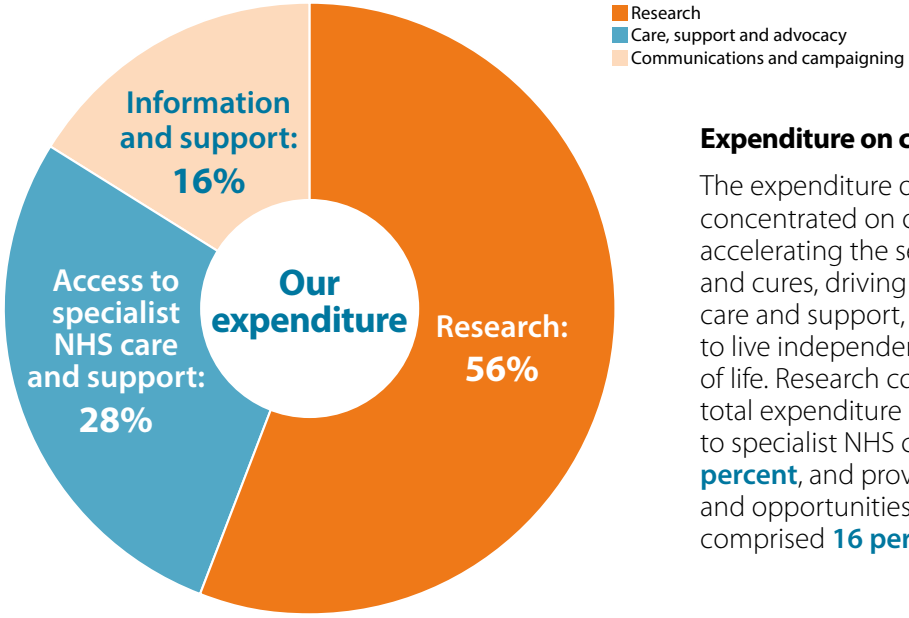
Thanks to individuals, company and trust supporters, we ended the year with a surplus of £488k. We achieved this while increasing our level of charitable activity.

As at 31 March 2017, the free reserves were at **£1.5m**. This is after setting up a designated reserve to part-fund three significant new projects over the next five years. These include a new centre in Oxford for Translational Neuromuscular Research, development of the NorthStar network and a gene therapy clinical trial. This is alongside a designation of **£500k** to improve clinical trial capacity across the UK.



The total income for 2016/17 was £7.6m

Income from donations, gifts, grants and fundraising activities totalled **£4.609m**. In addition, we received **£2.444m** in legacies. Investment income and other income amounted to **£557k**, of which **£65k** came from the Duchenne Forum, **£68k** from the Chief Scientist Office in Scotland, **£94k** from the SMA Trust, **£10k** from CMT UK and **£66k** from the Collagen VI Alliance. All of these partnerships are in place to fund research.



Expenditure on charitable activities

The expenditure on charitable activities concentrated on our strategic focus areas: to accelerating the search for effective treatments and cures, driving change for access to specialist care and support, and empowering individuals to live independently and improve their quality of life. Research comprised **56 percent** of the total expenditure on charitable activities. Access to specialist NHS care and support comprised **28 percent**, and provision of information, support and opportunities to enable independent living comprised **16 percent** of our charitable activity.

A full set of our 2016/17 Annual Report and Financial Statements is available on request. Download a copy from our website or call us on 020 7803 4800 and we'll send you a copy.

Duchenne Research Breakthrough Fund

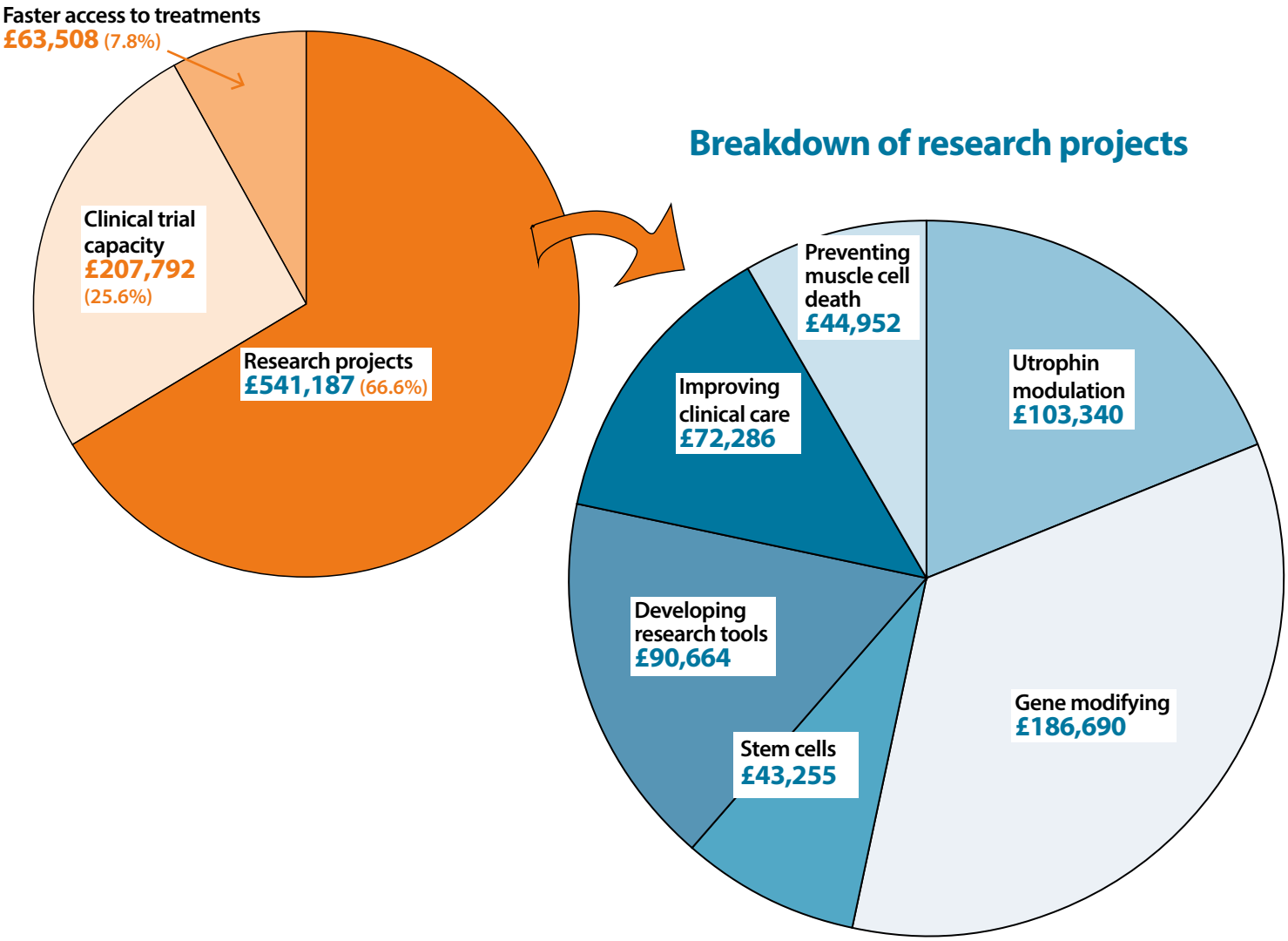
The impact of this Fund on people in the UK living with Duchenne

We have established several dedicated funds to enable our supporters to choose where their fundraising efforts are used. The Duchenne Research Breakthrough Fund is the largest of these.

With the generous support of individuals, Family Funds, trusts and corporate organisations who have fundraised and donated over **£3m** to the Duchenne Research Breakthrough Fund since its inception in 2012.

We have invested **£2.86m** in 28 research projects over the past five years. We will continue to invest these funds in only the highest-quality research into Duchenne muscular dystrophy.

The investments in 2016/17



In 2016/17 we invested £812,487 from the Duchenne Research Breakthrough Fund

Marking 50 years of support

On Thursday 30 June 2016, HRH The Duke of Edinburgh hosted a very special event at St. James's Palace. More than 200 charity friends and supporters attended the reception marking the support HRH The Duke of Edinburgh has given Muscular Dystrophy UK as Patron. We are hugely grateful to His Royal Highness for this significant support.

photo credit: Kii Studios Photography

Five new strategic commitments

In early 2017, we announced an investment of over £4.5m into five new transformational commitments to provide everyone living with a muscle-wasting condition with choices – to live a life unlimited, to be understood and never alone.

These investments are designed to make a profound impact on lives, from the moment of diagnosis, improving quality of life, seeking to extend them.

1. Changing the landscape for clinical trials by developing a major centre in the UK

Professor Dame Kay Davies, Professor of Anatomy at the University of Oxford, says:

"This is a very important time in the history of research and therapy into muscle conditions. MDUK has been a major contributor to this basic research for more than two decades. The funding of a new neuromuscular translational centre at Oxford ensures that they can build on this investment and deliver on effective therapies for paediatric and adult disorders. I am very excited to be part of this initiative."

We are entering an exciting era of treatments for rare, genetic conditions like muscular dystrophy. But as research continues to gain momentum – moving us closer to treatments – so does the demand for clinical trials.

Inadequate capacity in the UK – such as a lack of infrastructure and expertise – means centres are struggling to meet demand. Some centres have even had to turn down clinical trials for muscle-wasting conditions.

Working with Oxford University and the John Radcliffe Hospital, we will establish the multi-million pound Oxford Translational Research Centre to boost capacity for clinical trials. Alongside the major centres in Newcastle and London, this third centre will be a game-changer for individuals and families living with muscle-wasting conditions in the UK.

2. Investing in gene therapy to advance treatments for muscle-wasting conditions

Professor George Dickson, who has studied gene therapy for over 20 years and is one of the leaders of the UNITE-DMD project, says:

"Our work has consistently been supported by funding from MDUK, providing the means to develop these new therapies. This new investment will help to move them into the clinic for the benefit of patients and their families."

As a long-standing supporter of research into gene therapy, we are taking the next step of testing its safety in people living with muscle-wasting conditions in the UK.

UNITE-DMD is an international collaboration working on gene therapy. Once preclinical studies are complete, it will assess the safety of a gene therapy for Duchenne muscular dystrophy in a phase I/II clinical trial.

To date, there have been no gene therapy trials in the UK for muscle-wasting conditions. This particular gene therapy aims to treat Duchenne muscular dystrophy, but its development will refine and improve the technique generally for other muscle- wasting conditions in the future.

This four-year project is taking place in the UK and France. We are the lead UK funder of the project, in partnership with Action Duchenne. The French Muscular Dystrophy Association (AFM-Téléthon) is funding the French arm of the project.

3. Paving the way for trials, treatment and care

NorthStar programme

Professor Francesco Muntoni, Paediatric Neurologist at Great Ormond Street Hospital, says:
"The NorthStar study is a unique and effective consortium of all the UK neuromuscular paediatric centres. It is now expanding to include young men and adults with Duchenne. This will help the implementation and monitoring of optimal standards of care for this particular group – the pre-requisite for clinical trial readiness."

We have invested £1.45m in boosting the NorthStar network, the world's largest natural history study for Duchenne muscular dystrophy. This investment will help accelerate the development of treatments, by providing data to improve the design and evaluation of clinical trials. It also offers a unique platform to influence best practice in the care of Duchenne patients nationally.

NorthStar will also expand to include the collection of data from adults with Duchenne, in order to develop clinical trials and establish guidelines for best-practice care and support.

4. Supporting people, from the moment of diagnosis, to be understood and never alone

Here for you: Mental health matters

Sheila Hawkins, Muscular Dystrophy UK Trustee, says:
"Being diagnosed with a muscle-wasting condition is a bit like bereavement. You may need psychological support to help you through that isolating process. It's important that support is there for you as soon as you're diagnosed, so you realise you're not alone and someone will be with you on that journey. We at Muscular Dystrophy UK will help you lead a fuller life as soon as possible and help you get on with your lives without the condition taking over."

This project will help push for access to specialist psychological care and support from the moment of diagnosis to end-of-life for those living with muscle-wasting conditions. It is our commitment to making tangible changes to the current inadequate offering for all individuals and families living with a muscle-wasting condition.

We will be investing in better support for individuals and families, better support and training for healthcare professionals and pressing for NHS improvements.

5. Providing personal support to improve quality of life and independent living

Here for you: Clinic support

Dr Chiara Marini Bettolo, Consultant Neurologist, John Walton Muscular Dystrophy Research Centre, says:
"The new clinic role here in Newcastle will provide essential support to our patients and their families. It is vital that patients receive the necessary care and assistance at home and in the community. This role is pivotal to ensuring our users receive the highest quality health, education and social care services."

We have invested £550k in our new *Here for you: Clinic support* programme to address a growing need for support in local communities. This includes help accessing disability benefits, signposting to relevant services and understanding the realities of living with a muscle-wasting condition.

This new commitment will see our information and advocacy services staff sitting in clinics, alongside healthcare professionals, to offer rounded support. It will also see developments in clinical research and quality of life initiatives.

Raising awareness to beat muscle-wasting conditions

By providing a platform for individuals and families to speak out, raise awareness and highlight the impact of living with muscle-wasting conditions, we have continued to influence change.

Digital

49% increase in income received through the website

860+ people recruited to take part in events through Facebook ads

1,000 *Guardian* readers commented on our PIP story making it the most-commented on their website

15% more Facebook followers
27k (total)

14% more Twitter followers
12.9k+ (total)

45% more visitors to the website
423k (total)

Media

99% more pieces in regional media
4k+ (total)

43% more national news items
173 (total)

367 pieces in the media on mitochondrial IVF donation

2016 Charity Times
PR Team of the Year

£5m worth of free media coverage secured (Advertising Value Equivalent – AVE)

241 pieces in the media on PIP and Motability campaigns

Engagement

30% increase in engagement through email newsletters

100% more supporter stories shared in the media to raise awareness
30 feature stories (total)

Pride of Britain award for Northern Ireland family

Launched Content Advisory Group
People living with muscle-wasting conditions, who will help shape our content
25 (members)

Myotonic dystrophy storyline in **ITV's *Coronation Street***

Increases are based on 2015/16 figures

UK-wide support for Musc

ular Dystrophy UK's work

£4.6m raised in 2016/17

Thanks to generous donations, gifts and grants, as well as more people getting involved in our events and supporting our condition-specific appeals.

£593k raised by **148** Branches, Family Funds and fundraising groups

978 people raised **£448,250** at black tie dinners, dances and celebrity events

6,388 people raised **£548,500** by taking part in cycling, running, canoeing and walking events

£2.4m in legacy income received, through the generosity of **84** people who remembered Muscular Dystrophy UK in their Wills

£345k raised from events led by property industry

708 supporters raised **£574** by holding local events

5,800 runners raised **£215,500** by taking part in the MDUK Town and Gown 10k series in Oxford, Cambridge and Leicester

100%+ increase in funds raised by **200** people who took part in Move a Mile for Muscles events: **£69,650**

8,821 supporters took part in events across the UK.

Go orange for a day 2017 **38,085** people took part across the UK and raised **£36,269**

242 people raised **£139k** by skydiving in our Make Today Count event

367 people raised **£62k** by taking part in regional running events

Huge thanks to our

78 Family Funds who have raised a fantastic £2.4m to beat muscle-wasting conditions

Increases are based on 2015/16 figures

Working together, we drive change to beat muscle-wasting conditions

Muscular Dystrophy UK is the charity bringing individuals, families and professionals together to beat muscle-wasting conditions. There are more than 60 rare and very rare progressive muscle-weakening and wasting conditions, affecting around 70,000 children and adults in the UK.

We're committed to:

- accelerating the search for effective treatments and cures
- driving change for access to specialist care and support
- empowering individuals and families, and improving quality of life by giving a voice and connecting people.

With gratitude

Allergan International Foundation
Amrit Tatla
Anderson Strathern
Andrew Robertson
Anne Peterson
Association of Property Lenders
BGC International L P
Bill Ronald
British Telecommunications Plc
Bruce Wake Charitable Trust
Catherine Cookson Charitable Trust
CDE Global
CeX
Charles and Nicola Manby
Charles Scott
Christine and Robert Ogden
Comic Relief
Dudley and Geoffrey Cox Charitable Trust
Erica Leonard Trust
Goldman Sachs
Hogan Lovells
Ian Corner
ING Banking Services Limited
J P Moulton Charitable Foundation
Jeremy Pelczer
John Raymond Tijou Charitable Trust
Karen Lewis
Keith Rushton
Lloyds TSB Foundation for NI
Lloyds TSB Foundations
London Classified
Mackie's of Scotland
Mairi Leitch
MAP Nemaline
MariaMarina Foundation
Martin Hywood
Matalan Retail Limited
Mayo L. Marriott
McBains Cooper
Michael and Donna Thirkettle
Michele Pucci
Mrs Gladys Row Fogo Charitable Trust
Natalie Woodcock
NatWest Trust Administration
Next Plc
Oaktree Capital Management
Paul and Tracy Franklin
Payne-Gallwey Charitable Trust
Pennies
Raymond and Blanche Lawson Charitable Trust
Sir Alex Ferguson CBE
Smart Group
Tennants Consolidated Ltd
Tony and Frances Carey
Tony and Monica Moorwood
Voluntary Sector Investment Programme
The 29th May 1961 Charitable Trust
The A M Pilkington Charitable Trust
The Alice E Wood Charitable Trust
The Ann Jane Green Trust
The Annandale Charitable Trust
The Barbour Foundation

The Benham Charitable Settlement
The Borrows Charitable Trust
The Broughton Charitable Trust
The Charles and Elsie Sykes Trust
The Charles S. French Charitable Trust
The City Bridge Trust
The Clapp Family Charitable Trust
The Constance Travis Charitable Trust
The Cranbury Foundation
The D D McPhail Charitable Settlement
The Davis-Rubens Charitable Trust
The Donald Forrester Trust
The D'Oyly Carte Charitable Trust
The Eleanor Harvey Charitable Trust
The Eveson Charitable Trust
The G C Gibson Charitable Trust
The G D Herbert Charitable Trust
The George A Moore Foundation
The Hayward Sanderson Trust
The Hon Michael J. Attenborough CBE
The Horniman Children's Trust
The Hospital Saturday Fund
The John Booth Charitable Foundation
The John Jarrold Trust
The Joseph Strong Frazer Trust
The Kirby Laing Foundation
The Lady Hind Trust
The Leach Fourteenth Trust
The Lord Belstead Charitable Trust
The Lord Faringdon Charitable Trust
The Martin Connell Charitable Trust
The MEB Charitable Trust
The Melville Charitable Trust
The Miss J K Stirrup Charity Trust
The Misses Barrie Charitable Trust
The Northwood Charitable Trust
The P F Charitable Trust
The Paul Bassham Charitable Trust
The R G Hills Charitable Trust
The Rayne Foundation
The Shanly Foundation
The Sir Cliff Richard Charitable Trust
The Sir Edward Lewis Foundation
The Sir James Knott Trust
The Sunrise (Sidmouth) Charitable Trust
The Swire Charitable Trust
The Sylvia Aitken Charitable Trust
The Templeton Goodwill Trust
The Woodroffe Benton Foundation

We are hugely grateful to our enthusiastic and generous committee members whose support makes our events the best they can be: the Microscope Ball Committee, Sports Quiz Committee, Q Trust Quiz Committee, Pledge Dinner Committee and Town and Gown Committee.

We also value the dedication and commitment of those who fundraise for us through our Branches, Groups and Family Funds. Thank you – your efforts make a huge difference to the fight against muscle-wasting conditions.

Muscular Dystrophy UK relies almost entirely on voluntary donations and legacies to fund its vital work. While we cannot list every individual here, please know that we are sincerely grateful to everyone who has donated and fundraised for our work over the past year.

Muscular Dystrophy UK
Fighting muscle-wasting conditions

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www.musculardystrophyuk.org

Registered with FUNDRAISING REGULATOR

Our 2016/17 Financial Statements are available upon request. Download a copy from our website or call us on 020 7803 4800 and we'll send you a hard copy.
Muscular Dystrophy UK is the operating name of the Muscular Dystrophy Group of Great Britain and Northern Ireland (a company limited by guarantee: 705357
Registered Charity No 205395 and Registered Scottish Charity No SCO39445