Muscular Dystrophy UK

Fighting muscle-wasting conditions

Improving lives today and transforming those of future generations

IMPACT REPORT 2017/18

MUSCULAR DYSTROPHY UK

Every day counts when you're living with a progressive and potentially life-threatening muscle-wasting condition.

With over 70,000 people in the UK living with these conditions, Muscular Dystrophy UK is urgently searching for treatments and cures to improve lives today and transform those of future generations. Together, we're pressing for faster access to potential drugs and we're driving change to see better care and support to help people stay active, independent and connected.

Our continued investment into pioneering research has led to vital progress which, with better care, has improved both quality of life and life-expectancy.

We understand the everyday challenges of muscular dystrophy and muscle-wasting conditions, so we're here with information and advice, together with emotional and practical support, a network of local groups and an online community.

With your support, we can be here for everyone affected today, tomorrow and beyond. Together we will bring forward the day when we beat muscular dystrophy and muscle-wasting conditions.

Barry and Vicky de Bruin with their daughter Olivia and son Luke, who has Duchenne muscular dystrophy

Photo © Kii Photography

On the cover: Gianluca Luisi, member of MDUK's Young Disabled Persons' Working Group

Photo © Chris O'Donovan

WELCOME TO THE IMPACT REPORT

We are delighted to set out some of the highlights from 2017/18 of the progress we're making in our fight against muscle-wasting conditions, as well as our growing research investment.

We now work in a number of international partnerships to accelerate progress in research and are leading many innovative studies. Our research is leading to more clinical trials to test potential treatments for muscle-wasting conditions and we're also investing to build support for further trials.

Our campaigning work with families helped ensure access to Translarna to treat a specific mutation leading to Duchenne muscular dystrophy, but we know it is increasingly difficult to secure NICE approval and NHS funding for high-cost drugs for rare diseases, particularly in England. We will address this as a priority in 2018/19.

We continue to drive improvements in support and secured NHS funding for eight new specialist neuromuscular roles, including care advisors, physios, OTs and consultants, to support patients and families. Further training and learning opportunities were provided to healthcare professionals within our professional development programme.

Our direct services include the advocacy service which supported 52 percent more people compared with the previous year, and 229 children and adults received grants from the Joseph Patrick Trust to help purchase equipment, wheelchairs and assistive technology. The Trailblazers highlighted access issues with public transport, independent living, employment and leisure activities, and secured some important changes.

All our work depends on the support of so many people as donors, supporters and volunteers, and we're deeply grateful to all who generously enable the charity to deliver our objectives. Our Board and committee members provided valuable oversight and guidance. We also thank the staff team for their commitment and hard work. We know every day counts living with a muscle-wasting condition and we are determined to accelerate progress in research, and improve NHS care and support for independent living. We are determined to make further progress towards our goal in the year ahead.

Robert Meadowcroft, CEO

Prof Mike Hanna, Chair, MDUK

Photos © Kii Photography

RESEARCH

People with progressive muscle-wasting conditions live with an uncertain future. Currently, there are no cures and many conditions get worse over time.

That's why we're determined not only to accelerate scientific progress and improve lives as quickly as possible, but to innovate and collaborate to give research every chance to succeed.

Many conditions are ultra-rare, so we link researchers across the UK with those based internationally. We know we can beat muscle-wasting conditions more quickly when we work together.

Highlights from 2017/18

Over the past year, and with your valued support, we invested a further **£2.9 million** into:

- high-quality research
- continuing development of partnerships within the scientific community and industry
- increasing clinical trial capacity in the UK
- the launch of a new Research Line to explain current developments (see p6).

This brings our current investment in research to £9.7 million.

Professor Dame Kay Davies (centre) and colleagues at the MDUK Oxford University Neuromuscular Centre

Photo © Chris O'Donovan

WHAT WE ACHIEVED

High-quality research

By investing in the best quality science, we supported researchers to produce groundbreaking results for the world of muscle-wasting conditions. We awarded **13 new grants**, including **five PhD studentships**.

We have invested in the 'NorthStar' programme, the world's largest natural history study to speed up access to clinical trials, drive improvements in services and set national standards of care for children living with Duchenne muscular dystrophy. The investment included an increase in our support at **23 clinical centres** UK-wide to gather this information.

The investment has been extended to a PhD studentship to gather information from adults with Duchenne to help improve standards of care and study the effectiveness of potential treatments.

People with muscle-wasting conditions tell us they want to find ways to better manage their condition, so we funded the ACTMuS (Acceptance and Commitment Therapy) study. We also supported a fellowship exploring key issues of fatigue and sleep in myotonic dystrophy, and a studentship to understand the quality of life and care needs of men with Duchenne.

MDUK-funded research at St Andrew's University

Photo © Graeme Hart

We're grateful to : MAP Nemaline Family Fund for their support of cutting-edge research into the rare condition, nemaline myopathy

The Cranbury Foundation for their long-standing and generous support of our myotonic dystrophy research

The Sir Samuel Scott of Yews Trust and the Hospital Saturday Fund for grants towards MDUK-funded myotonic dystrophy research

The Greendale Charitable Foundation and The Childwick Charitable Trust for grants towards MDUK-funded research into FSHD

The Northwood Charitable Trust for support of our research in Scotland.

WHAT WE ACHIEVED

MDUK-funded research at MDUK Oxford University Neuromuscular Centre

We're committed to helping meet the growing demand UK-wide for clinical trials for treatments into muscle-wasting conditions through our **£1 million investment** in the MDUK Oxford University Neuromuscular Centre, which promotes the translation of scientific research into clinical trials and will improve the clinical trials' infrastructure for neuromuscular conditions.

Alongside our existing support of centres in Newcastle and London, we also **invested £60,000** to increase clinical trial capacity at Manchester Children's Hospital.

Partnerships

In partnership with the French muscular dystrophy association, AFM Téléthon and Généthon to develop products for rare conditions, we're building knowledge of the role and safety of gene therapy. While this work currently relates to Duchenne muscular dystrophy, it could also apply to a range of conditions in the future.

Clinical trial capacity

Although there are more potential treatments on the horizon than ever before, researchers and clinicians are warning us that current systems and structures are not adequately prepared to meet the demand generated by the rise in trials and treatments. Neuromuscular centres are having to turn down new trials owing to lack of capacity.

Research Line

We introduced this service to help people with muscle-wasting conditions make informed decisions about taking part in clinical trials, and understand the science around their conditions. The service includes an online resource: **www.musculardystrophyuk.org/progress-in-research/clinical-trials** that outlines current and relevant clinical trials, and can help to demystify what can often be confusing information.

Thank you to the Garfield Weston Foundation for their significant donation, and to the individual donors who raised an additional £50,000, to support the MDUK Oxford University Neuromuscular Centre this year.

VALUING THE PATIENT'S PERSPECTIVE

We're committed to funding the best and most relevant science for the people we support, so we have a 'gold standard' review and selection process. Alongside our Medical Research Committee's expert review and a rigorous international peer review process, MDUK's Lay Research Panel brings the all-important patient perspective. Alex Williamson, who has Charcot-Marie-Tooth disease (CMT), is the current chair of the Panel:

"We meet twice a year: once to review and rate the lay summaries of the research proposals to see if they make sense to us, and then to see which were successful and why. We score the proposals based on how valuable and exciting they are from a lay perspective. By giving the patients' perspectives at the scientific panel, the vice chair and I can also influence their deliberations.

"I feel the Panel makes a useful contribution to the selection of research to be funded. We've also been influential in getting quality of life research taken seriously. Whilst breakthroughs in treatments and cures are vital, so many of us have to live with the disease and need our quality of life improved in various ways.

"The current research landscape is exciting! We seem quite close to some major breakthroughs and I get so thrilled when we see proposals for clinical trials."

Alex Williamson

Photo © Chris O'Donovan

DRIVING CHANGE

Time is precious when you're living with muscular dystrophy, but it can take years for drugs to get from the lab bench to those who need them. We know every day counts for people with muscular dystrophy.

That's why we're pressing hard to get new treatments to people faster. We're also committed to ensuring everyone living with muscle-wasting conditions gets access to the specialist healthcare they need, no matter where they live.

Highlights from 2017/18

During the past year, we:

- secured NHS funding for eight specialist posts and supported clinical networks
- fought successfully for the approval of a drug for babies with the most severe form of spinal muscular atrophy (SMA) in Scotland, and continued to press for access UK-wide
- equipped community healthcare professionals to meet the needs of those living with muscle-wasting conditions.

Claire Chidzey and her son Ryan, who has Duchenne muscular dystrophy

Photo © Roger Moody

WHAT WE ACHIEVED

Specialist posts and clinical networks

With the support of individuals and families UK-wide, we strengthened services and secured NHS funding for **eight new neuromuscular roles via 11 clinical networks**.

These new roles will give people UK-wide better access, or access for the first time, to specialist healthcare. We've now secured a total of **81 new neuromuscular roles** across the UK, representing an **NHS investment of £5.6 million**.

In addition, we've funded MDUK advocacy and information officers who support patients and families at **six major muscle centres and clinics** across the country.

And, following a series of improvements introduced by the NHS and MDUK, the number of unplanned hospital admissions in London and the South East halved since 2012.

Physio session at St Thomas' Hospital

We're grateful to The William Allen Young Charitable Trust whose grant enables us to support families at the Great Ormond Street Hospital clinic, and to the Barbour Foundation for their grant towards our work at the John Walton Muscular Dystrophy Research Centre in Newcastle.

WHAT WE ACHIEVED

Specialist support at Royal Bristol Children's Hospital

Spinraza

SMA Type 1 is a severe condition affecting babies and young children, many of whom sadly die in the first years of life. Thanks to the hard work of campaigning families – backed by MDUK – there are now new drugs in clinic treating people affected by Duchenne muscular dystrophy and Type 1 SMA. An access scheme by pharma company Biogen means that babies and infants with Type 1 SMA have received the drug Spinraza*.

While not a cure, trials showed significant improvement in children, enabling them to achieve, or maintain, physical milestones that they would never reach without treatment, and that means families staying together for longer.

We'll continue to campaign for the drug to become available for SMA types 2 and 3.

Equipping community healthcare professionals

Because muscle-wasting conditions are so rare, healthcare professionals may hardly ever come across patients with these conditions. That's why we worked with professional bodies to develop online training modules for GPs and physiotherapists.

This year we saw a **16 percent increase** in GPs taking up our e-learning course and **17 percent** in physios completing these courses, meaning they can now better support people to live well.

Emma Vogelmann, MDUK Trailblazers Employability Officer

Photo © Chris O'Donovan

*Since May 2018 children in Scotland with Type 1 SMA have been able to access treatment on the NHS. However, in August 2018 NICE issued a draft decision not to recommend the treatment for NHS use in England. We are campaigning hard to reverse this draft decision and ensure an access scheme is put in place.

FIGHTING FOR TREATMENTS

Non-identical twins George and Harry Lockley were born in 2011. Just before his first birthday, George was diagnosed with SMA Type 2. Because Spinraza is only freely available to children showing symptoms of SMA before six months of age (consistent with SMA Type 1), George is not eligible to receive treatment.

Liz Lockley, pictured with Harry (l) and George (r): "When George was diagnosed with SMA, our lives changed forever. For a parent, it's heart-breaking to see your child gradually lose their physical abilities, particularly when it happens in parallel to their twin brother gaining new skills every day.

"While Spinraza is not a cure, it could help George maintain some of his strength and potentially gain new skills. Even if Spinraza could give George the ability to cough effectively, SMA would no longer be such a threat to his life. Simple things like having more arm strength could enable George to live a much more independent life. This would be invaluable to us and, more importantly, to George.

"It's so hard knowing there is a drug out there which could significantly increase the quality of your child's life, but it's not available for them to have. It was easier to accept when there was nothing. Evidence suggests that the earlier Spinraza is given the more effective it is; therefore, time is not on George's side."

MDUK continues to work with other SMA charities to fight for children like George to get access to treatment.

Liz Lockley with sons Harry (l) and George (r)

LIVING WELL WITH MUSCULAR DYSTROPHY

A diagnosis of muscular dystrophy can change everything. That's why we're here for everyone affected, from the moment of diagnosis and beyond.

We're here to help people live well with the condition. Because of the everyday challenges of muscular dystrophy, we're here to offer information and advice, emotional and practical support, a network of local groups and an online community.

Highlights from 2017/18

During the past year, we:

- successfully advocated for people's rights
- ensured the voice of young disabled people was heard and acted upon
- connected people living with muscle-wasting conditions with others in their communities
- provided support and information to people living with muscle-wasting conditions.

The WFA Disability Cup Finals supported by MDUK at St George's Park

Photo © Roger Moody

WHAT WE ACHIEVED

Advocating for people's rights

We expanded our information, advocacy and support services, to help **614 people** with muscle-wasting conditions get the services, benefits and equipment they were entitled to. This was an **increase of 52 percent** over the previous year, and represented a total of almost **£400,000 worth of support**.

Getting out and about is important for everyone. But people with severe disabilities often need extra equipment and space to use toilets safely and comfortably. MDUK became the new lead charity for the Changing Places consortium, campaigning for more public places and buildings to provide accessible toilet and changing facilities.

Our campaigning led to improvements in public transport, including more step-free access to stations, and making it illegal for taxi drivers to refuse to take disabled people or charge them extra. We also influenced Twitter to change their abuse policy to incorporate disability hate speech.

Growing the campaigning network

For many disabled people, video games can help reduce social isolation, relieve stress and improve mood. But many are unable to play because of their disability. We worked with global tech giant Microsoft, together with Vivek Gohil, who has Duchenne muscular dystrophy, to look at the impact of gaming on young disabled people. This was part of our ongoing initiative to improve access to gaming.

Trailblazers, our network of young disabled people who campaign on issues important to them, grew its membership to **more than 700** UK-wide. The network focused on improving access to travel and public transport, independent living and leisure activities.

During the year, **27** young disabled people took part in Moving Up, Trailblazers' work experience scheme, and **over 60 percent** went on to find paid work or education opportunities.

Gianluca Luisi, member of MDUK's Young Disabled Persons' Working Group

Photo © Chris O'Donovan

WHAT WE ACHIEVED

MDUK Trailblazers at a parliamentary reception

Photo © Chris O'Donovan

Connecting people

Our regional network of Muscle Groups across the UK continued to grow and campaign for vital improvements in specialist care. During the past year, **211 people – 62 percent of whom were new to the charity** – took part in our two national conferences, condition-specific information days and two family fun days in Birmingham and Doncaster.

Providing support and information to people living with muscle-wasting conditions

We supported **44,826 people** with information and advice, emotional and practical support. Through the Joseph Patrick Trust, our welfare arm, we **awarded grants totalling £310,000** to **229 adults and children** towards the cost of specialist equipment and assistive technology to help them live more independently.

Our new Research Line, which we launched in November, **answered 133 enquiries** in its first few months. Our helpline saw **an increase of 16 percent** in calls, and our new adaptations manual offered individuals and families living with muscle-wasting conditions guidance to live independently and adapt their homes appropriately.

MariaMarina Foundation generously awarded a two-year funding grant for our assistive technology fund

Dr Sofia Nnorom who manages MDUK's Research Line

Photo © MDUK

LEADING AN INDEPENDENT LIFE

We're committed to supporting people to stay active, independent and connected. For Vivek Gohil, an MDUK Trailblazers ambassador, accessible gaming helps him do just that.

"Living with Duchenne muscular dystrophy can be incredibly challenging; constantly adapting to muscle deterioration restricts independence, and you have to rely on parents or Personal Assistants for practically everything.

"Throughout life, I've always tried to find workable solutions to barriers I face because of an inaccessible environment. Assistive technology has helped me remain as independent as possible, and helped me maintain an amount of agency in life. Without this technology, I would have a limited quality of life; I'd become isolated and unable to communicate.

"Accessible gaming has been a passion of mine since I found it increasingly difficult to carry on gaming. Microsoft released their Xbox Adaptive Controller recently and it's going to revolutionise accessible gaming. By focusing on your ability and allowing you to position switches where you need them, you're able to game and interact with the wider world.

"Independence is a vital part of life. And disability or not, it's still possible to lead an independent life."

Vivek Gohil tests the new controller

Photo © MDUK

OUR FINANCIAL YEAR IN REVIEW

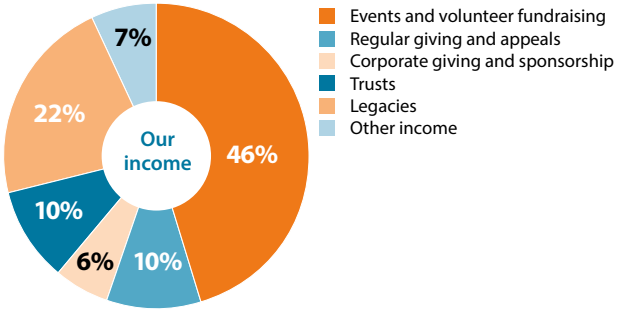
We had a successful year financially and ended the year with a planned net deficit of **£1,199,000**. This year saw our legacy income returning to **£1,564,000** after several years of exceptional generosity, and the value of our investments fell with the market, but despite this we still increased our level of charitable activity.

The planned net deficit for the year is the start of several years' planned deficits to drive research and fund our significant new projects over the next five years: the MDUK Oxford University Neuromuscular Centre, development of the NorthStar programme and database and a gene therapy clinical trial.

This will bring our unrestricted reserves back to the **£1.5 million** target to maintain the development of our charitable activity in the forthcoming years.

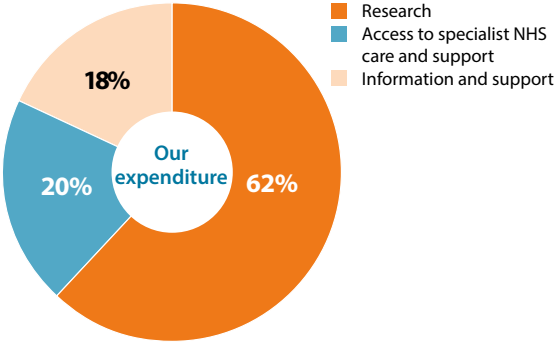
How we raised our money

The total income for 2017/18 was **£7,159,000**. Donations, gifts, grants and fundraising activities totalled **£5,127,000**, and in addition, we received **£1,564,000** from legacies. Investment and other income amounted to **£468,000**, of which **£75,000** was from the Duchenne Forum, **£33,000** from the Scottish Office and **£50,000** from Action Duchenne. All of these are partnerships to fund research.



Where we spent our money

The total expenditure for 2017/18 was **£6,065,000**. Expenditure on charitable activities was **£3,775,000** in respect of medical research, **£1,184,000** on access to specialist NHS care and support, and **£1,106,000** on provision of information, support and opportunities to enable independent living.



RAISING MONEY FOR BETTER LIVES

We're committed to being charity leaders in fundraising innovation, raising funds ethically to help build public trust in charities.

We encourage and support those who want to join us, using their generous offer of time, talent and money in the most effective way possible.

It's the support of our amazing fundraisers, volunteers, campaigners and those who want to change their communities, that enables us to do what we do.

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

Teams taking part in our Pedal Paddle Peak challenge event in the Lake District

Photo © Stuart Holmes

FUNDRAISING FOR FUTURE GENERATIONS

Diagnosed with limb girdle muscular dystrophy at the age of 23, Martin Hywood first got in touch with MDUK about five years ago. He says he's never looked back.

A lifelong Leeds United fan, Martin has secured support from the club and campaigned to raise awareness of muscular dystrophy and MDUK through a range of fundraising activities. He's raised **over £100,000** for MDUK, and was shortlisted for a 2018 Third Sector Volunteer of the Year award.

"My wife Michelle and I have three daughters – Lucie, Olivia and Skye – and we'd always wanted to help younger families living with muscular dystrophy. We decided to fundraise for research into treatments.

"My first fundraising venture was taking part in MDUK's first Move a Mile for Muscles event. About 25 of us walked a mile to my local pub and raised some funds. It might not have seemed like much, but it was the start of what is now my fundraising community: Hywood's Heroes.

"This group has grown to about 150 people – family, friends and many others – who want to do all they can to fundraise for the amazing work of MDUK, and they really do make a difference. I'm so lucky that people get on board when I ask them to. I never take this for granted.

"I've always wanted to be a regular dad and make my daughters proud of me and what I do. MDUK has helped my family and me and we want to give something back, so we make every effort to raise funds for research into treatments. It might not happen in my generation, or for me, but it's important we do it for future generations."

Michelle and Martin Hywood

SUPPORTERS DOING AMAZING THINGS ACROSS THE UK

Every event you take part in, every cake you bake, every mile you run, every gift you make, every card you buy and every pound you raise moves us forward. Thank you to every one of you for all you do to bring forward the day when we will beat muscular dystrophy.

6,895 people took on a range of challenge events for #TeamOrange and raised a fantastic **£678,045**

30,780 people helped schools and workplaces in the UK Go Orange for a Day and raised **£33,529**

Our Branches and Family Funds raised **£677,000**

Individuals and groups holding their own local events across the UK raised **£614,000**

130 people signed up to Move a Mile for Muscles across the UK and raised **£55,608**

Gayle Hoy, running the London Marathon for #TeamOrange

Photo © Chris O'Donovan

130 skydivers leapt out of planes to Make Today Count and raised **£123,044**

750 guests came to the Microscope Ball, a property industry gala, and raised a **record £365,000**

570 guests supported a range of special and black tie events, raising **£157,000**

3,167 played in MDUK's raffle and lottery and raised **£61,031**

9,742 individuals donated a total of **£603,829**

We received **£1,564,000** in legacy income with **45 people** remembering MDUK in their Wills

WITH GRATITUDE

who raise significant funds for MDUK at their annual gala

who support MDUK in more than **300 stores UK-wide**

whose employees have raised **more than £100,000**

for the unstinting support of their employees and customers who have raised **more than £330,000**

who supports MDUK's active projects and the Microscope Ball

whose CEO **Mike Townend** introduced the MDUK-branded Rubik's cubes in all Matalan stores, boosting income to help beat muscle-wasting conditions

for the privilege of being one of BGC Charity Day beneficiaries

who support our campaigning activities UK-wide

Muscular Dystrophy UK relies almost entirely on voluntary donations and legacies to fund our vital work.

Huge thanks to:

- our enthusiastic and generous committee members, whose support and tireless commitment make our events the success that they are: the Microscope Ball Committee, Sports Quiz Committee, The Q Trust, Pledge Dinner Committee and the Appeals Board
- our Branches, Groups and Family Funds: your dedication and commitment to fundraise for us make a huge difference in the fight against muscle-wasting conditions
- everyone who is involved on our committees, panels and groups, strategic and other consultations: your insight and expertise help make sure we're moving in the right direction
- every volunteer who gives their valuable time to MDUK: whether you're cheering on #TeamOrange, helping in our offices or moderating our online forum – every one of you is helping us beat muscle-wasting conditions.

Our new project developing psychological support for 18- to 25-year-olds has been fully funded by The BUPA UK Foundation, the 29th May 1961 Charitable Trust, and The Edward Cadbury Charitable Trust

WITH GRATITUDE

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

Allen & Overy
Anderson Strathern
AI Scheme Ltd
APL
BGC International L P
Bill and Jacky Ronald
Brit Insurance
Bruce Wake Charitable Trust
CeX
Charles and Nicola Manby
Charles Scott
Comic Relief
Dan and Claire Parker
Frances Carey
Genzyme
Halifax Foundation for NI
Hogan Lovells
Ian and Helen Carson
ING Banking Services Limited
Jeremy and Mary Champion
MAP Nemaline
MariaMarina Foundation
Matalan Retail Limited
McBains
Michele Pucci
Mrs Gladys Row Fogo Charitable Trust
PTC Therapeutics
Richard and Nicky Price
Sally Whittet
Simone Verri
Tennants Consolidated Ltd
The 29th May 1961 Charitable Trust
The Annandale Charitable Trust
The Barbour Foundation
The Broughton Charitable Trust
The W.A. Cargill Charitable Trust
The Charles and Elsie Sykes Trust
The Childwick Trust
The City Bridge Trust
The Constance Travis Charitable Trust
The Cranbury Foundation
The D'Oyly Carte Charitable Trust
The Edward and Dorothy Cadbury Trust
The Elizabeth Hardie Ferguson Charitable Trust Fund
The Eveson Charitable Trust
The G C Gibson Charitable Trust43
The Garfield Weston Foundation
The Greendale Charitable Foundation
The Holbeck Charitable Trust
The Hospital Saturday Fund
The Hugh Fraser Foundation
The Ian Fleming Charitable Trust
The Inman Charity
The James Tudor Foundation
The Mason le Page Charitable Trust
The Northwood Charitable Trust
The Pixel Fund
The Rayne Foundation
The Rosetrees Trust
The Sir Samuel Scott of Yews Trust
The Swire Charitable Trust
The Templeton Goodwill Trust
The William Allen Young Charitable Trust
Tony and Monica Moorwood
Winton Philanthropies
Yorkshire Building Society Charitable Foundation

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. Without you, we couldn't do what we do.

OUR PLANS FOR 2018/19

Improving lives today and transforming them in the future: accelerating research

We will:

- invest in high-quality research and accelerate steps to safe and effective treatments
- take forward our research priorities, by:
  - harnessing the power of genetics
  - increasing our understanding of the disease mechanism
  - facilitating drug development
  - improving quality of life
- take forward our key transformational commitments, to:
  - help meet the growing demand for clinical trials, through the MDUK Oxford University Neuromuscular Centre
  - develop the NorthStar programme to boost understanding of Duchenne muscular dystrophy
  - support the UNITE-DMD trial to evaluate the safety of gene therapy
- improve clinical trials infrastructure for all neuromuscular conditions
- provide more opportunities for parents of young children diagnosed with muscular dystrophy to raise funds for research.

Driving change for access to specialist care and support

We will:

- continue to reach more individuals and families living with muscle-wasting conditions, to ensure they get the information and support they need at every stage of their journey
- campaign for improved mental health support and develop new resources to support individuals and families at diagnosis
- secure additional NHS funding for specialist neuromuscular roles
- develop tools, events and resources to equip more health professionals to understand better the range of conditions and the support and care patients and families need
- improve emergency care by extending our Ambulance Action campaign and use of our condition alert cards
- press for faster approval of emerging treatments
- enlist the support of more parliamentarians across the UK via our network of All Party and Cross Party Groups on muscular dystrophy
- support more families UK-wide by building on the work of MDUK's information and advocacy officers.

Living well with muscle-wasting conditions: improving quality of life by enabling independent living

We will:

- support people living with muscle-wasting conditions by providing information, practical advice, advocacy and support
- begin to put in place an effective and sustainable regional support structure to engage volunteers around the UK providing mutual support, raising the profile of MDUK and increasing opportunities to get involved
- strengthen the support offered at diagnosis through our advocacy and support officers based in clinics and in the community, together with MDUK's support through the Helpline Accreditation programme
- ensure more fully-accessible toilets are available across the UK, by leading the UK-wide Changing Places consortium
- extend our support to young disabled people through the Trailblazers' work experience project, regional events and campaigns
- develop our online forum that enables people to meet each other and talk about the things that matter to them
- start to develop a new website and create a digital community that better meets the needs of people living with muscular dystrophy.

Sir Alex Ferguson and Sam Allardyce supporting MDUK at the BGC Charity Day

Photo © Kii Photography

Celebrity Sports Quiz

Photo © Kii Photography

Volunteers at the Town and Gown 10k

Photo © Kii Photography

Muscular Dystrophy UK
Fighting muscle-wasting conditions

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Our 2017/18 Financial Statements are available upon request. Download a copy from our website at www.musculardystrophyuk.org/publications/impact-reports or call us on 020 7803 4800 and we'll send you a hard copy.

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