

**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions



Making every day count

**Impact report
2018/19**

Every day Muscular Dystrophy UK is working towards a future with effective treatments and ultimately cures for all muscle-wasting and associated conditions and where there are no limits in life for people who are affected.

We believe this as passionately now as we did when we were established 60 years ago. It drives everything we do.

It is this vision that unites us all – from the researchers we support to the health professionals we train; from the people we help through our information and advocacy services to our supporters who inform, guide and campaign with us to make change happen.

We understand that muscular dystrophy changes everything. That's why we're here for anyone, right from the moment of diagnosis and beyond. We're here to help people take back some control of their lives and to live well with the condition. We understand the everyday challenges of muscular dystrophy, so we're here with information and advice, 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 are bringing forward the day when there are effective treatments available for all muscle-wasting and associated conditions.



Tanvi Vyas, MDUK Trustee



Prof Dame Kay Davies, MDUK-funded researcher at Oxford University



Hayley and Tommy Lloyd



Supporters at MDUK Town and Gown 10k

On the cover: Louise and Jacob Halling

Welcome to our impact report. It's been a year of pace and change as we renew our determination to find effective treatments for all muscle wasting and associated neuromuscular conditions and remove the barriers that stop people living full and independent lives. It's only with the support of our wider community and those who work with us that we've been able to deliver that change.

Sixty years ago when Muscular Dystrophy UK was first formed, research into muscle wasting conditions was largely neglected, the life expectancy for people living with Duchenne was around 14 years and attitudes towards people with disabilities were largely negative.

Today, pioneering research has led to over 150 clinical trials globally, better support and care has seen life expectancy increase and improved access to care and support, means that more people with muscular dystrophy have greater opportunities, visibility and aspirations than ever before. There is still a long way to go.

This year we made history, our campaigning work with families and other charities helped to secure access to Spinraza to treat SMA Types 1, 2 and 3. We will continue to press for change until everyone who needs it has access to it wherever they live in the UK. We know how difficult it is to secure approval and funding for treatments for rare diseases, particularly in England and we will continue to collaborate with partner charities to achieve changes to the approval system.

We continue to invest in world-leading research. This year we invested £1.2m into 10 new research projects and we are working in partnership with the University of Oxford to establish a world leading centre aimed at bringing new treatments to patients faster.

Working closely with you, we understand what 'change' means; the challenges that changes in your condition create; the questions the choices about trials open up; the changes in government assessments. In the following pages you will read about the work of our services to provide information, advice and support for people at the times when they need us. This year Robert Meadowcroft, our former CEO, who

led the charity for eight years stepped down and handed over to Catherine Woodhead in September. We thank him for his years of dedicated work and bringing the charity to where it is today.

We welcome Gabby Logan, as our new President and thank Sue Barker OBE who gave us 14 brilliant years of support as our President. We're delighted Sue has taken on a new role as Honorary Life President.

The change that has been achieved is only made possible through our supporters who make every day count. You – our individuals and families living with the conditions, our donors, fundraisers, volunteers, Board members, committee members, researchers, clinicians, care staff and our staff team –will help us to achieve a world with effective treatments and cures, and no limits in life for those affected by muscle-wasting and associated conditions. We're deeply grateful for your support, commitment and hard work.



Catherine Woodhead, CEO



Prof Mike Hanna, MDUK Chair



Prof Mike Hanna, Gabby Logan, Sue Barker and Catherine Woodhead at the MDUK National Conference 2018

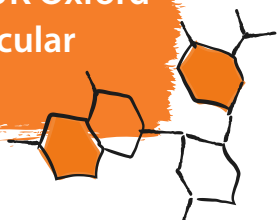
Searching for treatments and cures

What we achieved in 2018/19

Every day MDUK is working towards a future with effective treatments and ultimately cures for all muscle-wasting and associated conditions. We're committed to supporting researchers and doctors to carry out the best quality research and continue to invest in areas where we are looking to see change in the near future.

In 2018/19, with your support we **invested £1.2m** into 10 new research projects, and **£1.8m to support** UK clinical trial capacity and other activities that underpin vital research. This brings our **current investment in research to £9.7m**, including 50 world-class projects in the UK and internationally.

£1m+ invested
in the MDUK Oxford
Neuromuscular
Centre



Harnessing the power of genetics

MDUK-funded researchers at Newcastle University have used next-generation sequencing. This is an innovative technology that 'reads' the whole of an individual's genome (their complete set of DNA). It is faster and more precise than current genetic testing methods. Taking DNA samples from 56 families with unexplained muscle weakness, this technology enabled them to search for underlying mutations. They identified mutations in 14 different genes and in 23 families. This will help shape more effective clinical management and tailored care for people.

Partnerships

We are working in partnership with the University of Oxford to establish a world-leading centre aimed at bringing new treatments to patients faster.



Families visiting a research lab at the Royal Holloway, University of London

Photo © Chris O'Donovan/MDUK

**£1.2m invested
in 10 new research
projects**



Thanks to your generosity, we **invested over £1m in the MDUK Oxford Neuromuscular Centre**, which will carry out translational research and boost capacity for clinical trials.

Clinical trials and registries

Only a limited number of neuromuscular centres are currently able to carry out clinical trials, so we're working to ensure that centres across the UK have enough trained staff to support them and more patients have the opportunity to take part. Our financial support for clinical trial co-ordinators this year has helped to set up and run **45 different clinical trials**.

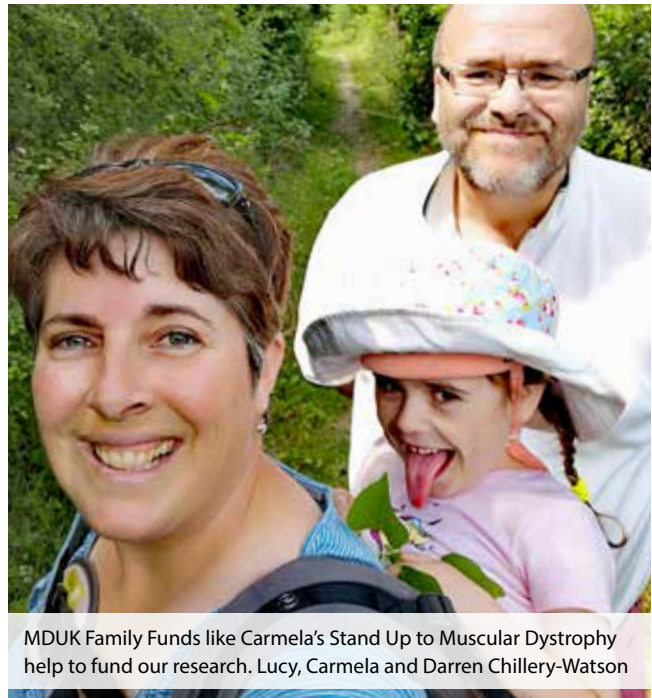
**£9.7m
current investment
in research**



Facilitating drug development

With generous support from family funds and others, we continued to support several patient registries, natural history studies and databases. In the case of rare conditions where the causes are poorly understood, these studies can provide useful data for researchers to follow the progression of a condition, and provide access to patients for clinical trials.

**£1.8m invested
to support UK
clinical trial capacity**



MDUK Family Funds like Carmela's Stand Up to Muscular Dystrophy help to fund our research. Lucy, Carmela and Darren Chillery-Watson

WHAT WE'LL DO NEXT

Accelerate research to develop effective treatments and cures

This year we published our three-year research strategy *Transforming lives through research*.

In 2019/20 we will:

- promote the theme of innovation and partnership that underpins all that we do and enables research to be given every chance to succeed
- encourage and support scientists and clinicians with new ideas and technologies to come into the area of research
- continue to invest in high-quality research to understand the underlying causes of disease, develop potential treatments and improve the quality of life of people living with neuromuscular conditions.

Thanks

Funding from the Gamma Trust, the James Weir Foundation and the Grace Trust helped kick-start Jarod Wong's research on bone health in Duchenne muscular dystrophy. The Dudley and Geoffrey Cox Charitable Trust and the N Smith Charitable Settlement are supporting Francesco Muntoni's new research into causation of congenital muscular dystrophy and congenital myopathy.

UNITE-DMD – international collaboration



I feel we are on the cusp of a new era."

Prof George Dickson

Prof George Dickson and Linda Popplewell

For over 20 years, MDUK has supported the work of Prof George Dickson at the Royal Holloway University of London to design, test and refine a gene therapy for Duchenne muscular dystrophy (DMD), which is now ready to be tested in boys for the first time. Prof Dickson has recently retired and Linda Popplewell is continuing his work, together with teams from the UK and France. They aim to start recruiting patients in 2019.

"Gene therapy in general – and DMD gene therapy in particular – is beginning to prove successful, and I feel we're on the cusp of a new era. An effective and safe gene therapy could be almost curative in younger patients. In older patients or in those with Becker muscular dystrophy, it could stabilise the disease in the long term, improving quality of life, life span and life chances," said Prof Dickson.

"I leave behind a brilliant research team under the leadership of Linda Popplewell, which will continue to elucidate new treatments and opportunities not only in Duchenne, but in the whole muscular dystrophy field."

Linda Popplewell feels honoured to continue Prof Dickson's work.



Photo © Chris O'Donovan/MDUK

“This fantastic opportunity to lead on such an exciting project is humbling but empowering. The project focuses on trialling a gene addition therapy for DMD that could have universal patient applicability and be long-lived in action. I worked with Prof George Dickson to secure and manage this grant and with his retirement now take on the reins on my own.

“It’s an exciting time in the muscular dystrophy field with many therapies currently in clinical trial. I have a realistic hope that it won’t be too long before a number of these therapies will receive approval from the relevant authorities for prescribed use in patients,” said Linda.

“MDUK funding has always been at the core, enabling support for my research, having funded our research on exon skipping and gene therapy in the early days, along with the French charity AFM. By focusing on top-rated and expert-approved research, MDUK funding has yielded extraordinary contributions,” said Prof Dickson.

Thanks

Our family funds and donors who support our Duchenne Research Breakthrough Fund, enabling us to fund groundbreaking research like this.

Driving change for specialist care and support

What we achieved in 2018/19

Time is precious when you're living with a muscle-wasting condition, but it can take years for drugs and treatments to get from the lab bench to those who need them. MDUK is at the forefront of a movement for change bringing together people to have a voice and deliver lasting change.



Photo © Chris O'Donovan/MDUK

Emma Vogelmann, MDUK Employability Officer, at a Parliamentary drop-in

Together, making history

Working in partnership with other charities, doctors, individuals and families, we put pressure on decision-makers to make Spinraza, the first ever treatment for spinal muscular atrophy (SMA), available for those with SMA types 1, 2 and 3. In 2018/19, access was secured in Scotland and at the start of 2019/20 NICE approved the treatment for use in England. We are currently fighting for access to the treatment for everybody who could benefit and for Northern Ireland and Wales to give approval too.

**34% increase
in physiotherapists
completing specialist
online training**



Investment in specialist roles and services

We secured **£511k worth of funding** for **12 new NHS-funded specialist neuromuscular roles**, including consultants, nurses and physiotherapists. Since 2013, we've secured **93 new roles** and saved a further 15. This **total NHS investment of £6.4m** means more people across the UK with muscle-wasting conditions have access to the specialist support they need.

Working with health professionals

When health professionals understand the impact of muscle-wasting conditions on the everyday lives of people, they can provide the best possible care. During the past year, we launched four new online courses for nurses, occupational therapists and teachers so they can better meet the needs of those with muscle-wasting conditions. These courses have been taken over 2,000 times. And for our existing courses, we saw a **34 percent increase** in the number



Valenee and Joanne Gosine

Photo © Suki MakMDUK

of physiotherapists completing their module and a further 150 GPs completing theirs.

Influencing governments

Working with the All Party Parliamentary Group on Muscular Dystrophy, we launched a major report in the Westminster Parliament, which will guide our campaign for **appropriate mental health support**. Twenty-five MPs pledged to support the report's findings too. We continue to provide support for cross-party groups in the Houses of Parliament, Scottish Parliament, Welsh Assembly and Northern Ireland Assembly.

Mental health matters

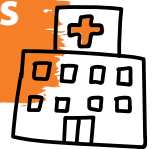
Muscle-wasting conditions can affect all aspects of life. This year we launched a **virtual clinical psychology service**, offering telephone reviews and counselling for parents of children who are newly diagnosed or going through a difficult time.

This is a pilot project and early reports have been positive. We'll use the results to campaign for the delivery of improved mental health services nationally and shape future service provision.

Thanks

The psychology service gave us an opportunity to build a new relationship with the Tom and Sheila Springer Charity, a new trust to us. Their grant enabled us to launch the pilot project.

93 specialist roles
secured via NHS
funding since 2013



WHAT WE'LL DO NEXT

Drive change for access to specialist NHS care:

- campaign for system change to the drug approval process across the UK so that people can get new treatments faster
- support health professionals to build their understanding of muscle-wasting conditions and their role in providing high-quality care
- use our influence to increase the availability and quality of NHS specialist support
- improve the reach and the quality of the physical and mental support for individuals and families living with muscle-wasting conditions.

They understood what I was going through

At MDUK, we're determined that everyone with a muscle-wasting condition has access to the **best possible healthcare locally**. So we're leading the drive to improve the standards of clinical support across the UK through our Centres of Clinical Excellence awards.

A panel of health professionals and patient representatives developed the criteria for the awards, while patients gave their views at **muscle group meetings** and online. This helped determine which centres were delivering the very best care.

The Sheffield Teaching Hospitals NHS Foundation Trust was among 17 centres recognised in our 2018 UK-wide audit. Rotherham mum of two, Jayne Small, talks about what it means to have access to a **specialist support team** there.

"I was first diagnosed with muscular dystrophy four and a half years ago. I had gone to the GP with concerns about my walking and getting up and down steps. Two months later, a neurologist told me it was likely I had a genetic neuromuscular disorder and I was devastated. I've had lots of tests to find out what type of muscular dystrophy it is, and we still don't know. The good news is that we're still trying, and I have a much more positive outlook on life.

"Eight months after my first consultation with a neurologist, I realised I wasn't coping very well and needed support outside of my family. The neurologist put me in touch with the Hallamshire Hospital's specialist neuromuscular care advisor who also made contact with clinical specialist physiotherapists.

"The main support was they understood what I was going through. They listened to me and gave me advice in so many different areas. They came out to my home and spoke through the difficulties I was having physically, mentally and logistically. I was working then, so they helped with practical support too.

"You can also talk to other people going through similar things – you don't feel like you're on your own."

Over the past few years, Sheffield Teaching Hospitals NHS Foundation Trust has played a key role in raising awareness of neuromuscular conditions, organising and running training days and events for GPs, patients, carers and families. These events, which have been hugely popular, have helped further educate patients, families and their carers on ways they can better manage their condition. Patients have also helped to establish and decide discussion topics – with clinicians responding and acting on feedback to focus events on specific topics such as the importance of exercise and available financial support.

Dr Channa Hewamadduma, Consultant Neuromuscular Neurologist, says, "the adult neuromuscular service at the Royal Hallamshire and Northern General Hospital is a well-established, comprehensive, diagnostic and therapeutic service with a range of subspecialist interests in peripheral nerve, muscle and neuromuscular junction disorders.

"We are hoping to grow with a number of projects to increase research and further benefit patients. This award will galvanise the team to keep striving for **clinical excellence**."





They listened to me and gave me advice in so many different areas. They came out to my home and spoke through the difficulties I was having physically, mentally and logistically.

Photo © Roger Moody/MDUK

Jayne Small

Photo © Roger Moody/MDUK

Living well with a muscle-wasting condition

What we achieved in 2018/19

Being diagnosed with a muscle-wasting condition means adjusting to a new and unexpected reality, so it's important to have easy access to the information and support you need. That is why we provide free, expert information, resources and confidential support online, over the phone, in communities and in hospitals.

Information and support

Our helpline team continue to provide information, practical advice and support and listen to people's concerns; we answered 1,052 calls, a **26 percent increase** on last year's number. We supported 21,710 people in total.

25,000
understand more
about their condition after
downloading our info factsheets



We also provide support through our information resources and online forum. **Over 56,000 people** visited our website's care and support areas and downloaded **25,000 info factsheets**. In addition, **3,000 people** used our online forum to share experiences, and support each other. Our Research Line **helped 415 people** find out more about the latest developments and clinical trials.

Advocacy

People face a range of direct costs because of their condition. To help tackle these issues, our advocacy team helps them get the benefits, care and services they are entitled to. We also advise on housing adaptations and education support. This year we **supported 920 people**, securing **£754k** worth of support for them.

Thanks

Generous funding from the Bank of Scotland Foundation, the Northwood Charitable Trust and the Templeton Goodwill Trust enables us to support people in Glasgow and reach out to more people living in the north of Scotland.

Equipment grants

Through the Joseph Patrick Trust (JPT), we gave **£331k in grants** that provided 236 people with practical aids, equipment and assistive technology to improve their quality of life. JPT expanded its range of grants to include smart home and environmental controls to support everyday living.

Bringing people together

Our regional network of muscle groups continues to grow, enabling people to share their experiences and discuss local and national issues that affect them or that are a barrier to living independently. We also held two family fun days that attracted over 250 people, over half being new to the charity.

Thanks

We're able to run these groups across the country thanks to support from the Lawson Trust, the Liz and Terry Bramall Foundation, The George A Moore Foundation, the Sylvia and Colin Shepherd Charitable Trust, the Patricia and Donald Shepherd Charitable Trust, the Annie Tranmer Charitable Trust, the Charles S French Charitable Trust, The Fowler, Smith and Jones Trust, the Lord Belstead Charitable Trust.

Changing Places toilets

People with disabilities often need extra equipment and space to allow them to use toilets safely and comfortably.



We continued to lead the Changing Places consortium of charities campaigning for more accessible toilet and changing facilities in public places. There are now **1,263 registered Changing Places toilets** across the UK and we secured a significant partnership with the Department for Transport to administer a £2m grant programme to ensure there are adequate Changing Places facilities in motorway service stations in England.



Photo © Chris O'Donovan/MDUK

Supporters trying out assistive technology at the MDUK Information Day in Cambridge in February

£2m grant
to ensure adequate Changing Places facilities in motorway service stations in England



Young campaigners

Trailblazers is a network of **783 young disabled** people who work to remove the barriers to living full and independent lives. The Trailblazers' Moving Up work experience scheme for young disabled people has **supported 36 young disabled people**, over 60 percent of whom have gone on to find paid work or education.

Engaging volunteers

We rely on the fantastic support from volunteers for much of our work. This year we began an

exciting programme of work to ensure we're properly supporting our volunteers and to explore how we can increase the reach and impact of our support services by placing volunteers at the heart of their delivery.

WHAT WE'LL DO NEXT

Improving quality of life by enabling independent living. We will:

- improve the reach and quality of our advocacy support
- identify the injustices and barriers to full participation in society that people affected by a muscle-wasting condition experience and campaign on key issues to bring about lasting change
- provide direct financial support to help people meet the costs of equipment and adaptations
- secure improved access to Changing Places toilet facilities through Muscular Dystrophy UK's leadership of the Changing Places consortium.



Sheila Hawkins, MDUK Trustee, with granddaughter Willow

Thanks

Last year the Bupa UK Foundation funded our new programme of wellbeing camps for young people living with muscle-wasting conditions. They were so excited to hear of the camps' success that they committed a second grant this year to offer this fulfilling experience to even more young people.

Changing the landscape for disabled people



Conrad Tokarczyk

“Trailblazers campaign on issues that matter most to young disabled people and the real-life experiences of disabled people are at the heart of every campaign.”

This is what appealed to Conrad Tokarczyk when he came across Trailblazers in 2014. A graduate in health sciences who has previously worked for the NHS, he’s been a Trailblazer ever since.

“I got involved with Trailblazers’ employability project by sharing my experiences of the barriers I’ve faced as a disabled person looking for employment. I thoroughly enjoyed the Working Group sessions hosted by Emma Vogelmann, Trailblazers

Employability Officer, and this strengthened my desire to become more involved with the group.

“On many occasions I’ve gone to job interviews only to discover I couldn’t get into the building or park my car. I’ve lost count of the number of times I’ve been offered a job/interview, only to have to pass because of access issues. I hoped that by sharing my experiences, I could play a small part in breaking down barriers and help to **create a brighter future for young disabled people.**”




 Trailblazers has taught me that when enough strong-willed people with a shared objective work together, you can achieve anything.”

Photo © Chris O'Donovan/MDUK

“Trailblazers has taught me that when enough strong-willed people with a shared objective work together, you can achieve anything. They successfully collaborated with software giants **Microsoft** to launch the very first adaptive controller, and with social media giant **Twitter** to implement more robust measures to protect disabled people from online abuse.

“The **Ready and able** report – the result of Trailblazers work with young disabled people and employers – contains a number of recommendations. I believe Trailblazers will successfully collaborate with policy-makers, Government and employers to break

down barriers to employment and, if some of the recommendations are implemented, Trailblazers once again will have changed the landscape for disabled people.”

Thanks

The Employability Project was funded by generous long-standing supporter the City Bridge Trust. This complements and adds value to the work experience programme they support through Moving Up.

Your support of our vital work

What we achieved in 2018/19

Together you've raised a **whopping £6,628m** during the past year.

The dedication and generosity of our supporters makes everything we do possible. You are vital to ensuring more people with muscle-wasting and associated conditions can enjoy better lives every day. Thank you to all of our amazing fundraisers, volunteers, donors, campaigners and those who are changing their communities.

More than 9,000 people got involved in events across the UK. And thanks too for the support of our corporate partners, trusts and foundations, our branches, family funds and other fundraising groups. We're also incredibly grateful to those who chose to remember MDUK with a gift in their Will.

You're all helping to make every day count for people living with muscle-wasting conditions in the UK today.

- 62 people jumped out of planes and **raised a breath-taking £70,705**
- **28,403 people helped** their schools and workplaces Go Orange for a Day and **raised £36,250**
- **120 runners** took part in the Great North Run and raised **a record £75,835**
- **7,704 people** took part in six different challenge events
- 1,386 guests attended a range of special events **raising £530,000**
- A dinner featuring MDUK Ambassador and Masterchef finalist Nawamin Pinpathomrat, and the friends and family of one of our key supporter family funds **raised £50,000**
- Our Family Funds and branches **raised £500k**
- **120 runners** took part in the London Marathon and **raised £320k**

£500k raised
by Family Funds
and branches



£50k raised
at a dinner featuring
Masterchef
finalist Nawamin
Pinpathomrat



£784k
raised by you
taking part in
runs UK-wide



£530k raised
from guests
attending special
events





Ox Close Primary School goes Orange for a Day



Supporters at the MDUK Celebrity Sports Quiz at Lord's



Andrea of #TeamOrange at the London Marathon



Clare Balding, Jon Richardson and Martin Hywood at the 2018 BGC Charity Day

Photo © Kiri Studios Photography and Film/MDUK

Photo © Chris O'Donovan/MDUK

Working together to change lives



Thomas Savill, then MDUK Corporate Development Executive with Martin Donnelly of Matalan

For us at MDUK, corporate partnerships are much more than big cheque presentations; they're about people getting together to change lives. The majority of our current and previous partnerships have been generated by our families, supporters, trustees, and employees.

These are people who know our charity well, who want to get involved in something really worthwhile and who can inspire their friends and colleagues to get involved too.

Here's one example of how that happens.

Rubik's Cube produce MDUK-branded keyrings for us to sell in **Matalan stores**, thanks to a long-term supporter's relationship with Matalan.

The keyring proved popular; it increased awareness of the Rubik's brand, its association with MDUK, and raised more than £150k.

Mike Townend, then CEO of Rubik's Cube, talks about how and why he wanted to support MDUK:

"After a classmate of mine sadly died from muscular dystrophy, my whole family became lifelong supporters of the charity, including my 84-year-old



 The impact that MDUK has on children and families certainly aligns with one of our key values of 'Think Family'.

Photo © MDUK

mother, who still collects. Having run the London Marathon for MDUK in 2017, I was reminded of the charity's amazing and essential work.

"Rubik's are delighted by the generosity and support of Matalan; this three-way partnership provides 'win-win' for everyone.

"In a busy and highly commercial world, it is rewarding and motivating to take time out to help and support a charity like MDUK.

"It also gives employees a sense of pride in the company they work for, to know that it has a sense of social responsibility."

Martin Donnelly, Senior Retail Operations Manager at Matalan, has been involved in fundraising for MDUK for many years:

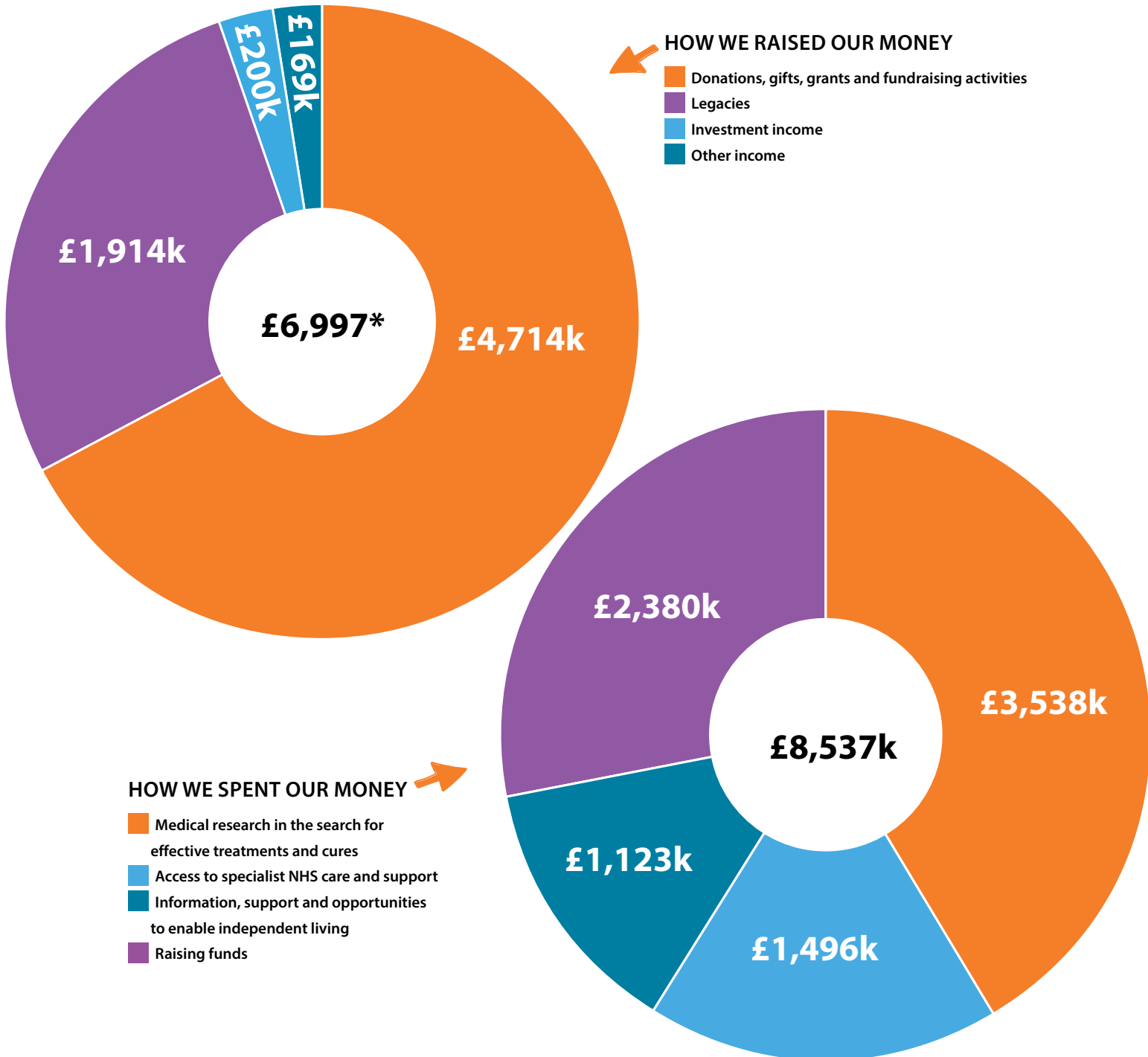
"As a family value retailer, it is important for us that the fundraising we do is compelling to our colleagues and customers. The impact that MDUK has on children and families certainly aligns with one of our key values of 'Think Family'.

"The partnership has involved some of our stores selling Rubik's Cube keyrings, and it has certainly been a success. The iconic recognisable product is fantastic to support fundraising. Our customers are getting a great quality, pick-up line and feel they are making a generous donation to a really worthwhile charity."

Our finances

Thanks to the generosity of individuals, families, branches, groups, corporate partners, trusts and foundations, as well as continuing support from legacy donors, and those who took part in MDUK events across the UK, the year ended as planned.

This included a planned deficit, to bring our unrestricted reserves back to our £1.6m target for the development of our charitable activities in the years to come.



*In addition to our regular income of £6.9m, we also received £2m to be distributed on behalf of the DfT to expand the availability of Changing Places toilets across the motorway network in England.

Our full set of accounts is available upon request, or from www.muscular dystrophyuk.org/publications/impact-reports

Here for everyone

There are an estimated 70,000 people in the UK living with any one of 60 different muscle-wasting and associated conditions. At MDUK, we believe everyone living with a condition should have what they need to live full and independent lives. Here are some of the ways we supported people during 2018/19:



25,000

understand more about their condition after downloading info factsheets

3,000

visited our online forum to support each other and talk about the things that matter to them



415

learnt more about relevant research and clinical trials by speaking to our Research Line team

50

world-leading research projects currently in progress in the UK and internationally

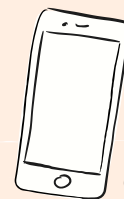
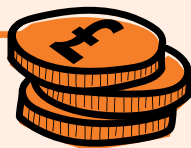


920

got the care and services they're entitled to after getting advice from our team

236

able to live more independently, thanks to JPT grants for specialist equipment



21,710

got practical support and expert info from us online, over the phone, in communities, in hospitals

783

Trailblazers get to challenge the barriers stopping them leading full and independent lives



Thank you

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

Alexander Acloque
Anderson Strathern
APL
BGC International L P
Bill and Jacky Ronald
Bolt Burdon
Brit Insurance
CeX
Charles and Nicola Manby
Comic Relief
Dan and Claire Parker
Frances Carey
Full Story Marketing
Gill and George Hubb
Henry Oldfield Trust
Hogan Lovells
Ian and Ann McNeil
Jeremy and Mary Champion
John Booth Charitable Foundation
John G. Watson
MAP Nemaline
Matalan Retail Limited
McBains
Mrs Gladys Row Fogo Charitable Trust
OneFamily
Old Mutual Wealth
PTC Therapeutics
Peter and Frances Meyer
Portview
Mayo Marriott
Mackies's Taypack
Oison Crawley
Rubik's Cube
Sally Whittet
The 41 Club
The Annandale Charitable Trust
The Belfast Cathedral Sitout
The Barbour Foundation
The Broughton Charitable Trust
The Charles and Elsie Sykes Trust
The City Bridge Trust
The Constance Travis Charitable Trust
The Cranbury Foundation
The D'Oyly Carte Charitable Trust
The Eveson Charitable Trust
The Ian Fleming Charitable Trust
The Inman Charity
The Northwood Charitable Trust
The Sir Samuel Scott of Yews Trust
The Templeton Goodwill Trust
The William Allen Young Charitable Trust
Tony and Monica Moorwood
The Exilarch's Foundation
The Adint Charitable Trust
The Albert Edward Procter Charitable Trust
The Ann Jane Green Trust
The Annett Charitable Trust
The Annie Tranmer Charitable Trust
The Bank of Scotland Foundation
The Boost Charitable Trust
The Chapman Charitable Trust
The Charles S French Charitable Trust
The Clapp Family Charitable Trust
The D D McPhail Charitable Settlement
The Denley Family Settlement
The Dudley and Geoffrey Cox Charitable Trust
The Fowler, Smith and Jones Trust
The George Moore Foundation
The Gordon Fraser Charitable Trust
The Grace Trust
The IBB Trust
The JK Young Endowment Fund
The JAH Trust
The James Weir Foundation
The JFH Wiseman Will Trust
The Joseph Strong Fraser Trust
The Lawson Trust
The Liz and Terry Bramall Foundation
The Lord Belstead Charitable Trust
The Lord Faringdon Charitable Trust
The MEB Charitable Trust
The Melville Charitable Trust
The N Smith Charitable Settlement
The Norah and Fred Roberts Memorial Trust
The PF Charitable Trust
The Patrick Trust
The Roger Vere Foundation
The Sir Edward Lewis Foundation
The Sir James Knott Trust
The Sir James Roll Charitable Trust
The Sir John Fisher Foundation
The Sunrise (Sidmouth) Charitable Trust
The Thomas Sivewright Catto Charitable Trust
The Tilehouse Trust
The Tom and Sheila Springer Charity



Soho Coffee Co. teamed up with and fundraised for MDUK

Thanks



who year on year raise funds for MDUK at their Christmas Gala



who support MDUK in more than 300 stores



whose fantastic employees and supporters have raised over £350k



who introduced MDUK-branded Rubik's Cubes into Matalan stores to boost income



for the honour of being chosen again as a BGC Charity Day beneficiary



who support our campaigning activities



who produced a special flavour of crisps and donated a percentage of the income to us



for raising over £64k for us in memory of their late colleague Simon

We're hugely grateful 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, The Clay Pigeon Shoot Committee and the Appeal Board.

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

Muscular Dystrophy UK relies almost entirely on voluntary donations and legacies to fund our vital work. We receive no government funding for our core charitable activities. Our Campaigns, Care

and Support team is currently administering a grant provided by the Department of Transport to expand the availability of Changing Places Toilets across the UK motorway network.

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.

Royal Patron

HRH The Prince Philip, Duke of Edinburgh KG KT

Patrons

Professor Alan Emery
Ian Corner
Bill Ronald
Sir Sydney Samuelson CBE
Keith Rushton

President

Gabby Logan (since October 2018)
Sue Barker OBE (until October 2018)

Honorary Life Presidents

Sue Barker OBE (since October 2018)
J Alexander Patrick CBE DL
Professor Martin Bobrow CBE FRS FMed Sci

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Karen Attenborough
Sophia Bergqvist
Frances Carey
Jeremy Champion
Candida Crewe
Charity Crewe
Sebastian Crewe
Sir Alex Ferguson CBE
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Sarah Kelly
Simon Knights
Charles Manby
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Senior Leadership Team

Robert Meadowcroft, Chief Executive Officer
(until September 2018)
Catherine Woodhead, Chief Executive Officer
(from September 2018)
Dr Kate Adcock, Director of Research and Innovation
Rob Burley, Director of Campaigns, Care and Support
Nikki Hill, Director of Communications and Marketing
Alec Raven, Director of Development
Jenny Howard, Director of Finance
(until March 2019)
Wojtek B Trzcinski, Finance and Resources Director
(from July 2019)

Remembering Peter Andrews who was honoured to take on the role of Patron shortly before his death in February 2019 following lifelong support of MDUK.

Our 2018/19 Financial Statements are available upon request. Download a copy from our website at www.muscular dystrophyuk.org/publications/impact-reports 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)



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