Muscular Dystrophy UK

Fighting muscle-wasting conditions

Making every day count

Impact report 2019/20

About us

Muscular Dystrophy UK is committed to creating a future where there are effective treatments and ultimately cures for all muscle-wasting and associated conditions and no limits in life for people who are affected. This vision drives everything we do; even more so today than when we began over 60 years ago.

This vision unites our UK-wide community of people: from the researchers we support, to the healthcare professionals we work with; 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.

A diagnosis of muscular dystrophy can change everything, and it can often help to talk to someone about it. Our team is here, from the moment of diagnosis, to help people take back some control of their lives and live well with the condition.

There can often be challenges when you live with a such a rare condition. That's why we offer information and advice, emotional and practical support, a network of local groups and an online community to interact with. And we'll help you get the care, support and equipment you're entitled to.

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.

Remembering Alexander Patrick CBE DL

It was with immense sadness that we learned of the passing of Alexander Patrick in April 2020. Alexander, an Honorary Life President of MDUK, made a huge, life-long contribution to the fight to beat muscle-wasting and associated conditions. His brother, Andrew, had Duchenne muscular dystrophy and died when he was just 13 years old. Their father, Joseph Patrick, became one of the three founders of what was first known as the Muscular Dystrophy Group, in 1959. Alexander's generous long-term support has contributed to the potential treatments we're seeing today, and the Joseph Patrick Trust that he established has awarded grants to thousands of people to buy the equipment they need to live independently. We will be forever in his debt.

On the cover: Four-year-old Aadi Wilson, who has spinal muscular atrophy (see p10)

Welcome

Welcome to our impact report, in which we report on a year of pace and change on a different scale from previous years. After starting with our usual determination to find effective treatments and cures and remove the barriers that stop people living full and independent lives, the year ended with us all in lockdown, facing uncertainty as the COVID-19 pandemic touched every area of our lives.

After being on track to achieve our income target for the year, we felt the significant and immediate impact of the pandemic. We ended the year £383k below target, with an estimated £2.8m drop in income against our 2020/21 budget.

We moved quickly to adapt to the new landscape, with an effective risk management policy and a multi-pronged approach. We established a Board Emergency Sub-Committee who worked with our Senior Leadership Team to mitigate the impact of the pandemic, we launched a programme of virtual services and fundraising events, initiated a clinical advisory group, and created a consortium of nine neuromuscular charities to ensure we had accurate and clear guidance to share with our community.

We also had to respond quickly to the financial impact, by reducing expenditure and overhauling the budget. In May 2020, we had to make the difficult decision to restructure the charity from 85 to 55 staff members, creating a new financial model for long-term sustainability. We deeply regretted having to say goodbye to valued staff.

You'll see, in reading this report, that we remain as committed as ever to making every day count for people with muscle-wasting and associated conditions.

In 2019/20, we funded nine new research grants, bringing our portfolio to 50 projects into 14 different conditions. We've been involved in the early stages for access to Namuscla for non-dystrophic myotonia, Raxone for Duchenne muscular dystrophy, and Zolgensma and risdiplam for spinal muscular atrophy.

We were also delighted to see the appointment of Prof Laurent Servais as Professor of Paediatric Neuromuscular Diseases at our MDUK Oxford Neuromuscular Centre.

In our work with specialist neuromuscular services we secured 11 new NHS-funded roles, representing a total NHS investment of £6.9m per year. Our advocacy team secured over £1.5m worth of benefits, equipment and services for people with muscle-wasting conditions. This reflects the scale of challenges many face in getting the support they're entitled to. We raised these concerns directly with ministers when we presented our report highlighting the experiences of 600 people living with muscle-wasting conditions, and we'll continue to raise these concerns to make the systems fit-for-purpose and reduce the anxiety and stress they cause.

At our 2019 National Conference in October, we marked 60 years of progress, bringing promising therapies, an explosion of clinical trials, and better support and care. We've also seen improved life expectancy, and a greater awareness of the rights of disabled people enshrined in law. We recognise there's still so much more to do, and we simply couldn't do it without your valued support.

We'd like to thank our President, Gabby Logan MBE, along with our wonderful volunteers, fundraisers, supporters and donors who have graciously given their time and money during the year, and our dedicated Trustees and staff team. The support from every one of you, particularly during the pandemic, has helped to make every day count for people living with muscle-wasting and associated conditions.

Catherine Woodhead, Chief Executive

Prof Mike Hanna, MDUK Chair

Searching for treatments and cures

What we achieved in 2019/20

MDUK is committed to working towards a future with effective treatments and ultimately cures for all muscle-wasting and associated conditions.

With your generous support, we were able to fund nine new research projects and PhD studentships, bringing our portfolio to around 50 projects into 14 different conditions.*

Harnessing the power of genetics

MDUK-funded researchers published a paper showing they could correct a mutation commonly found to cause Ullrich congenital muscular dystrophy (UCMD). Using two genetic tools – exon skipping and genome editing – Prof Carsten Bönnemann (NIH, US), Prof Francesco Muntoni (University College London) and others designed molecular patches and molecular scissors to remove the exon from the gene message, resulting in improved assembly of the collagen VI scaffold outside the cells. Further research could lead to the development of a potential treatment for UCMD.

Thank you

Thanks to all the families who fundraise for this important UCMD research

Improving the quality of life

Cough assist machines are an important element of care for some people whose muscle-wasting conditions cause respiratory weakness. Dr Patrick Murphy, in his MDUK-funded project at Guy's and St Thomas's Hospitals, is using an artificial lung to identify optimal settings for clinical benefit.

MDUK funds
50 research grants into 14 conditions

Keeping families up to date with MDUK-funded research projects

Photo © Chris O'Donovan/MDUK

* As our Chief Executive mentioned on p3, MDUK had to respond quickly to confront the huge and immediate impact of the COVID-19 pandemic on our income. We had to make many difficult decisions, including withdrawing a small number of grants and cancelling our 2020 grant round.

MDUK-funded researchers at Royal Holloway, University of London

Photo © Chris O'Donovan/MDUK

Promoting innovation and partnership

As an executive member of the European Neuromuscular Centre (ENMC), MDUK supported the ENMC to present eight workshops in 2019/20, seven of which included UK clinicians, researchers and patient representatives.

Encouraging innovation in neuromuscular research

In 2019/20, we awarded a grant to Dr Arianna Fornili at Queen Mary University of London to support a PhD student to screen for molecules that alter myosin function, using state-of-the-art computational methods. This work could lead to the development of potential treatments for nemaline myopathy.

Prof Laurent Servais, Professor of Paediatric Neuromuscular Diseases at the MDUK Oxford Neuromuscular Centre

WHAT WE'LL DO IN 2020/21

- Continue to focus on the high-quality research we are already supporting to understand the underlying causes of muscle-wasting conditions.
- Continue our support for PhD studentships and encourage scientists with new ideas and technologies to come into this area of research. By building on existing scientific study to develop a new generation of therapies, the ultimate goal is to treat all people, whatever their muscle-wasting condition.
- Use seed funding to drive innovation and influence our partners and others to do the same. Through a new partnership, we will work with Healx to deliver treatments for facioscapulohumeral muscular dystrophy (FSHD). Healx uses artificial intelligence (AI) technology to identify existing drugs to repurpose and combine to treat rare conditions.
- Help meet growing demand by facilitating access to clinical trials through our investment in the MDUK Oxford Neuromuscular Centre.
- Continue our support for patient registries.

Thank you

We're grateful to all of our fundraisers whose generous support helps to push forward MDUK's groundbreaking research.

THE MDUK OXFORD NEUROMUSCULAR CENTRE

Prof Matthew Wood, Director of the MDUK Oxford Neuromuscular Centre and Professor of Neuroscience at the University of Oxford

Photo © Kii Photography/MDUK

A partnership between MDUK and the University of Oxford, the MDUK Oxford Neuromuscular Centre aims to drive research into potential treatments from the lab into the clinic. The Centre's Director is Prof Matthew Wood, and in September 2019 Prof Laurent Servais joined the team as Professor of Paediatric Neuromuscular Diseases.

Expanding the Centre's research portfolio

Two of the Centre's researchers received MDUK grants in the past year to investigate new methods for the delivery of treatments for neuromuscular conditions.

Dr Suzan Hammond is developing molecular patches for SMA that can cross from the blood into the central nervous system. This research could lead to potential treatments that are easier to receive than others, such as Spinraza.

Prof Matthew Wood and his team are investigating new delivery methods for gene therapy. While focussing on gene therapy for Duchenne muscular dystrophy, the project's findings will be valuable for the development of gene therapies for other muscle-wasting conditions.

A new chapter in the utrophin story

Prof Angela Russell and Prof Dame Kay Davies and their teams have been working on ezutromid. This drug was designed originally to treat Duchenne muscular dystrophy, by increasing the amount of utrophin (a protein related to, and with the potential to act as a substitute for, dystrophin).

The Oxford teams' work could provide a new lead for the development of utrophin replacement therapy.

Good news for myotonic dystrophy research

With MDUK funding, Prof Matthew Wood and his team have shown that a new type of molecular patch is beneficial in a mouse model of myotonic dystrophy type 1.

They have developed a new type of molecular patch linked to peptides (protein fragments), which could penetrate cells more efficiently. In the mouse model, the patch was able to get into the muscles, heart and diaphragm, and it reduced myotonia. There needs to be more research before the patches reach the clinic, but these are encouraging steps towards developing a potential treatment.

Thank you

Thanks to our supporters' hard work and outstanding fundraising, in early 2020 we reached the £1.0m mark towards our commitment to the MDUK Oxford Neuromuscular Centre. The Q Trust, a group of long-term supporters who hold a number of events to support MDUK in memory of their friends Quentin Crewe and Mark and Jemima Reynolds, led the fundraising for this vital project.

Driving change for specialist care and support

What we achieved in 2019/20

Time is precious when you're living with a muscle-wasting condition; it's important drugs and treatments get to those who need them, as quickly as possible. MDUK has continued to play a role in influencing change and removing barriers that stop people with muscle-wasting conditions from getting what they need to lead full and independent lives.

Bringing together clinical teams and families at The Robert Jones and Agnes Hunt Orthopaedic Hospital, which MDUK recognised as a Centre of Clinical Excellence in 2019

Photo © The Robert Jones and Agnes Hunt Orthopaedic Hospital

Access to treatments

At the start of 2019/20, NICE approved Spinraza, the first treatment for people with spinal muscular atrophy (SMA) types 1, 2 and 3. Approval came first in Scotland, followed by England, Wales and Northern Ireland. This was great news for many individuals and families with SMA, who had campaigned long and hard for this with us, other charities and clinicians.

In England, Spinraza is available through a managed access agreement (MAA). We're pleased to play a key role on the Managed Access Oversight Committee (MAOC), to identify any issues in implementing the MAA and make sure the data collected can help secure permanent access to the drug.

We are also a member of the MAOC for Duchenne muscular dystrophy treatment, Translarna, and this year have been involved in the early stages of the approval processes for:

- Namuscla, for non-dystrophic myotonia
- Raxone, for Duchenne muscular dystrophy
- Zolgensma and risdiplam, for SMA.

Investment in specialist roles and services

When you live with a rare muscle-wasting condition, it's often difficult to get access to the specialist support you need. That's why we've continued to work with specialist neuromuscular services to make sure this situation changes. In 2019/20, we secured **11 new NHS-funded roles.** Since 2013, we've secured **102 new specialist neuromuscular roles** and **saved 16 from being lost** to the NHS, representing a total **NHS investment of £6.9m per year**.

102 specialist roles secured via NHS funding since 2013

Supporting the development of healthcare professionals

In our work to make sure people living with muscle-wasting conditions receive the best possible care, we present a programme of events for specialist

Individuals and families joined MDUK and other charities to campaign for approval for Spinraza

Photo © Chris O'Donovan/MDUK

neuromuscular healthcare professionals. This includes national conferences for care advisors and physiotherapists, various regional and online training opportunities. During 2019/20, **332 healthcare professionals** took part in our events, and **more than 2,300** took our online training modules.

Influencing governments

Before the December 2019 UK General Election, we launched our *Manifesto for Muscles* to highlight how MPs could best support people in their communities living with muscle-wasting conditions. Of the 248 candidates who pledged their support for the manifesto, 39 were elected to the House of Commons. This gives us a strong base of support to help influence key issues over the next few years.

We continue to provide support for the cross-party groups on muscular dystrophy in the Houses of Parliament, Scottish Parliament, Welsh Parliament and Northern Ireland Assembly. In this way, we can ensure issues affecting people with muscle-wasting conditions remain high on the political agenda across the UK.

Thank you

Without the generous support from Simplyhealth Community Fund, The Pixel Fund, BUPA UK Foundation and Comic Relief Tech for Good, we wouldn't have been able to make the progress we have in ensuring people with muscle-wasting conditions have access to the support and services they need.

WHAT WE'LL DO IN 2020/21

- Continue fighting for faster approval and availability of new treatments.
- Support healthcare professionals to offer high-quality care.
- Use our influence to increase the availability and quality of NHS specialist support.
- Collaborate with neuromuscular specialist services to address the impact of COVID-19 on the vital NHS services for people with muscle-wasting conditions.

He deserves the very best

"We're lucky to have such a beautiful son, and he deserves the very best. We'll do everything to give him the greatest life we can."

Mark and Panna Wilson joined MDUK, other charities, clinicians and families like theirs to campaign for the spinal muscular atrophy (SMA) treatment, Spinraza, to become available. Aadi, their four-year-old son, has SMA.

The campaign continued for 18 months – a long and often emotional process – before NICE approved the drug for use in England.

"The delays were incredibly frustrating and completely unnecessary. When we recount the story to our friends, they can't believe how slow the whole process was. We were overjoyed when NICE approved Spinraza's use.

"We have to travel to Sheffield for Aadi's treatment as our local NHS trust in Leicester cannot deliver it. Aadi keeps us positive and, like him, we face every challenge with a determination and a smile," said Mark.

Spinraza is the first treatment for SMA types 1, 2 and 3. The treatment first became available in Scotland in 2018, and NICE approved it for use in England through a managed access agreement (MAA) in 2019. Families in Wales and Northern Ireland now have access to the drug too. Access to Spinraza is currently available to those who meet certain criteria, which MDUK is seeking to expand.

"Aadi keeps us positive and, like him, we face every challenge with a determination and a smile."

The Wilson family

Living well with a muscle-wasting condition

What we achieved in 2019/20

Being diagnosed with a muscle-wasting condition can mean adjusting to a new and unexpected reality, so it's important to have easy access to the information and support you need. That's 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 supported people with muscle-wasting conditions by providing information, practical advice and support, and listening to people's concerns. The team supported **1,009 people over the phone**, **1,118 people on email** and **1,098 people with face-to-face advice and support** in neuromuscular specialist clinics.

£1.5m+
secured in benefits, equipment and services; 985 more people supported to get what they're entitled to

Over 57,000 people visited our website's care and support areas and **downloaded 22,000 information factsheets**. In addition, **3,000 people shared experiences** and supported each other on our online forum. **More than 470 people** called our Research Line to find out about the latest research developments and clinical trials.

Advocacy

Our advocacy team helps people with muscle-wasting conditions to get the benefits, equipment and services they are entitled to, and advises on housing adaptations and education support. The growth in demand for this service continued, and **we supported an additional 985 individuals, securing more than £1.5m worth of support** for people using the service. This represents a seven percent increase in volume and more than double the total value of support our team secured in 2018/19.

Thank you
We were able to engage with more people living in Scotland thanks to the Northwood Charitable Trust's generous funding.


Building and strengthening relationships at MDUK events

Photo © Kit Photography/MDUK

Equipment grants

Through the Joseph Patrick Trust (JPT), we **supported 234 people** to improve their quality of life. We awarded grants worth a **total of £279k** for people to use towards the cost of vital practical aids, equipment and assistive technology.

Bringing people together

By bringing people together throughout the year, we provided opportunities for people to build and strengthen relationships with others who have muscle-wasting conditions. A total of **811 people took part** in our information and support events and membership of our **Muscle Groups grew to 3,071 people** during the past year.

In October, **312 people came together** at our National Conference to reflect on 60 years of progress since MDUK started. Our Facebook Live feed gave another 544 people the opportunity to join the event, too.

22,000 downloads of our information factsheets, helping people understand more about their condition


Supporters at our National Conference in London in October 2019

Photo © Chris O'Donovan/MDUK

Changing Places toilets

Some disabled people can't go out because standard accessible toilets don't meet their needs. Changing Places toilets do. Thanks to the work of the Changing Places Consortium, which we continued to co-chair, there are now:

- **1,483 registered Changing Places toilets** across the UK
- **16 new Changing Places toilets** at hospitals across 10 NHS Trusts
- Changing Places toilets in **almost 100 Tesco stores**.

We continued to administer the **Department for Transport's £2.0m grant** to increase the number of Changing Places toilets in motorway service stations in England.

Removing barriers

Many people with muscle-wasting conditions face barriers that stop them from living full and independent lives. In our work to influence decision-makers to remove these barriers, we campaigned for improvements to the benefits system and raised concerns about the employment experience of young disabled people.

We published two reports:

- *Below standard: MDUK's assessment of the benefits system*, for which 592 people with muscle-wasting conditions shared their experiences
- *Ready and able: Removing the barriers that prevent young disabled people from finding employment*.

Working with volunteers

An amazing army of volunteers support our work in many ways. We formed a Volunteer Steering Group to improve our support and their experience and, to help shape this work, we produced a volunteer handbook. We also piloted a range of volunteer-led support groups.

Thank you
We're grateful to The Patrick Trust for their generous support which enabled us to progress our volunteering project during the year.

WHAT WE'LL DO IN 2020/21

- Continue providing information, advice and advocacy support – needed more than ever, following the impact of the COVID-19 pandemic.
- Engage in the development of the UK Government's National Disability Strategy to ensure it helps to address the injustices and barriers to full participation in society that people with muscle-wasting conditions experience.
- Provide direct financial support to help people meet the costs of the equipment and adaptations they need.
- Secure improved access to Changing Places toilet facilities across the UK through our co-leadership of the Changing Places Consortium.

Changing the landscape for disabled people

> **“I feel the welfare system needs less judgement and more empathy for people needing financial support.”**
> Chloe Smith, Jenson’s mum

Jenson Schroeder

Chloe Smith knows what it’s like to struggle to get the benefits you’re entitled to. Mum and carer to four-year-old Jenson, who has an undiagnosed muscle-wasting condition, Chloe shares her experiences of a flawed system.

“Jenson is a joy to be around. Our perfect baby boy. He cannot talk other than to say ‘Mum’, and he’s unable to walk. He’s suspected to be on the autism spectrum, and although we’ve been referred to the autism team, there’s a two-year wait. In addition, he’s globally delayed, and entirely dependent on myself and his dad, Rikki.

“After Jenson’s diagnosis, I dropped days at work to care for him. This brought financial challenges, so I applied for the Disability Living Allowance.

“I found the whole process incredibly difficult. The form is detailed and specific, and I was upset and stressed as it was just after Jenson’s diagnosis. At that time, you don’t need additional pressure.

“I wasn’t offered help completing the form. And I couldn’t apply for the mobility component because Jenson wasn’t yet three, even though his diagnosis means he may not walk until he’s older, or even ever.

“I also wasn’t eligible for Carer’s Allowance as I’m just over the threshold, despite caring for Jenson 35-plus hours a week.

“We live in a first-storey flat and have to carry Jenson up the stairs to get to it. There’s no parking and, because it’s not big enough for all of Jenson’s equipment, we have to keep his walker at his grandmother’s house, six miles away. We applied for local housing but removed ourselves from the waiting list because of the stress it was causing.

“I’m so thankful MDUK is campaigning on this and raising awareness of what families like ours have to go through, and providing direct support to help people get the benefits they’re entitled to. I feel the welfare system needs less judgement and more empathy for people needing financial support.”

In addition to campaigning for improvements to the benefits system, MDUK can support you to get the benefits you’re entitled to. Contact us at info@musculardystrophyuk.org or on 0800 652 6352.

Your support of our vital work

What we achieved in 2019/20

The COVID-19 pandemic had a huge impact on our final end-of-year figures but with your support, we ended the year with a phenomenal £5.9m in fundraised income.

Thank you for everything you did to help people with muscle-wasting conditions enjoy better lives every day:

- a record **8,000+ runners** took part in MDUK's Oxford and Cambridge Newton Town and Gown runs
- The Q Trust Great Chefs' Dinner **raised £137k**, with support from Prue Leith, the Galvin Brothers, Margot Henderson, Rowley Leigh, Matthew Fort and Tom Parker Bowles
- 1,196 guests at a range of special events **raised £596k**
- 93 runners in the 2019 London Marathon **raised £287k**
- our biggest-ever team of runners **raised a record £109k** for us in the 2019 Great North Run
- **8,657 people** took part in six different challenge events
- 340 property industry guests at our annual Microscope Ball **raised a record £372k**
- 120 schools, businesses and individuals who took part in Go Orange for a Day and Go Bright in Scotland and Northern Ireland **raised £35k**
- skydivers across the UK **raised £80k**
- our Family Funds, branches and fundraising groups **raised over £349k**
- runners taking on local running challenges **raised over £42k**
- regional corporate companies **raised £86k**

£349k+ raised
by Family Funds and branches

£137k raised
at The Q Trust Great Chefs' Dinner with celebrity support

£287k raised
by runners in the 2019 London Marathon

£596k raised
from guests attending special events

Beverley Knight, Gabby Logan and Kirsty Gallacher take to the trading floor for MDUK at the 2019 BGC Charity Day

Photo © BGC Official photography

Over 5,000 runners line up for the start of the 39th MDUK Oxford Newton Town and Gown 10k

Photo © Kii Studios Photography and Film/MDUK

The property industry coming together for a record fundraising Microscope Ball at the Hilton, Park Lane

Photo © Kii Studios Photography and Film/MDUK

Nikita Ellithorn, one of our top #TeamOrange fundraisers at the London Marathon 2019

Photo © Vincent White/MDUK

Team GEFCO taking on Peddle Paddle Peak in the Lake District

Photo © MDUK

Roy Fenner, who lives in Derbyshire, started something big when he took on a challenge in 2018. He wanted to make a difference for his son and ended up inspiring his colleagues to do the same.

"My youngest son, Owen, is 16 and has SEPN1 myopathy, a rare form of muscular dystrophy. Like many parents, you want to try to help as much as possible, so I decided to take on a challenge that was hard for me.

"I took on the world's largest half-marathon – the Great North Run – in 2018. It was a fantastic day, my family supported me and a good friend ran with me.

"The fundraising support from friends and family was amazing, and then word of my challenge travelled quickly around GEFCO, the company I work for. GEFCO believes in support, and a senior director put out a note about my challenge among the 15,000 employees worldwide. Almost instantly, donations started coming in from around the globe."

Roy raised £5,870 and was a top #TeamOrange fundraiser in 2018.

"After the race, other colleagues said they'd like to do a charitable event for MDUK. In 2019, we entered a team in Pedal Paddle Peak (PPP) in the Lake District.

"Again, this was a fantastic experience and there's already enthusiasm for the 2021 event."

Roy introduced MDUK to the Marketing and HR team at GEFCO to collaborate and take on a challenge in 2019. After the success of the PPP event, GEFCO entered seven teams in a bespoke event for their staff, which went on to raise £7,215 for MDUK.

"Roy is one of a community of outstanding supporters for MDUK. Challenging himself with the Great North Run was one thing, but then he went that extra mile for us by taking on PPP with his colleagues. That was quite a few extra miles, to be fair!

"After the race, other colleagues said they'd like to do a charitable event for MDUK. In 2019, we entered a team in Pedal Paddle Peak in the Lake District. Again, this was a fantastic experience and there's already enthusiasm for the 2021 event."

"We're grateful Roy got his community of friends and colleagues involved in supporting something so personal to him. He's an inspiration to us, to his colleagues and friends, and to Owen. If you're reading this thinking you can take on a challenge and get your workplace to fundraise for us, please do get in touch!"
Krishan Solanki, MDUK Head of Events

Find out more at www.musculardystrophyuk.org/fundraising-events or get in touch with us at events@musculardystrophyuk.org

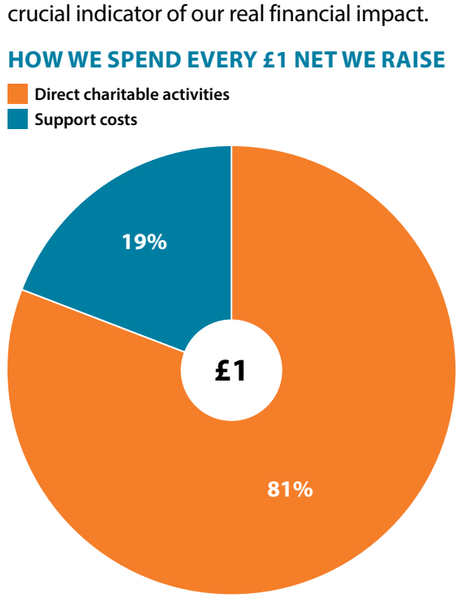
Our finances

Thanks to the generosity of all of our donors and event participants, as well as continuing support from legacy donors, we ended the year in a strong financial position, despite the challenges of the pandemic.

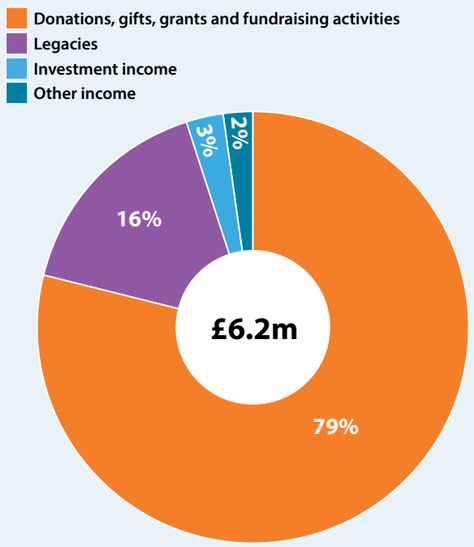
In 2019/20, we raised £6.2m, comprising £5.9m in fundraised income, £200k in investments and £100k other income, and we spent £6.3m. Our fundraising income was £383k less than planned as an immediate result of the pandemic and lockdown from March 2020. Our cost of raising funds was £2.3m; our cost of direct charitable activities £4.0m. On an operational level, we ended the year with a small deficit of £149k. However, the pandemic also brought investment losses of £473k, which resulted in an overall reduction in funds of £622k. Despite that, we still ended the year with £2.4m of unrestricted funds, comprised of £1.6m in designated and £842k in free reserve funds.

We continued to distribute the £2.0m grant on behalf of the Department for Transport to expand the availability of Changing Places toilets across England's motorway network. We also secured 11 new NHS-funded neuromuscular specialist roles. Thanks to MDUK's work in this area since 2013, the NHS is now investing an additional £6.9m per year in these services. While we don't reflect this figure in our financials, it's a crucial indicator of our real financial impact.

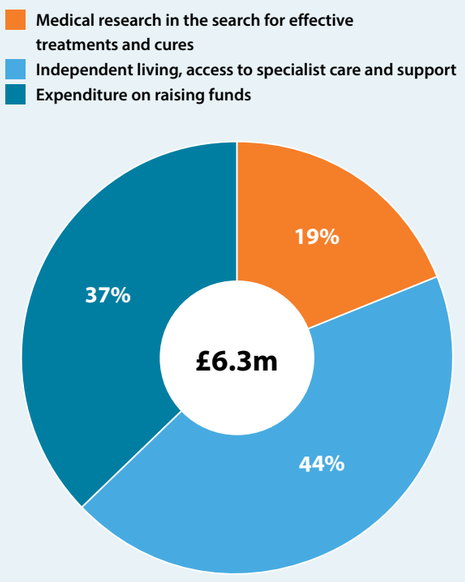
HOW WE SPEND EVERY £1 NET WE RAISE



HOW WE RAISED OUR MONEY



HOW WE SPENT OUR MONEY



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

Here for everyone

Here are some ways MDUK supported people living with muscle-wasting conditions to live full and independent lives, during 2019/20:

£6.9m per year
additional NHS investment to give more people access to specialist support across the UK

£1.0m
raised towards our commitment to the MDUK Oxford Neuromuscular Centre

3,000
visited our online forum to support each other and talk about the things that matter to them

470
learnt more about relevant research and clinical trials by speaking to our Research Line team

25,335
understood more about their condition or got support from us online, over the phone or in person

234
individuals able to live more independently thanks to JPT grants for specialist equipment

985
received the care and services they were entitled to after advice from our team

1,483
registered Changing Places toilets UK-wide, making it possible for more disabled people with complex needs to enjoy outings

£1.5m
worth of benefits, services and equipment secured for people with muscle-wasting conditions

MDUK currently funds 50 research studies into 14 different conditions

Every day, we're working towards a future with effective treatments and ultimately cures for all muscle-wasting and associated conditions, and we won't stop until there are treatments and cures for all. We cannot do this without your support.

Thank you

We're always immensely grateful to all our donors for your ongoing support but this year your commitment has gone way beyond anything before. The COVID-19 pandemic has upended the world, and you've helped us to rapidly adapt and respond to the huge and unavoidable gaps in our income. It's hard to put into words what your support, on every level, has meant. And on behalf of the community that relies on our services now, more than ever, we offer you a heartfelt thank you.

BGC Charity Day
Bill and Jacky Ronald
BUPA UK Foundation
Carpe Diem Santorini
CEX
Chapman BBDSP
Charles and Nicola Manby
Comic Relief
Dan and Claire Parker
Frances Carey
GEFCO
Invesco Perpetual
Jeremy and Mary Champion
John Watson and Janis Higgie
KPMG (Birmingham)
London Stock Exchange
Mackie's of Scotland
MAP Nemaline
MariaMarina Foundation
Matalan
Michelle Anthony
Michele and Dahlia Pucci
Newton
Next Plc
Odyssey
Pavers Foundation
RE & Newline Group
Redevco
Rubik's Cube
Sally Whittet
Simplyhealth Community Fund
SOHO Coffee Co.
The City Bridge Trust
The Constance Travis Charitable Trust
The Cranbury Foundation
The Estate of Peter and Nancy Andrews
The February Foundation
The Kilpatrick Fraser Charitable Trust
The Lennox Hannay Charitable Trust
The McAlister Family
The Northwood Charitable Trust
The Patrick Trust
The Pixel Fund
The Sir John Fisher Foundation
Tony and Monica Moorwood

While we cannot list every individual here, please know that we are grateful to every one of you for your support.

The Q Trust's Great Chefs' Dinner in 2019, hosted by Prue Leith

BGC Charity Day 2019

We were honoured that BGC invited us once again to take part in their 2019 Charity Day in London. BGC holds this event every year to honour colleagues lost in the events of 9/11, by distributing 100 percent of their global revenues made on the day to charities worldwide. Along with a number of MDUK families, our President Gabby Logan MBE (pictured right), Beverley Knight, Monty Panesar, Kirsty Gallacher, Lee Dagger and Sam Allardyce represented us.

Our committees

A special thank you to our Microscope Ball Committee, our Sports Quiz Committee, The Q Trust, The Clay Pigeon Shoot Committee, the Appeal Board, the Content Advisory Group, our branches, groups, Family Funds and every individual who fundraises for us. You play an invaluable role in communities across the UK.

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Our 2019/20 Financial Statements are available upon request. Download a copy from our website at www.musculardystrophyuk.org/publications/impact-reports.

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