

**Muscular  
Dystrophy UK**

Fighting muscle-wasting conditions



**An extraordinary year**

**Impact report**

**2020/21**

**Seventy-thousand adults and children in the UK live with a form of muscular dystrophy, which weakens the muscles in the limbs, heart and lungs. Imagine getting weaker every day, finding it difficult to walk, to stand, to laugh, to cough, to breathe. Until one day, it stops your heart. Too many children and adults die way too young. There's no cure. That's why we're so committed to funding research into treatments and improving access to specialist care, information and support for independent living.**

Our commitment to creating a future where there are effective treatments and ultimately cures for all muscle-wasting conditions and no limits in life for people living with them comes from a vision that drives everything we do. Even more so today than when the charity began more than 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 helpline 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 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're bringing forward the day when there are effective treatments available for all muscle-wasting conditions.

## Celebrating our Royal Patron, HRH Prince Philip



We were deeply saddened to learn in April 2021 of the death of His Royal Highness, Prince Philip, our Royal Patron. It's hard to put into words how privileged we feel to have had his unwavering support for more than 50 years. He took a genuine interest in the work of the charity, and was always keen to hear about the pioneering research we fund into treatments and cures for muscle-wasting conditions.

When Prince Philip became our Patron in 1966, very few people knew or understood what muscular dystrophy was. Over the years, he witnessed real advances in the search for treatments and cures, as well as in clinical support and care for people living with muscle-wasting conditions. We're grateful for the role he played in making this progress possible.

On the cover: seven-year-old Carmela Chillery-Watson, who has LMNA-CMD, and her dad, Darren, who was shielding last year to keep her safe from coronavirus

# Welcome



**Welcome to our impact report, in which we reflect on a very different year in the life of MDUK and, indeed, the world. Our year ended on a far more positive note than it started, and it's only with the dedication and support of our community, a community like no other, that we're able to look back on an extraordinary year and ahead with renewed ambition and determination.**

When the pandemic hit, it brought lockdowns, fear, panic and uncertainty. One thing we knew for sure was that MDUK had to continue to be there for our community at a time when, arguably, they needed us more than ever. We had to act quickly and pragmatically. Our Trustees supported us to come up with a plan that involved difficult decisions but enabled us to focus our energies on being there for our community. We reduced the size of our team, put more than half of our team on furlough, cancelled our new research grant round, and transferred our young campaigning network, Trailblazers, to pan-disability charity, Whizz-Kidz. This helped us keep our frontline services going, support our helpline team to work from home, and collaborate with clinicians and other charities to keep our community updated with coronavirus guidance and information.

Virtual connections became a vital lifeline. Not only in how we could continue operating as a charity, but in how our community responded to our Muscles Matter series of online seminars, and to our virtual fundraising events. We're proud of the MDUK team for their innovation and creativity in adapting, and are hugely grateful to our community for their extraordinary support. We were delighted that our wonderful President, Gabby Logan, our Vice Presidents, Ambassadors, volunteers, Trustees and celebrities went the extra miles for us too.

Despite the labs closing for a period, our long-term investment in research is paying off, and we remain on the cusp of change, with the fantastic news that seven new treatments emerged for a range of muscle-

wasting conditions (see p8). This is a result of the foundations charities such as ours have built over decades, with your support, and we'll continue fighting for access to treatments as they become available.

It will take time to recover fully from the effects of the £2.3m gap against the planned budget for 2020/21 that the pandemic brought, but with your support, we're able to invest in new high-quality research again. And, thanks to the passionate campaigning of the Changing Places consortium, which we co-chair, the government's £30m investment in Changing Places toilets in England will give thousands more disabled people access to a range of venues.

As a charity and a sector, we're also addressing the wider global issues of climate change and racism, diversity, equality and inclusion, by identifying what we can do to create a better, safer future for generations to come.

We'd like to thank every one of our valued donors, fundraisers, volunteers, our President, Gabby Logan, our dedicated Trustees, staff team and committees for your support. We're humbled and grateful for your help in making a difference, every day, in the lives of everyone in the UK who lives with a muscle-wasting condition. Throughout the report, we've shared thoughts from our community about our support and role last year. And I'm sure you'll all be proud to read of the progress made during a year like no other.



Catherine Woodhead  
Chief Executive

Prof Mike Hanna  
MDUK Chair

# Searching for treatments and cures

Accelerating research to develop effective treatments and cures

**The financial impact of the COVID-19 pandemic meant we weren't able to award any new research grants last year, and we had to withdraw a small number of grants too so we could focus on supporting as many of our ongoing research investments as possible.**

We know this was disappointing for our community, but we're pleased to report that research has been moving ahead in our 40 live projects in the UK and through international partnerships (see our feature on nemaline myopathy research on p5). And we will be funding new research grants again in the year ahead.

## UNITE-DMD moving ahead

Until April 2020, we were funding the UK clinical work of the UNITE-DMD study – an international collaboration on gene therapy for Duchenne muscular dystrophy. We're delighted that trial sponsors, Généthon, and their partners, Sarepta Therapeutics, have taken over financial support and are taking the trial forward with clinical research teams in France, the UK and other international sites.

## Encouraging communication and collaboration

During the past year, MDUK supported the European Neuromuscular Centre (ENMC) to present seven online workshops, many of which included UK clinicians, researchers and patient representatives. MDUK is an executive member of the ENMC, which exists to encourage and facilitate communication and collaboration in neuromuscular research among its members.

## Explaining research

Through our MDUK Research Line, we continued supporting people who wanted to find out about new studies, treatments and clinical trials for muscle-wasting conditions.

### Thank you to our community

You helped us to keep research moving forward.  
We achieve so much more when we work together.



**FROM OUR  
COMMUNITY**

**"MDUK and the info online has been amazing. It's made me feel as though there is still someone out there fighting for people like me."**





### Nemaline myopathy research

We held an international grant call for research into nebulin-related nemaline myopathy, in 2016. We funded two grants: one to Prof Carina Wallgren-Pettersson at the University of Helsinki and Samfundet Folkhaelsan in Finland, and the other to Prof Coen Ottenheijm at VU University Medical Centre, Amsterdam.

These grants, which have now ended, have improved our understanding of the condition, and provided new tools for diagnosis.

Dr Wallgren-Pettersson and her PhD student, Lydia Sagath (both pictured right, with MDUK Editorial Lead, Ruth Martin) have developed techniques to identify disease-causing mutations in the nebulin gene. **These faster and more sensitive diagnostic tools increase the chances of identifying the genetic cause of nemaline myopathy, and other neuromuscular conditions.**

Some of the techniques still need further development before use in a diagnostic lab.

Thanks to this research, we now know more about the interaction of nebulin with other proteins, and its role in the muscle. We also know how certain changes to the nebulin gene may cause nemaline myopathy. It's still early days, but this could lead the way for the development of treatment targets.

Prof Ottenheijm (pictured above left) and his team, in collaboration with other nemaline myopathy experts, investigated a particular process that breaks down proteins inside cells, called the ubiquitin-proteasome pathway. There is evidence to suggest that this process contributes to muscle wasting (known as

atrophy) in people with nebulin-related nemaline myopathy.

Using patient biopsies and mouse models, this project has given us a better understanding of the mechanisms that underlie atrophy in nebulin-based nemaline myopathy. Identifying MuRF-1 as an important protein in this process and as a potential target for therapeutic intervention opens the door for a new phase of research.

**The nebulin gene is large and has regions within it with multiple repeats of the same DNA code. Changes to the number of these copied regions (called copy number variations) can cause nemaline myopathy. This size of the gene and the presence of copy number variations make the study of the nebulin gene somewhat challenging.**



**“At a time when there were huge challenges to fundraising, MDUK was still able to do a research grant call again this year. It was a great achievement.”**

**“Helpful and knowledgeable as always and prompt in replying.”**

**“Always there when needed.”**

## MDUK Oxford Neuromuscular Centre

Since launching in 2019, the MDUK Oxford Neuromuscular Centre has grown to include 16 research groups spanning five University of Oxford departments and two services in the NHS Oxford University Hospitals Foundation Trust. The research focuses on a range of conditions, including muscular dystrophies, myopathies, neuromuscular junction disorders and channelopathies, and mitochondrial diseases.

With a mission to develop enhanced clinical trial capacity for adults and children, there are more than 10 clinical trials taking place at the Centre, although the pandemic has delayed the setting up of several of these trials.

After the first lockdown halted scientific research at the Centre, researchers now have access to the laboratory again and research has resumed.

## John Walton Muscular Dystrophy Research Centre, Newcastle

Over the years, we've supported several researchers at this Centre at Newcastle University, which Prof Volker Straub leads. The team has many research interests and we've supported several of their efforts, such as work using cutting-edge techniques in genetic sequencing and analysis to identify 14 new genetic changes that lead to limb girdle muscular dystrophy.

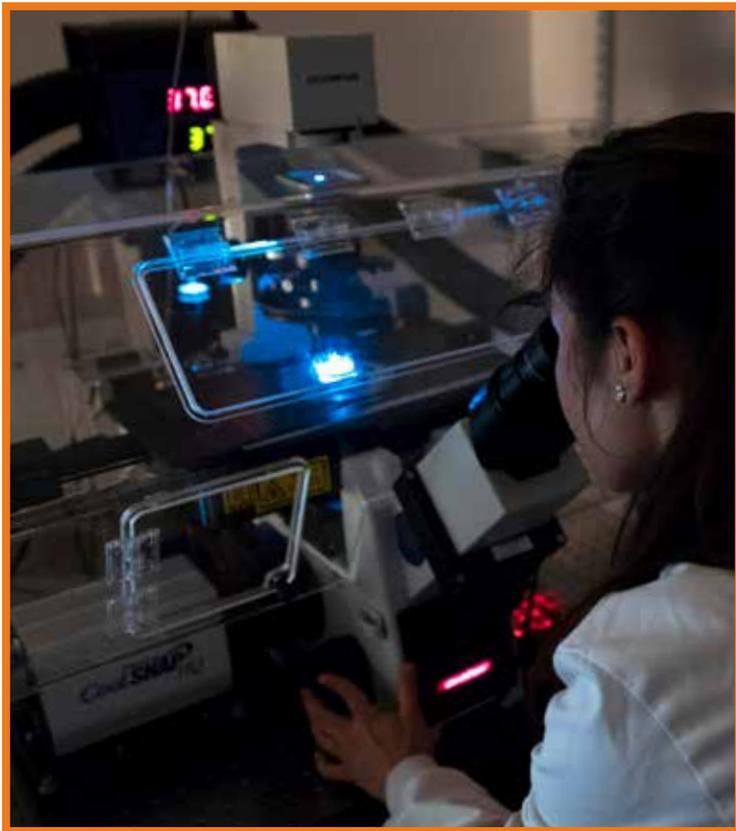
Other team members have been investigating a process called fibrosis – a symptom of many muscular dystrophies, which contributes to muscle weakness. Fibrosis happens when muscles become damaged and are replaced with fat and scar tissue, preventing them from functioning properly. The team has shown that with MRI, by using a substance that binds to areas of fibrosis, you can measure the progression of fibrosis, and assess response to treatments in a mouse model of Duchenne muscular dystrophy. Eventually, doctors could use this substance as a tool to measure drug response in human clinical trials, or monitor the health of people with neuromuscular conditions. But there's more work needed to make sure it's safe for human use.

As part of our commitment to supporting trial readiness, we also support four patient registries at Newcastle University:

- UK FSHD Patient Registry
- UK Myotonic Dystrophy Patient Registry
- Myotubular and Centronuclear Myopathy Patient Registry
- Global Registry for COL6-Related Dystrophies.

It can be difficult to find patients for trials for rare conditions, so we're very proud to support these registries. It's also an exciting time, with several clinical trials in the pipeline for many of these conditions.





## IN 2021/22, WE WILL:

- invest in high-quality research to understand the underlying causes of muscle-wasting conditions and harness the power of genetics, by funding a focused research grant round matched to the restricted funds we hold
- encourage scientists with new ideas and technologies into neuromuscular research, building on existing scientific study to develop a new generation of therapies, and supporting PhD students
- facilitate access to clinical trials through our investment in the MDUK Oxford Neuromuscular Centre
- support patient registries
- use seed funding to drive innovation and influence our partners and others to do the same; using core costs only, continue our partnership with Healx
- facilitate drug development and continue funding the NorthStar programme, the world's largest natural history study in Duchenne muscular dystrophy
- increase our understanding of the disease mechanism through our continued support of research projects
- improve the quality of life of people with muscle-wasting conditions, by developing evidence-based interventions, through our partnership with Healx.

**Despite the huge financial impact of the COVID-19 pandemic on our charity, we remain committed to campaigning for access to treatments. During the past year, we worked with individuals, families, clinicians and other patient groups through the assessment processes for seven new treatments, and engaged in the NICE methods review.**

## Spinraza

The first treatment for spinal muscular atrophy (SMA), Spinraza is now available to eligible people with SMA types 1, 2 and 3 through a Managed Access Agreement (MAA) in England, Wales and Northern Ireland, and through the ultra-orphan pathway in Scotland.

During the past year, we worked with other patient groups and clinical experts to press the NHS to extend the MAA's eligibility criteria to everyone who could benefit from it.

We're urging Trusts and Health Boards to extend the rollout to eligible adults, and hoping to secure permanent access to the treatment through our role on the Managed Access Oversight Committee (MAOC).

## Risdiplam and Zolgensma

Last year, SMA treatment Risdiplam became available across the UK, first through a Compassionate Use Programme and then through an Early Access to Medicines Scheme (EAMS). Together with patients and other charities, we successfully challenged some Trusts and Health Boards to implement the EAMS.

With SMA UK, we made a joint submission to the Scottish Medicines Consortium (SMC) for its review of SMA gene therapy, Zolgensma, representing patients at the Patient and Clinician Engagement meeting and at the New Drugs Committee. The SMC approved the treatment for NHS use and, after we engaged in the NICE assessment, it was approved for NHS access in England.

## Translarna

In our role on the MAOC for Translarna, a treatment for Duchenne muscular dystrophy, we:

- helped navigate the impact of COVID-19 on data collection in what was due to be the final year of the MAA
- called for an extension to the MAA
- kept families abreast of developments.

As 2020/21 ended, we welcomed the news that NICE, NHS England and NHS Improvement, along with manufacturer PTC Therapeutics, were exploring options to extend the MAA. In Scotland, we led a joint submission to the SMC by six charities after which the SMC made the treatment available through the 'ultra-orphan pathway'.

## Idebenone

Last year, the manufacturers of Duchenne muscular dystrophy treatment, Idebenone, halted access to it and withdrew plans to assess it through NICE. This followed an interim review they commissioned of clinical trial findings. We worked with clinicians and other charities to support those affected by this decision.

## Mexiletene

We represented patients during the SMC and NICE assessments of Mexiletene, a treatment for myotonia in adults with non-dystrophic myotonic disorders. The SMC approved it for use on the NHS in Scotland while the assessment process continues in England.

## Avalglucosidase alfa

We represented patients at the NICE Scoping Workshop for avalglucosidase alfa, a potential treatment for Pompe disease.

*Pictured opposite: eleven-year-old Luca Fernandes, who has Duchenne muscular dystrophy, has been on Translarna since September 2016*



# Driving change for specialist care and support

Influencing change and removing barriers that stop people with muscle-wasting conditions from living full and independent lives

We want to make sure people with muscle-wasting conditions receive the best possible care and support, so they can live well. This involves many different professional roles to identify and meet people's needs, from the point of diagnosis and throughout their lives.



## Access to specialist NHS care from a multidisciplinary team

Over the past year, we secured NHS funding for seven new specialist neuromuscular roles, including consultants, nurses and physiotherapists. Since 2013, we've helped secure **109 new specialist neuromuscular roles** in the NHS and **saved a further 16** from being lost. This represents a **total NHS investment of £7.5m per year** in specialist services that wouldn't otherwise be available.

We help specialist health professionals develop their skills and share best practice to give people living with muscle-wasting conditions the best possible care. During 2020/21, we adapted and ran many virtual meetings for our regional and national neuromuscular networks, and launched

an online professional development module for palliative care specialists. In total, **more than 2,000 health professionals** took our online training.

## Influencing governments

In our work to make sure issues affecting our community get political attention across the country, we support the cross-party groups on muscular dystrophy in the Houses of Parliament, Scottish Parliament, Welsh Parliament and Northern Ireland Assembly. In 2020/21, we got these key groups together for a number of virtual meetings.

**£7.5m per year**  
total NHS investment in  
specialist services



**FROM OUR  
COMMUNITY**

**"My specialist didn't know what to do – MDUK was more reassuring than everyone else."**



"We've always found MDUK to be a great example of a patient organisation supporting and empowering people to engage in the NICE appraisal process. Not only do members of MDUK's team appear before NICE committees, but they identify and support individuals directly affected by the conditions to give evidence too, by sharing their experience and views. It's a really effective approach and ensures that committee members hear the patient's experience and perspective, gaining an understanding of the broader experience of the whole community. This is best practice and serves people living with muscle-wasting conditions very well. We value MDUK's collaborative approach to working with us."

**Heidi Livingstone, Public Involvement Adviser, The National Institute for Health and Care Excellence (NICE)**

"We were extremely grateful to MDUK for the role they played during the pandemic, in co-ordinating communication between patient groups and neuromuscular specialist clinicians. Charities, like ours, and health professionals were inundated with requests for information and advice about coronavirus from people with muscle-wasting conditions, particularly in the initial stages of the pandemic. It was challenging for people to both interpret information being provided by the Government and to keep up to date with it. Having MDUK's support in relaying queries to health professionals, and agreeing positions on key issues that were then approved by neuromuscular experts, was invaluable."

**Liz Ryburn, Support Team Manager, Spinal Muscular Atrophy UK**

"As the pandemic began to unfold and little was understood about the risk to people living with muscle-wasting conditions, clinicians were inundated with questions from concerned patients and families. As group of clinicians, we were grateful MDUK took on the vital role of co-ordinating dialogue between us and the muscle-wasting community. This meant we could keep on top of supporting individual patients, while MDUK kept on top of producing and maintaining a central, easily accessible source of accurate, up-to-date and trusted information relating to coronavirus."

**Prof Ros Quinlivan, Professor of Neuromuscular Disease, Department of Neuromuscular Diseases at UCL Queen Square Institute of Neurology**



### **Thank you to our community**

By sharing your skills, your expertise, your knowledge, your lived experience, and your influence, you helped us to keep on top of COVID-19 guidance and advice. We achieve so much more when we work together.

**"Sharing information with our community demonstrated leadership for the whole muscular dystrophy community."**

**"Knowing MDUK was working so closely with clinicians and reacting with speed to what was happening in the news, made us feel a lot safer when it felt precarious for us at the time."**

**"I was impressed with MDUK working with other groups to get questions from the whole community and they were amazing at keeping clinicians involved."**



**FROM OUR  
COMMUNITY**

**"Successfully obtained PIP. The booklet  
very useful and the personalisation  
help via telephone very good."**





## IN 2021/22, WE WILL:

- **fast track access to treatments**, to get drugs from the lab bench to people with muscle-wasting conditions, by improving access to clinical trials at UK neuromuscular centres and ensuring clinical trials are designed robustly, and by engaging in the relevant approval processes
- **support professionals** so that better-trained and supported staff provide improved care, and more people with muscle-wasting conditions get the support they need
- **improve access to NHS specialist support**, by driving improvements in specialist neuromuscular care across the UK, identifying the challenges faced by neuromuscular services as a result of the COVID-19 pandemic, and working in partnership with services to overcome them
- **provide professional development** to health and care professionals through regional neuromuscular networks, online modules and virtual events
- **use our influence to improve NHS mental health services** for people with muscle-wasting conditions.

*“Excellent support. MDUK was the only organisation giving vital information to us about shielding.”*

*“Great to have the resources online and the muscle seminar was excellent.”*

*“MDUK gives me the hope that people with muscle-wasting conditions are supported and looked after.”*

# Living well with a muscle-wasting condition

Making sure our community has easy access to the information and support they need

**Our team is here with information and support for anyone facing a new diagnosis or a progressing muscle-wasting condition, for anyone who needs support to get the benefits they're entitled to, and for anyone who's unsure how to go about adapting their home.**

## Adapting, collaborating, speaking out

At the start of the pandemic, we recognised our role as a trusted source of information and advice for our community. We responded by:

- collating and interpreting coronavirus guidance and information so it applied to people living with muscle-wasting conditions
- bringing together a group of neuromuscular clinicians to co-ordinate their responses to questions from the community
- making sure our community had the updated, accurate information they needed
- bringing together nine neuromuscular charities, co-ordinating communication between us and the clinicians
- raising concerns about the potential impact of the Coronavirus Bill on people with muscle-wasting conditions



- bringing together charities to challenge NICE guidance that initially suggested people with underlying conditions, including muscular dystrophy, might be denied acute treatment for coronavirus
- successfully campaigning for higher priority access to vaccines for people with muscle-wasting conditions.

## Information, support and advocacy

When the pandemic hit, we adapted our helpline service so we could continue supporting our community in a rapidly changing situation. Despite reduced resources:

- we responded to **2,126 phone and email requests** for support
- **83,000 people** visited our website's care and support areas (a 46 percent increase on last year), with **22,000 downloads** of info factsheets
- **3,200 people** engaged in on our online forum – **seven percent more** than last year
- we helped **168 people** find out more about research and clinical trials
- supported **250 people** struggling to get the benefits, services and equipment they were entitled to
- the coronavirus guidance page on our website received **45,000 views** in 2020/21.

## Equipment grants

We weren't able to offer any equipment grants because of the financial impact of the pandemic on our charity, but re-opened the scheme in February to review applications in April 2021.

**FROM OUR  
COMMUNITY**

**"MDUK's personal touch meant everything. It was all about the people and making sure each individual was looked after and everyone was okay."**





### Bringing people together

We developed a series of online seminars to replace our usual in-person offering of events. Our Muscles Matter series (as pictured above) of **14 online seminars**, covering condition-specific and general topics, got **1,487 bookings** from **854 individuals**, and **2,388 YouTube views**.

### Changing Places

As co-chairs of the Changing Places consortium, we continued working with the Department for Transport (DfT) and finalised a new partnership with the Ministry of Housing, Communities and Local Government (MHCLG) to increase the number of accessible toilet facilities across England.

### Thank you to our community

In the midst of the pandemic, you – our community like no other – created opportunity out of disappointment, hope in the midst of despair, togetherness out of isolation. You helped us continue to be there for everyone with a muscle-wasting condition.

### IN 2021/22, WE WILL:

- **support independent living** by offering high-quality, accessible support for everyone on the phone, online and, when possible, face to face; we will deliver our virtual Muscles Matter series and resume our Muscle Group meetings – initially virtually
- **support young disabled people into work**, through our Moving Up project
- **improve access to Changing Places toilets**, by working with our co-chair of the Changing Places consortium, PAMIS in Scotland, and working with the DfT and MHCLG to increase provision of these facilities in England
- **continue to sponsor the Powerchair football leagues** with the Wheelchair Football Association and the Scottish Powerchair Football Association.

“The innovation and resilience the charity showed, coming up with new ideas, gave me confidence.”

“When the pandemic hit, you could see the charity saying ‘what do we do differently?’”

“There was a bedrock of solid MDUK foundation, always some security.”

# Decades of support from the property industry

Because of the pandemic, last year's Microscope Ball had to be cancelled for the first time in its 37-year history. Undeterred, the hardworking and dedicated committee came up with a plan B and, with the full support of the property industry, **raised an astonishing £80,000** for MDUK.

As life locked down, the property industry heroes took on huge physical challenges and many also generously donated the money they would have spent on their Microscope Ball table directly to MDUK.

Michelle Anthony, Microscope Ball Committee Chair, said: "The Microscope Ball is close to all the committee's hearts and it is a privilege to chair this group of extraordinary individuals that make the ball a success, year on year.

"For me personally, it was a unique opportunity to donate our collective time and efforts to giving back to a community that was underfunded even before the current crisis unfolded.

"The generous long-term supporters of the event donated the cost of their tables from the Ball direct to the charity, and they got dressed up and joined the committee

by dancing and donating on the day the Microscope Ball would have taken place."

In addition to the incredible donations, four committee members also took on fundraising challenges:

- Harry Foster, Portfolio Director at Landsec, took on the 2.6 Challenge. Although he had only ever ran 5k, he completed 26 miles, pushing his son Freddie in his car for the last lap
- Guy Bowring, Director at Tuckerman, did a 5,000 press-up challenge with his daughter Annabelle
- Jonny Lee, Partner at Knight Frank, ran a marathon over five days with his wife and two friends
- Adam Cradick, Executive Director at CBRE, kayaked the length of the Thames, covering more than 250km over the course of a week.

ThirdWay took on our #Big60Challenge and, with

around 50 employees taking part, they raised more than £6,000. Artemis Interiors and Hunter Contracts completed a 100-mile cycling challenge, and special thanks to the West End Agents Society who donated a most generous sum of £10,000. You'll also read on p20 how Landsec supported the #WalkWithCarmela fundraising challenge.

**An extra special thank you** to these companies who also supported MDUK during the pandemic: 5plus Architects, Artemis Interiors, Ashill, CBRE, Colliers, Derwent, Exigere, Faithdean plc, Henigan Consulting, JMW Solicitors, Knight Frank, LCA, Levy, Overbury, Oxygen Asset Management, Quantem Consulting, Redevco, Rougemont Property Consultants, The West End Office Agents Society, Tuckerman.



The Microscope Ball started in 1984 within the property industry, in support of a colleague whose child had been diagnosed with muscular dystrophy. It quickly became a key date in the property industry calendar and to date has raised around £3m, to help MDUK fund world-leading research and vital support for families.

# Your outstanding support in an extraordinary year

In the year we all had to spend staying at home – to shield, to work, to protect those closest to us – you used your time to join our virtual events, take on challenges, and connect online with shining stars. When it felt like the world had stopped, you kept going.

It's remarkable to think of last year as a year of opportunity. But you imagined new ways to fundraise when the old ways no longer worked and helped fill the funding gap that the pandemic wrought on our plans.

- **1,139 runners** took part in our Virtual Town and Gown events
- 101 participants in the Virtual London Marathon **raised £122,556**
- 3,411 YouTube views across our three Virtual Celebrity Sports Quizzes, **raised £25,392**
- the property sector joined in virtual events in lieu of the cancelled Microscope Ball and **raised £80,968**
- our Family Funds and Branches **raised £206,000**
- by partnering with regional businesses, we **raised £48,519**
- 51 supporters took on their own 2.6 Challenge during lockdown and **raised £48,017**

In a year of fear and darkness, you brought colour and courage. You danced, you stood firm, you quizzed, you laughed, you wrote, you talked, you shared, you shone, you cooked, you baked, you ran, you walked, you swam, you zoomed. You made muscles matter. **On behalf of everyone who relies on MDUK's services and support, we thank you.**



# Your outstanding support in an extraordinary year

Among our community of volunteers, we have peer supporters, fundraising event organisers, JPT or Lay Research panellists, online forum moderators, Muscle Group meeting chairs, Trustees and a raft of incredible pro bono supporters. This community of outstanding individuals makes a huge difference in every corner of MDUK's work, and last year they made *all* the difference.

## Multi-tasking volunteer

**Ian Gordon, our longest-serving Trustee, was part of MDUK's Emergency Committee and, with his wife Kari, volunteered on our helpline every Friday for 10 months too.**

"MDUK Chair Prof Mike Hanna formed and chaired our Emergency Committee to ensure MDUK survived, at least to the end of the year. Acting as early as we did and taking some very tough decisions, put MDUK in a much better position than many organisations that put off making those hard choices.

"While it was tough at times, we also found it rewarding to work on the helpline. I'd volunteered for Citizens Advice and Kari had a lot of experience dealing with various agencies to get appropriate support for our son, Ben, who has limb girdle muscular dystrophy."

**Vivek Gohil, a peer support volunteer, was also a panellist on our Muscles Matter 2020 seminar on assistive technology**

"I'm always happy to support MDUK, as they have supported me for over a decade, especially helping me to get my foot in the door to work in the gaming industry. As a panellist

last year, I could tell people about assistive technology, a tool that improves life, aids independence and helps your mental health. I use a computer for most of my hobbies and work, so my whole life is thanks in part to this technology."

## Virtual technical support

When we put on our first online quiz in April last year, Simon Maunder and Ben Fox from production company, Chimera, offered their expertise and behind-the-scenes support.

"We've been supporting MDUK for many years and were delighted to help the charity during the pandemic. We were very proud to produce their first online event, and we all learnt a lot along the way about going virtual!"

## A digital helping hand

"I worked at MDUK for a number of years and made friends with lots of wonderful supporters and staff. On hearing the news that staff were being furloughed, I volunteered an hour of my day for several months to help with social media and emails. It was really lovely being able to help."

**Alexa Taylor, Digital Consultant**

## Supporting a charity isn't all about fundraising

"Helping with behind-the-scenes work can be equally rewarding for the individual and just as valuable for the charity. I volunteer with the MarComms team because that's where my skills and experience lie. A few hours a month helping do the things a large corporate takes for granted is a great way to make a difference, and find a new perspective on your industry."

**Lindsey Armstrong, of MDUK's Content Advisory Group, also helped shape MDUK's marketing surveys**

## Sharing my story

"Being a panellist on the Muscles Matter Employment seminar was a rewarding experience as it gave me the opportunity to share my story, views of living with CMT 4C, and working full-time. I enjoy being part of these events as I get to learn from individuals' and organisations' experiences, and highlight the gaps still being faced by individuals with a disability looking for employment or within employment. It gives me the platform to be the voice for other individuals with disabilities that have not yet discovered theirs."

**Priyaneet Kainth**



Alexa Taylor, right  
Priyaneet Kainth, left  
Ian and Kari Gordon, centre



# Your outstanding support in an extraordinary year

We're tremendously grateful to all of our valued celebrity supporters, including Gabby Logan, our current President, and Sue Barker, our former President, who went the extra mile for us during the pandemic. Whether it was supporting the Walk With Carmela campaign, doing a #MusclesMatchdaySelfie, helping with our sports quizzes or the BGC Charity Day online, or raising awareness for us on your social media channels, every one of you made a positive difference. Thank you.

## Walk With Carmela

Last year, seven-year-old Carmela Chillery-Watson (pictured on our cover) became our Wonder Girl. We benefited from amazing pro bono support: Landsec, one of our corporate sponsors and the UK's largest commercial property development and investment company, gave us free media space on the Piccadilly Lights, Europe's largest digital billboard; Atomic London, a creative agency, transformed Carmela into an 8-bit digital character, and Eboy made the Carmela character into a film on the billboard.

"It seemed desperately unjust that MDUK was suffering so much, especially because clinically extremely vulnerable people like Carmela were not only shielding but now facing a lack of support when they needed it more than ever. Cat Martyn, one of our account directors who was on furlough, volunteered to help. I'm really proud of how we used the free advertising space and I'm delighted the campaign had such long-term traction."

**Jon Goulding, CEO at Atomic London**

"Carmela's story was enough for me to get on board. The feeling I got from helping was incredible, and the whole team had a bigger goal in mind when working on this account."

**Cat Martyn, Account Director at Atomic London**



# Our finances

Thanks to the generosity and loyalty of individuals, families, branches, groups, corporate partners, trusts and foundations, as well as continuing support from legacy donors, and those who took part in our virtual events across the UK, the impact of the pandemic on the charity's finances was not as severe as we had first anticipated.

In 2020/21, we raised a total of £5.5m compared with £6.2m in the previous year. Our income comprised £3.9m in fundraising income, £150k in investments and £1.5m in other income, £1.3m of which came from government grants (£505k from the Coronavirus Job Retention Scheme and £799k in Changing Places Project grants for future use). The substantial reduction of £2m in general fundraising income, compared with the 2019/20 budget, was a result of the pandemic and our limited ability to run our regular fundraising events during the lockdown.

These restrictions also affected our operations and expenditure level, with more than 60 percent of our staff furloughed in the first six months of 2020/21. In the first half of the year, we also suspended some operations and postponed new projects, including a new research grant round. This represented a £2.4m (40 percent) reduction in charitable expenditure and a £1.2m (50 percent) reduction in fundraising expenditure, from having to cancel or postpone events. Despite these challenges, we kept our financial commitment to all existing multi-year research projects, and prioritised support to our community throughout the pandemic.

The reduction in costs and the recovery of investment losses we experienced in March 2020 helped to increase the reserves to £2.7m. This strengthening will offer us some stability, as we believe our sector will continue to experience the impact of the pandemic for at least the next two years.

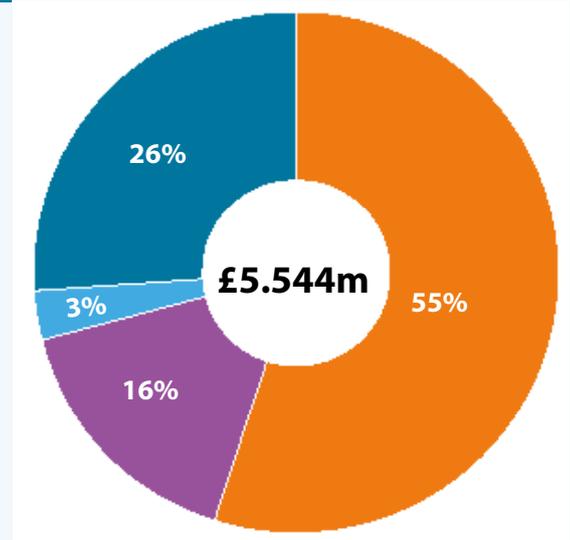
## HOW WE SPEND EVERY £1 NET WE RAISE

- Direct charitable activities
- Support costs



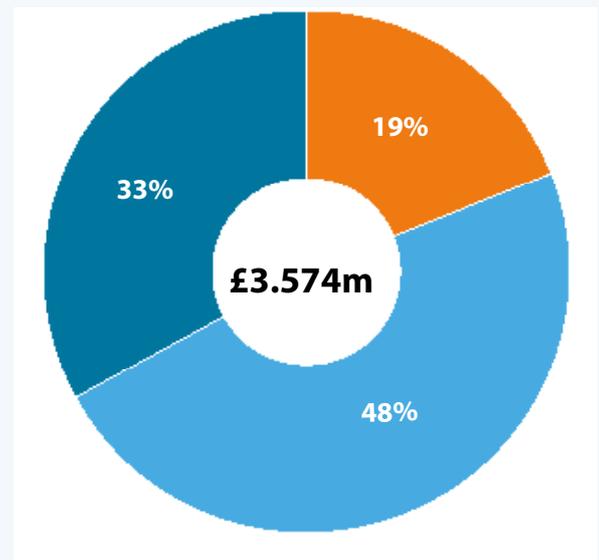
## HOW WE RAISED OUR MONEY

- Donations, gifts, grants and fundraising activities
- Legacies
- Investment income
- Other income



## HOW WE SPENT OUR MONEY

- Medical research in the search for effective treatments and cures
- Independent living, access to specialist care and support
- Expenditure on raising funds



# Thank you

A huge and very special thank you to our Celebrity Sports Quiz Committee, The Q Trust Committee, Microscope Ball Committee, The Clay Pigeon Shoot Committee, the Appeal Board, the Content Advisory Group, our branches, groups, Family funds and every individual who fundraises for us. Your support enables us to focus on what matters the most: keeping people with muscle-wasting conditions supported, informed and at the heart of everything we do.

BGC International LP

Bill and Jacky Ronald

Biogen

CeX

Charles and Nicky Manby

Charles Scott

Childwick Charitable trust

City Bridge Trust

Cookalong.TV

Dan and Claire Parker

Dr Sally Whittet and Professor

Michael Joy OBE

Eveson Charitable Trust

Frances Carey

Francesco Muntoni

Hugh Fraser Foundation

Ian and Moira Andrews

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JMW Solicitors

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Mail Metro Media

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Martin Smith

Matalan Retails Ltd.

Mayo L Marriott

Michelle Anthony

National Lottery Community

Fund

Patricia Orr

Peter and Frances Meyer

Professor Kate Bushby

Roche

Sarepta

Tennants Consolidated Ltd

The Bergqvist Charitable Trust

The Cranbury Foundation

The Edinburgh Trust

The estate of Mary Wilson (nee Banks)

The Exhilarch Foundation

The February Foundation

The McAlister Family

The Northwood Charitable Trust

The Patrick Trust

The Row Fogo Charitable Trust

Tony and Monica Moorwood

True Colours Trust

Vodafone plc

**And a huge thank** to Gabby Logan, Sue Barker, Charlie Hodgson, Alex Horne, Russell Howard, David Moyes, Monty Panesar, John Regis, Jon Richardson, Ryan Sidebottom, Graeme Swann, Phil Tufnell, Dennis Wise, Alec Stewart, Tyrone Mings, Dominic West, Jack Wilshere and Andy Zaltzman for supporting our virtual events in your own unique and brilliant ways.

While we cannot list every individual here, please know that we appreciate the generosity of every single MDUK supporter.

MATALAN

ARTEMIS  
INTERIORS



COOKALONG.TV

Mail METRO MEDIA

Daily Mail The Mail MailOnline METRO METRO... i Evening Standard The Telegraph

bgc CHARITY DAY

rhubarb chairs  
ECLECTIC FURNITURE AND DESIGN

marchmont  
INVESTMENT MANAGEMENT



CHIMERA  
content. delivery.

# Here for everyone

Here are some ways MDUK supported people during the past year:



**£7.5m per year**

additional NHS investment secured, to give more people access to specialist support across the UK



**83,000**

visits to the care and support info on our website

**3,200**

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

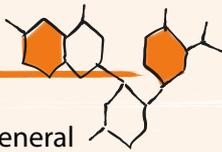


**168**

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

**22,000**

downloads of condition and general info factsheets from our website



**45,000**

website views, keeping our community aware of what coronavirus guidance meant for people with muscle-wasting conditions



**1,639**

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



**250**

people supported to get the benefits and equipment they're entitled to



**2,126**

individuals and families got support and info from our team

## MDUK currently funds 40 research studies into a range of conditions

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



### Royal Patron

HRH Prince Philip, Duke of Edinburgh KG KT  
(deceased April 2021)

### Patrons

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

### President

Gabby Logan MBE

### Honorary Life Presidents

Sue Barker OBE  
Professor Martin Bobrow CBE FRS FMedSci  
J Alexander Patrick CBE DL (deceased April 2020)  
Baroness Celia Thomas of Winchester MBE

### Our Vice Presidents

Anil Ahir  
The Hon Michael Attenborough CBE  
Karen Lewis-Attenborough  
Sophia Bergqvist  
Frances Carey  
Jeremy Champion  
Candida Crewe  
Charity Crewe  
Sebastian Crewe  
Victoria Elliston  
Sir Alex Ferguson CBE  
Andrew Graham  
Matthew Kelly  
Sarah Kelly  
Simon Knights  
Charles Manby MBE  
Nicola Manby  
Andrew Martin  
Ian Mathieson  
Ann McNeil  
Valerie Patrick  
Jeremy Pelczer  
Julian Pritchard  
Michael A Thirkettle  
Andrew J Weir  
Alex Wellesley Wesley  
Guy Weston

### Our Research Vice Presidents

Professor Kate Bushby MD FRCP  
Professor Patrick Chinnery FRCP FMedSci  
Professor Dame Kay Davies CBE DBE FRS FMedSci  
Professor George Dickson PhD  
Dr David Hilton-Jones MA MD FRCP FRCPE  
Professor Darren Monckton PhD  
Professor Francesco Muntoni FRCPCH FMedSci  
Professor Mary Reilly MD FRCP FRCPI FMedSci  
Professor Volker Straub MD PhD  
Professor Sir Douglass M Turnbull MBBS (Hons) MD PhD  
FRCP FMedSci  
Professor Matthew Wood MBChB MA DPhil FMedSci

### Board of Trustees

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Marcus Brown (Treasurer)  
Michelle Anthony (co-opted March 2020)  
Michael Armstrong  
Martin Cardoe  
Ian T Gordon  
Joe Gordon  
Sheila Hawkins  
Louisa Hill  
Scott Keown (co-opted March 2020)  
Claire O'Hanlon MBE  
Richard Price (until March 2020)  
Charles Scott  
Baroness Celia Thomas of Winchester MBE  
Tanvi Vyas  
Robert Warner

### Senior Leadership Team

Catherine Woodhead, Chief Executive  
Dr Kate Adcock, Director of Research and Innovation  
Rob Burley, Director of Campaigns, Care and Support  
Emma Jones-Parry, Associate Director of Development  
Stephen Mooney, Director of Marketing and Communications  
Wojtek B Trzcinski, Finance and Resources Director

**We look ahead with hope, courage and ambition,  
knowing the privilege of having you in our corner.  
Thank you for making every day count for people  
living with muscle-wasting conditions.**

Our 2020/21 Financial Statements are available upon request. Download a copy from our website at [www.muscular dystrophyuk.org/publications/impact-reports](http://www.muscular dystrophyuk.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)



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