

Trustees

Candidate Information 2025



A message from our Chair



Thank you for your interest in joining the Board of Trustees of Muscular Dystrophy UK, the leading charity for over 60 muscle wasting and weakening conditions.

For over 60 years, we've been growing a strong, supportive community – bringing together people living with muscle-wasting and weakening conditions, their families and carers, healthcare professionals, scientists, supporters, volunteers, and donors. Together, we've driven progress once thought impossible. We connect everyone affected by these conditions – those living with them and those around them – to ensure access to the care, support, and treatments they need to thrive, both physically and mentally. From the moment of diagnosis and throughout every stage of life, we're here to help people live as fully and confidently as possible.

This is a very exciting time for Muscular Dystrophy UK. We will shortly publish our bold new strategy to guide our work over the next decade. With it, we aim to transform diagnosis, reach every person with a muscle wasting condition, enhance universal support and enable people to live well and independently with their condition.

We have big ambitions – and with a strong financial foundation, diverse income streams, and robust external partnerships, we're ready to scale our impact.

We are looking for passionate and committed individuals with significant strategic leadership knowledge and experience to join our Board of Trustees. You will play a vital role in shaping our long-term strategy, safeguarding our financial sustainability, and championing our mission to support everyone affected by muscle wasting conditions. We're looking for individuals who share a deep commitment to our values, have a clear understanding of the responsibilities of charity trustees, and can recognise and promote good governance within a charitable organisation.

I look forward to working with you and I am excited to see what you can bring to Muscular Dystrophy UK.

Professor Michael Hanna



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**Improving
lives today
and
transforming
lives in the
future.”**

About us

We're the leading charity for over 110,000 people in the UK living with one of over 60 muscle-wasting and weakening conditions.

We connect our community of people living with muscle wasting and weakening conditions, and all the people around them, friends and family, healthcare professionals and scientists, so that everyone can get the healthcare, support and treatments needed to feel good, both mentally and physically.

We support people through every stage of their life, from the point of diagnosis to living the best life possible.

Our mission

- We share expert advice and support people to live well now.
- We fund groundbreaking research to understand the different conditions better and lead us to new treatments.
- We work with the NHS towards universal access to specialist healthcare.
- Together, we campaign for people's rights, better understanding, accessibility, and access to treatments.

Our values

Stronger together

We believe in the power of community. That the whole is greater than the sum of its parts. Because the more of us who come together, the greater the impact we'll make.

Forward thinking

We're here for every single one. Whoever you are. Wherever you're from. You are our sole focus. We set ourselves clear targets and measure our impact.

Here for you

We are here for everyone, but we know support isn't one-size-fits-all. We take the time to listen to every individual, so we can tailor our support to you.

Never Stop

We've already made advances that would have been unthinkable just 10 years ago, and we are determined to go even further and faster.

Support

We believe it is vital that people have easy access to the information and support they require throughout their experience of living with a muscle-wasting or weakening condition. We provide personal, free, expert information, resources and confidential support, covering every topic from the latest research to money worries, physical symptoms and emotional well-being.

Our helpline Service

Our helpline team provide practical advice and support and listen to people's concerns. The five topics people contact us most about are welfare information requests, care plan/alert cards, the cost of living, housing and adaptations advice and an introduction to MDUK. We responded to these requests by phone, email or through neuromuscular clinics. People also visit our website care and support area and use our online forum to share experiences and to support one another.

Our advocacy service

Our advocacy service supports people who may be struggling to get the care and services to which they are entitled – providing advice or acting on their behalf. We support people through this service, but also provide people with the information and skills to advocate for their own needs.

Providing grants

As well as supporting people to access financial support, we also provide grants through our grant giving arm, the Joseph Patrick Trust, to help meet the costs of powered mobility equipment. We have also launched a one-off cost of living grant for individuals with muscle-wasting and weakening conditions this year.

Muscle Group sessions and Muscles Matter seminars

We bring our community together through our Muscle Group session and our online Muscles Matter seminar series.

[Find out more.](#)



Research

High-quality research plays a key role in our ambition to improve the lives of people living with a neuromuscular condition, helping us to better understand these conditions and maximise treatment improvements.

Our research strategy, 'Transforming lives through research', remains the driving force for our research activity. We continue to support high quality research that deepens our understanding of neuromuscular conditions and support studies into ultra-rare conditions.

Our grant awards

All research projects we fund have gone through a rigorous international peer review process to ensure that we are funding the best quality science that is relevant for people with muscle-wasting conditions.

The European Neuromuscular Centre

We are an executive member of the European Neuromuscular Centre (ENMC), a network of research charities from across Europe who bring experts together to tackle challenges found in the field of neuromuscular research.

Our Research Line

We ensure patients and families can find out about new studies, treatments, and clinical trials for muscle-wasting conditions.

[Find out more.](#)



2023/2024 in numbers

£1.3m

We funded 11 new research projects totalling £1.3m.

£9.5m

We raised £9.5m. A 16% increase on the previous year.

1,500

We had nearly 1,500 pieces of media coverage with a potential reach of 356m. A 23% increase in volume of coverage year-on-year.

3,000

Nearly 3,000 people were supported through our helpline.

530,000

There were nearly 530,000 visits to our website, up one third on the previous year.

160

More than 160 people attended our Information Days across the UK.

3.2m

Our reach on Facebook was 3.2m, up 140% on the previous year.

500

Nearly 500 people were provided with a cost-of-living grant by us.

500

Nearly 500 healthcare professionals attended our six upskilling webinars.

150

Over 150 people were supported through our advocacy service.

Our fundraising year in numbers:



£427,000

at our annual Microscope Ball thanks to the support of the property industry

£39,500

raised at the BGC Charity Day thanks to the appearance of our President Gabby Logan MBE, football manager David Moyes and comedian Russell Howard, alongside families from our community

£835,373

raised from 7,853 participants signing up to 43 different running events around the country

£2.9m

from 72 individual legacies.

£90,000

raised from our inaugural Double Your Donation campaign that ran for a week in December

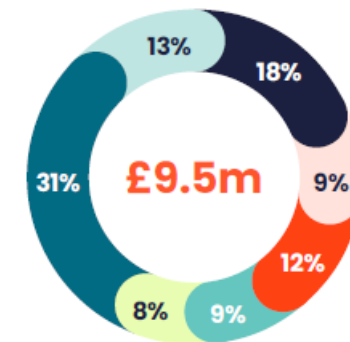
MUSCULAR
DYSTROPHY
UK

Impact Report 2023/24

Together we are stronger

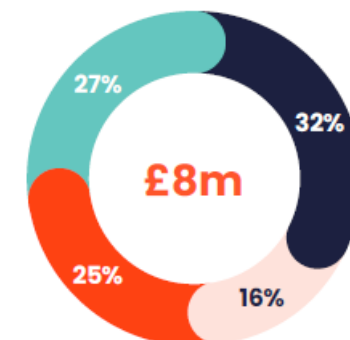


Total income



- Events and promotions (£1,726k)
- Direct marketing (£824k)
- Major Donors and Corporate (£1,106k)
- Trusts (£894k)
- Regional development (£768k)
- Legacy (£2,920k)
- Other income (£1,270k)

Total expenditure



- Fundraising (£2,596k)
- Access to specialist care and support (£1,233k)
- Independent living (£2,037k)
- Medical research (£2,176k)

Role Description

Role title:	Trustee
Time Commitment:	Min. of x4 Board Meetings per year. Committee meetings as appropriate. To attend the Annual General Meeting (October) and other national events as appropriate. Other fundraising, campaigning or support commitments as they might arise.
Location:	Hybrid & London
Remuneration:	This is a voluntary position. Reasonable expenses will be reimbursed.

Overview of the role

This is a truly exciting time in Muscular Dystrophy UK's journey. We're preparing to launch a bold new strategy that will shape our work for the next decade—setting ambitious goals to transform the diagnostic experience, reach every individual affected by a muscle wasting condition, improve universal support, and empower people to live well and independently. It's an exceptional opportunity to join the Board of a financially stable organisation with diverse income streams, strong external partnerships, and a high-performing, collaborative Senior Leadership Team, Trustee Board, and Chair.

We are seeking passionate and committed individuals to join our Board of Trustees. As a Trustee, you will play a vital role in setting the strategic direction of the charity, ensuring its financial stability, and safeguarding its mission to support people affected by over 60 rare and progressive muscle wasting conditions.

You will sit as a member of the Board of Trustees of Muscular Dystrophy UK representing the Charity's membership:

- To ensure that the Charity fulfils its charitable objects
- To hold the Charity's executive to account for operational performance
- To ensure that the Charity complies with charity law

Key areas of responsibility

- Further Muscular Dystrophy UK's vision, mission and operational objectives
- Support the appropriate governance of Muscular Dystrophy UK in the interest of current, potential and future members
- Take collective responsibility for decisions made by the Board of Trustees
- Be accountable to the membership for the Board of Trustees decisions and the performance of Muscular Dystrophy UK
- Act as an ambassador for the Board of Trustees and Muscular Dystrophy UK as required
- Contribute specific skills, interests and contacts in order to support Muscular Dystrophy UK activities
- Adhere to the Trustees' Code of Conduct at all times.
- Attend Trustee meetings and other meetings as required
- Foster and encourage good relations between staff and the Board of Trustees
- Take part in training sessions provided for the benefit of Trustees
- Be fully aware of Trustee responsibilities under law

Person Specification

Alongside the skills and experience outlined below, we're looking for engaging individuals who bring a genuine passion for joining the Board at Muscular Dystrophy UK.

- A strong commitment to Muscular Dystrophy UK's values and goals
- Strong strategic leadership knowledge and experience
- Excellent communication and teamwork skills
- Understanding of governance responsibilities within a charitable organisation
- Willingness to act as a support and critical friend to the executive team

In addition, we would particularly welcome applications from candidates with experience of any of the following:

- Investment management
- Clinical experience of neurological conditions
- Clinical research experience
- Human resources and culture development
- NHS health and care systems and commissioning

We are committed to building a diverse and inclusive organisation that reflects the communities we serve. We actively encourage applications from individuals of all backgrounds, particularly those from underrepresented groups including people from ethnic minority backgrounds, LGBTQ+ individuals, and those with lived experience of conditions we represent. We believe that diversity strengthens our work and helps us better support our beneficiaries.



How to apply

If you are interested in the opportunity to join the Board of this amazing charity, please provide the following with your application:

- An up to date CV with details of two referees (we will not contact them without your prior permission)
- A support statement (no longer than two A4 sides) which addresses how you meet the main criteria and explains your motivations for applying

All applications are being handled by our recruitment partner, Trustees Unlimited (part of the Russam group).

Applications should be uploaded via the Trustees Unlimited website:

<https://trustees-unlimited.co.uk/roles/muscular-dystrophy-uk-trustees-muscular-dystrophy-uk-august-2025/>

The next steps

Closing date for applications:

Monday 22nd September 2025

Interviews with Muscular Dystrophy UK:

7th or 14th (AM) October 2025

