Vice Chair

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 seeking to appoint a Vice Chair to support me in my role as Chair and to play a key role in leading the organisation forward, helping Muscular Dystrophy UK achieve its ambitious vision for the future.

As Vice Chair, you will act as a supportive and critical friend to the Chief Executive and deputise for me when needed. You'll bring solid strategic experience from the public, private, or voluntary sectors, along with strong communication skills and a good understanding of what it means to be a charity trustee, helping ensure the Board runs smoothly and upholds strong governance. We're looking for someone with credibility, proven leadership — ideally at Board level — who is a strategic thinker, a great communicator, and brings commitment to our values and mission and a genuine passion for joining the Board.

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

Professor Michael Hanna

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

> "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.

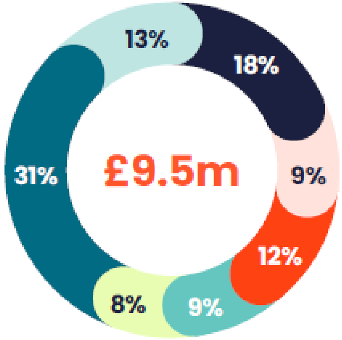
£90,000
raised from our inaugural Double Your Donation campaign that ran for a week in December

MUSCULAR DYSTROPHY UK | OUR MUSCLES MATTER

Impact Report 2023/24

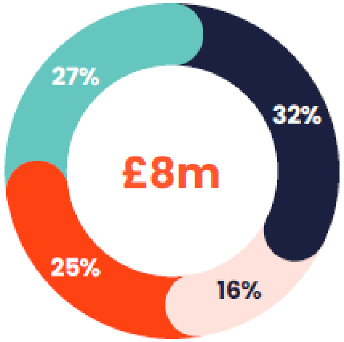
Together we are stronger

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:	Vice Chair
Time Commitment:	c.20 days per year
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.

The Vice Chair is a Trustee of Muscular Dystrophy UK and, alongside the responsibilities of a Trustee, supports the Chair in leading the Board to ensure strong governance and strategic oversight. They act as a supportive, critical friend to the Chief Executive and may deputise for the Chair when required.

Key areas of responsibility

- Support the Chair in providing leadership to the Board and ensuring it functions effectively.
- Deputise for the Chair in their absence, including chairing meetings and representing the charity at events.
- Work closely with the Chair and Chief Executive to ensure the Board sets and monitors the charity's strategic direction.
- Promote high standards of governance and ensure compliance with legal and regulatory requirements.
- Foster a collaborative and inclusive Board culture, encouraging diverse perspectives and constructive challenge.
- Act as a sounding board and mentor to other Trustees, particularly new appointees.
- Represent the charity externally, helping to build relationships with stakeholders, funders, and partners.

Person Specification

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

- Proven leadership experience, ideally at Board level within the charity, public or private sector.
- Understanding of charity governance and the responsibilities of Trustees.
- Strong interpersonal and communication skills, with the ability to maintain relationships, build consensus and manage differing views.
- Commitment to the mission and values of Muscular Dystrophy UK.
- Strategic thinker with sound judgment and integrity.
- Availability to commit time (circa 20 days a year) and energy to the role.

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

If you would like to have a confidential discussion about this role, please contact Melissa Baxter at Trustees Unlimited on 07789 985229 or melissa.baxter@trustees-unlimited.co.uk.

All applications should be sent to:
applications@trustees-unlimited.co.uk.

The next steps

Closing date for applications:

Monday 22nd September 2025

Interviews with Muscular Dystrophy UK:

7th or 14th (AM) October 2025