

Chief Executive

Candidate Information 2024



A message from our Chair



Thank you for your interest in the role of Chief Executive Officer with Muscular Dystrophy UK, the leading charity for over 60 muscle wasting and weakening conditions.

For over 60 years, we've been building our community of individuals living with muscle wasting or weakening conditions, families and carers, scientists, health professionals, supporters, volunteers, and donors. Making advances that would have been unthinkable just ten years ago.

We connect our community of more than 110,000 people, and all the people around them. So they can get the healthcare, support and treatments they need to feel good, mentally and physically. Through advice and support, research, campaigning, and fundraising.

We are seeking to appoint our next inspirational leader for Muscular Dystrophy UK.

You will have demonstrable broad strategic and organisational leadership experience within a complex and / or national charitable organisation and will have worked closely with boards, senior management teams and external stakeholder groups. You will be a strong communicator – able to promote the work of the charity to the media, government, health committees and the wider public. Good business / financial awareness is also a must and the creativity to consider the new opportunities – in terms of collaborative working and funding partnerships. You will also have excellent interpersonal qualities with an ability to connect and empathise with our community; and have a real passion to deliver effective support, treatments and cures for all muscular dystrophy and allied neuromuscular conditions. With strong foundations, and setting an ambitious strategy for the future, this role represents an exciting opportunity for an individual with a strong commitment to and enthusiasm for Muscular Dystrophy UK and our important work, in what is an increasingly important field.

As Chair, 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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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.



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

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.](#)



2022/2023 in numbers

£1.3m

awarded for research including 14 new grants, bringing the portfolio to 43 active research grants being supported, with a total cost commitment of £6m

£8.2m

income generated

2,663

people living with, or affected by, a muscle-wasting condition supported through our phone and email support service

10

treatment appraisals on which we were active, with two treatments recommended by NICE for NHS use

99,103

visits to the care and support sections of our website

15,696

unique page views to our online forum allowing people to share experiences and support each other

3,973

online views of our muscles matter seminars

1,857

views of the Standards of Care for Adults with Duchenne muscular dystrophy videos

470

attendees at our Allied Health Professional upskilling webinars

80

participants at our Physiotherapy Conference

Our fundraising year in numbers:



£424,000

at our annual Microscope Ball; a record breaking sum.

£36,700

at our first ever Games Night.

£36,000

raised at the BGC Charity Day thanks to the appearance of Gabby Logan MBE and Sam Allardyce alongside our families.

£12,000

raised from the participants from schools, workplaces and communities across the UK who took part in our *Go Bright* event.

£2.9m

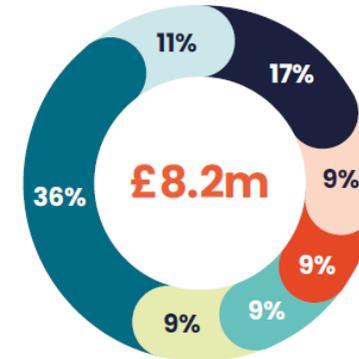
from 62 legacies.

£31,000

won by Gabby Logan by appearing on ITV's *Celebrity Catchphrase* and Channel 4's *I literally just told you*.

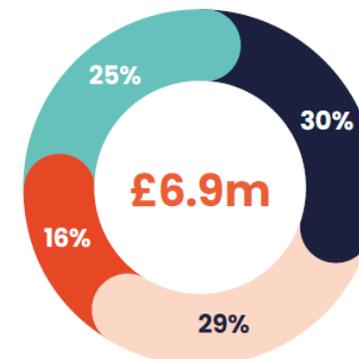
£318,000

raised by the 7330 participants who took part in our Town & Gown events.



Total income

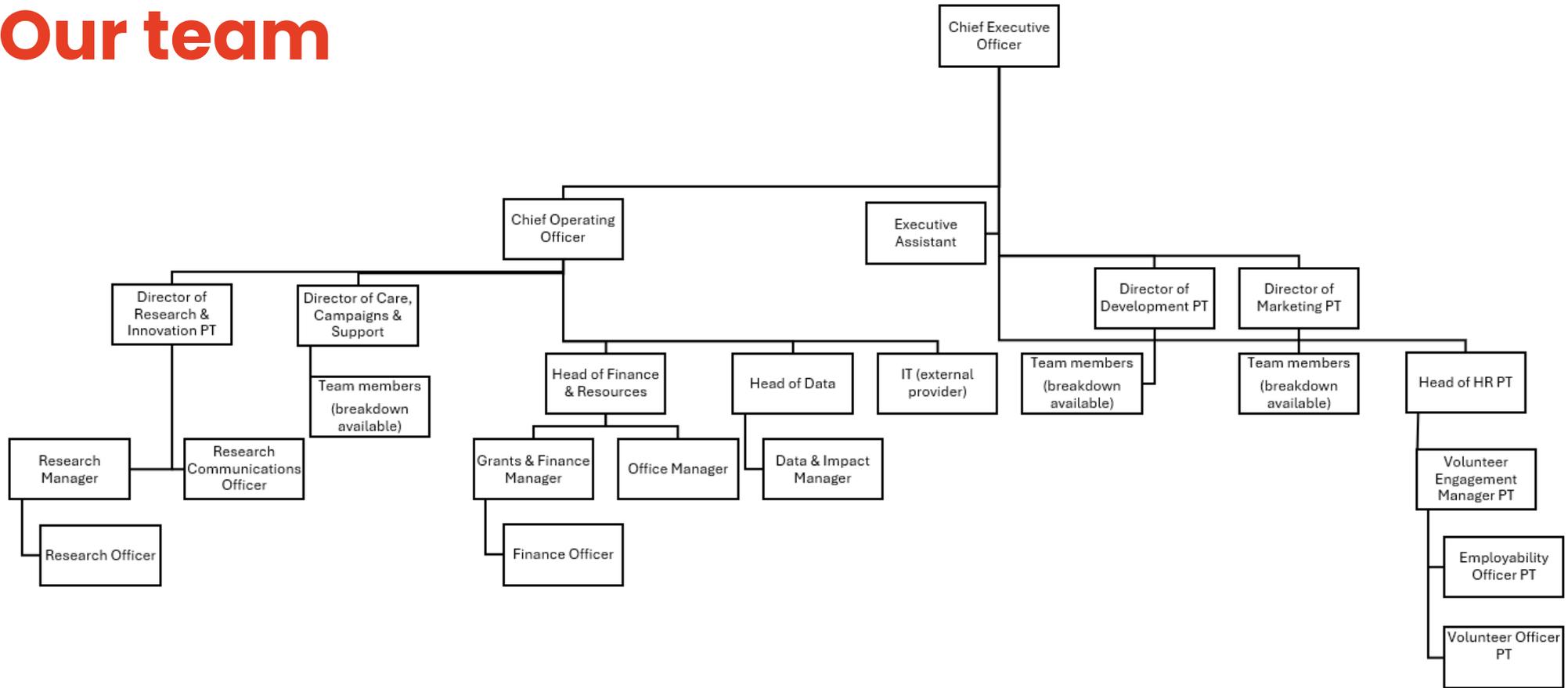
- Events and promotions (£1,394k)
- Direct marketing (£771k)
- Major Donors and Corporate (£773k)
- Trusts (£707k)
- Regional development (£769k)
- Legacy (£2,944k)
- Other income (£863k)



Total expenditure

- Fundraising (£2,030k)
- Medical research (£1,997k)
- Access to specialist care and support (£1,110k)
- Independent living (£1,719k)

Our team



Directors

Our Senior Leadership Team

[Find out more](#)

Trustees

Muscular Dystrophy UK, a company limited by guarantee and a registered charity, is governed by a Board of Trustees.

[Find out more](#)

Presidents and Patrons

About our presidents and patrons

[Find out more](#)

Vice presidents

The role of Vice President is an honorary position offered to our most committed and influential supporters.

[Find out more](#)

Role Description

Job title:	Chief Executive Officer
Location:	National Office, London SE1, Hybrid
Responsible to:	Chair of the Board of Trustees
Responsible for:	COO, Two Directors (Communication and Development), Executive Assistant and Head of HR
Salary:	£120,000 per annum

Overview of the role

The CEO provides overall leadership in terms of the strategic development and operational management of Muscular Dystrophy UK. The key purpose of the CEO role is to inspire and lead the charity to support ground breaking research to drive the development of effective treatments and cures, to ensure access to specialist NHS care and support, to provide excellent direct services and promote opportunities to enable individuals and their families to live independently with the best possible quality of life.

The CEO will ensure the charity is a high performing organisation with clear strategic objectives that engages widely and works effectively through partnerships to achieve its goals. The CEO oversees and develops the financial performance of the charity which underpins the pace of strategic developments. The CEO reports to the Chair and is accountable to the Board of Trustees.

Key areas of responsibility

Strategic Development and Impact

- Lead the development and delivery of Muscular Dystrophy UK's strategic plan, ensuring impact and progress are measured against stretching objectives which are monitored and reviewed at regular intervals.
- Establish effective partnerships and relationships with relevant UK and international organisations to accelerate research in neuromuscular conditions and to ensure emerging treatments reach patients with minimal delay.
- Communicate the goals and impact of the charity widely and effectively to individuals and families living with neuromuscular conditions and to external stakeholders through a range of channels press/media and digital channels.

Operational Development

- Ensure the charity supports outstanding, peer reviewed basic and translational research and ensures emerging treatments reach patients with minimal delay working with regulatory bodies such as NICE, the Scottish Medicines Consortium and the MHRA.
- Ensure effective strategic partnerships are in place with external bodies such as the MRC, Wellcome Trust, and the NIHR, to support the development of knowledge and understanding of neuromuscular conditions.
- Ensure the effective development and management of Muscular Dystrophy UK's direct services to individuals and families, monitoring and keeping under review their impact, value for money and the overall structure of the organisation.
- Ensure the progress of the charity overall in meeting objectives and outcomes is kept under regular review and report accordingly to the Trustees and other stakeholders.

Effective Governance

- Ensure the Board receives regular and appropriate reports on the progress of the organisation in achieving strategic objectives and implementing decisions made by the Board, including performance against the operational targets and financial budget set for the year.
- Work with the Chair and the Appointments and Remuneration Committee to ensure the retention of a high performance Board with trustees individually and collectively having the necessary skills and experience and also ensure succession planning is in place.
- Ensure the Chair and the Board of Trustees are advised of potential and current risks and their mitigation.
- Act as or work closely with the designated Company Secretary, ensuring the Board and the charity overall operate to a high level of governance, in accordance with the Memorandum and Articles of Association and meeting all legal and regulatory requirements. This will take into account the separate requirements which may be in place within the four countries of the UK.
- Ensure appropriate Committees are in place, working with the Chairs to maintain high performing members, who can support the charity to deliver its objectives, and who may be future Board members.



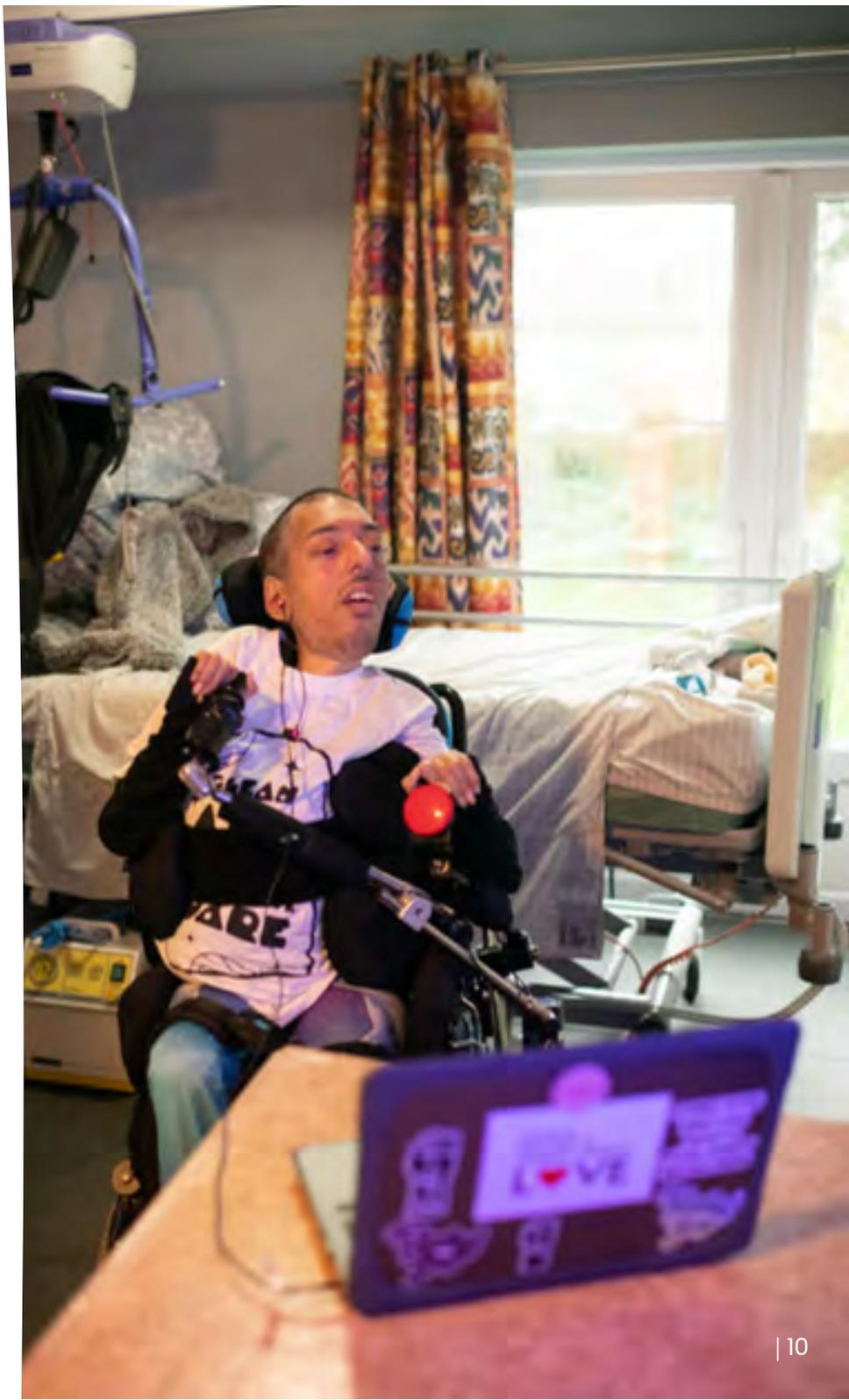
Finance and Risk Management

- Maintain and develop, as necessary, the charity's rigorous approach to financial planning with tight expenditure controls and effective short term and medium term forecasting, and ensure the COO provides comprehensive reports to the Finance Committee and the Board.
- Identify opportunities for income growth with the Director of Development and closely monitor and highlight emerging trends in supporter engagement, volunteer recruitment and income development which influence the charity's short term and long term position.
- Support the Director of Development in driving first class performance in fundraising and general income generation, ensuring regular and timely financial reports and accounts are provided by the COO to the Finance Committee and the Board.
- Ensure a comprehensive, up to date risk register is maintained with risks identified, assessed and, where possible, removed or mitigated.
- Maintain effective HR practices across the charity and ensure compliance with all HR legislation and legal requirements including GDPR.

Management

- Provide effective leadership to the Senior Executive Team and able to motivate the wider staff team.
- Provide effective support and leadership to the HR function and ensure the charity's staff team has the skills, experience, commitment and culture required to deliver the agreed goals.
- Ensure that the organisation's values and policies are relevant, fair and consistently implemented.
- Ensure that effective mechanisms are in place to facilitate effective two-way communication with staff and volunteers.
- Lead and be responsible for the overall development of the staff team and the charity as a whole and to be flexible within broad remit of the role.

It should be noted the above list of duties is indicative only and not exhaustive. The CEO is expected to perform all such additional duties as are reasonably commensurate with the role and the needs of the charity.



Person Specification

With financial stability, diverse income streams, strong external networks and a high-quality, supportive, and constructive Senior Leadership Team, trustee board and Chair, Muscular Dystrophy UK presents a truly excellent opportunity for an experienced leader to build on the solid foundations and outstanding achievements to date. In addition to the criteria below, we're looking for individuals with high levels of emotional intelligence, empathy, personal integrity and honesty with a demonstrable commitment to our vision and values.

Education/training and knowledge

- Educated to degree level or similar
- Evidence of continuing professional education and management/leadership development.

Experience

- Significant leadership experience gained at senior level in a complex environment, ideally with good, first-hand knowledge of the research or health sectors, working with patients, families or vulnerable people.
- Evidence of leading the development and delivery of organisational strategy, key targets, service improvements and management of change.
- Solid track record of effectively managing resources and budgets, with experience of delivering long term financial sustainability and stewardship of valuable resources.
- Ability to forge and nurture effective partnerships and collaborative relationships with a range of organisations both inside and outside the research, healthcare and/or charitable sectors and also with patients and their families.
- Demonstrable evidence of strategic development and leading and inspiring people / organisations and developing effective partnerships.



Skills and personal attributes

- A strong strategist, able to work with the Board to define a clear direction for Muscular Dystrophy UK and then able to articulate that vision both within and outside the organisation.
- Must have a mature understanding of charity governance and the respective roles and responsibilities of the non-executive Board and the senior leadership team.
- Ability to ensure effective financial planning operates across the charity with tight financial controls and effective risk management in place.
- Must have a high level of financial acumen, able to monitor and analyse emerging income trends and also identify potential areas for efficiencies and cost reductions.
- Ability to inspire, lead, motivate and manage staff and volunteers and develop the capacity of the Senior Leadership Team so that activities are coordinated and delivered across the whole organisation.
- Ability to be an active listener, empathetic to the needs of the MDUK community.
- Ability to engage and enjoy the confidence of a diverse group of staff, volunteers and external stakeholders.
- Ability to delegate appropriately while identifying when support is required.
- Very strong written and oral communication skills with the ability to represent Muscular Dystrophy UK at all levels both internally and externally.
- Resourceful and resilient with complex problem-solving, decision-making and analytical skills.
- Ability to demonstrate a coaching / mentoring style at all levels in the organisation.
- Ability to work with clarity, openness, and with a sense of determination to deliver agreed objectives.



Other requirements

- Willingness and ability to develop an understanding of disability issues and the impact of muscle-wasting conditions.
- Commitment to working within the policy and principles of Equal Opportunities.
- Ability to work outside of normal office hours with evening and weekend meetings including some outside the UK.
- Strong support for the aims, goals and values of Muscular Dystrophy UK.



How to apply

If you are interested in the opportunity to lead this amazing charity and build on the fantastic achievements to date, 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 Russam on 07789 985229 or melissa.baxter@russam.co.uk

The next steps

Closing date for applications:

Monday 3rd June 2024

Preliminary interviews with Russam:

Thursday 13th & Friday 14th June 2024

Interviews with Muscular Dystrophy UK (in London):

8th, 15th & 16th July 2024 (dates TBC)