MPS Society

SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES

Job Title:	Chief Executive Officer
Reporting to:	Chair of the Board of Trustees
Hours:	35 hours per week (part time may be considered for the right candidate). Flexible to meet the needs of the organisation
Location:	Amersham, Buckinghamshire / hybrid (2 days a week in the office). Flexible to meet the needs of the organisation

An exciting opportunity

This is a rare and genuinely exciting opportunity to lead the UK's only dedicated charity supporting children, adults and families affected by MPS, Fabry disease and related lysosomal storage disorders. Following the current Chief Executive's planned move to become Managing Director of Rare Disease Research Partners (RDRP) in January 2027, the incoming CEO will take the helm of an organisation with over forty years of history, a trusted national reputation and a growing role on the international rare disease stage. The successful candidate will shape the strategic vision for more than 1,800 families, oversee the close partnership between the Society and its research subsidiary RDRP, and champion the patient and family ethos that sits at the heart of the organisation's work. It is an opportunity to combine ambitious strategic leadership with deeply meaningful, human impact, working alongside a committed Board, Senior Leadership Team and wider community of clinicians, researchers and pharmaceutical partners.

Why join us

- A close-knit, values-led culture. With just over thirty staff across the Society and RDRP combined, this is a place where the CEO can know the team personally, work closely with families day-to-day, and see the direct results of decisions rather than managing at a distance through layers of bureaucracy.
- Genuine autonomy to shape direction. The Board is explicitly looking to the new CEO to bring fresh thinking on technology, AI, and digital tools, and to give real freedom to modernise fundraising, services, and engagement rather than simply maintaining what already exists.
- A stable foundation to build from over forty years of track record, trusted relationships and a strong national reputation mean the incoming CEO can focus energy on vision and growth rather than firefighting or rebuilding credibility from scratch.
- Proximity to cutting-edge science: the Society's close relationship with RDRP gives the CEO regular exposure to advances in rare disease research and treatment access, while day-to-day research leadership sits with the RDRP Managing Director, allowing the CEO to focus on strategy, people and sustainability.

- A high-visibility, high-influence platform. Regular contact with government, pharmaceutical companies, clinicians and international rare disease bodies offers strong opportunities to build a public profile and personal network well beyond the charity sector.
- A team that already shares the mission. Staff are described as passionate about the Society's aims, and as having a family-first ethos, so the new CEO inherits a culture to lead and empower rather than one that needs to be built from the ground up.
- Work with a different kind of return. Beyond salary and career progression, this role offers the less tangible reward of knowing that strategic and financial decisions translate, into better support for families facing some of the rarest conditions in the country.

Key Responsibilities

Strategy & Policy

- Define and deliver the Society's strategic vision and refreshed three-year operating plan, ensuring clear priorities, measurable progress, strong financial sustainability, income diversification and effective reporting to Trustees.
- Provide strategic oversight across communications, fundraising and engagement activity, ensuring internal information flow is strong and that these areas are aligned, mutually reinforcing and focused on the Society's long-term objectives.
- Accountable for maintaining knowledge of all appropriate regulatory legislation while keeping Trustees informed of information relevant to the operational running and strategic direction of the Society.
- Oversee the development, implementation and Board approval of MPS Society policies, while fulfilling the role of Data Protection Officer.

Leadership

- Work with the Board, Senior Leadership Team and RDRP Managing Director to ensure clear governance, assurance, communication, decision-making, and effective operational alignment between the MPS Society and RDRP.
- Lead and empower the Senior Leadership Team through effective delegation, early involvement in strategic discussions, clear accountability and support for individuals to flourish.
- Ensure that appropriate systems, policies and management arrangements are in place to support effective organisational performance, risk management and regulatory compliance.
- Foster a forward-thinking, creative and learning-oriented culture that supports flexibility, continuous improvement, role development and opportunities for staff.
- Balance growth, innovation and external influence with the Society's disease-specific expertise, specialist identity and trusted connection with the MPS community.

Membership

- Ensure the Society continues to meet the evolving needs of members through a trusted, community-centred and specialist approach, with the patient and family voice at the heart of strategy, service design and decision-making.
- Anticipate and respond to emerging needs across the life course, including transition to adult services and later life care, as advances in treatment mean more people are living longer with rare conditions.

External Engagement / Collaboration

- Build and maintain senior-level relationships with statutory bodies, government agencies, pharmaceutical partners, clinical expert centres and other key stakeholders to support the Society's objectives, influence policy and practice, and protect its professional reputation.
- Strengthen the Society's role as a trusted partner within the healthcare system, using external partnerships and policy influence to improve visibility, support, treatment access and outcomes for people affected by MPS, Fabry disease and related conditions.
- Maintain strong horizon scanning across rare disease policy, diagnosis, treatment development, research, data and access pathways, ensuring the Society is prepared to respond to emerging opportunities and risks.
- Champion the responsible use of evidence, patient insight, real-world data and patient-reported outcomes to support service development, research, policy influence, treatment access and organisational decision-making.
- Responsible for leading on and driving political advocacy both within the UK and internationally, where applicable
- Champion the MPS Society in the UK and overseas, building awareness of Fabry, MPS and related diseases through engagement with rare disease bodies, patient organisations and other key audiences.
- Ensure the Society can demonstrate its impact and value to members, funders, partners and stakeholders across charitable services, advocacy, research and external partnerships.
- Accountable for all communications with the press and agreeing all press statements.
- Governance work in partnership with the Chair and Board of Trustees to ensure effective governance, strategic oversight, risk management and regulatory compliance.
- Ensure Trustees receive timely, accurate and appropriate information to support effective decision-making.

General responsibilities

- Lead and participate in appropriate team and organisational meetings.
- Adopt a positive approach to personal and professional development, including annual / mid-year performance review with line manager (Chair of the Board).
- Attend training events relevant to the specific responsibilities of the role.
- Attend UK and international events out of hours where required.
- Carry out any other reasonable duties as requested by your line manager (Chair of the Board)

Changes to key responsibilities

If for any reason it is necessary to make changes to the responsibilities in this job description this will be discussed in advance between the post holder and your line manager (Chair of the Board).

Further information

Location and working hours

This senior role requires flexibility in working hours and location. Whilst full time hours are 35 hours per week, due to the seniority and influence of the role working additional hours is often necessary.

It is primarily offered on a hybrid basis with a minimum of 2 days in our Amersham office each week. As part of the role, UK and overseas travel is necessary, which may on occasion include early morning and/or evening working and sometimes overnight stays. We have policies in place to ensure that hours worked during the weekend are fairly compensated through TOIL.

Salary will be agreed according to experience and pro-rata for part-time hours.

For an informal discussion about the role or the work of the MPS Society, please contact Dr Fiona Stewart on 07553 681 319. Kindly note, meetings with other relevant people will be available to shortlisted candidates at interview stage.

Key Personal attributes

- Self-motivated, with the drive to lead the organisation through a period of change and transition.
- Unquestionable probity and personal integrity, given the trust placed in the CEO by families, Trustees and partners.
- Exemplary written and verbal communication skills, able to convey complex scientific and clinical information to audiences ranging from clinicians to families with no prior knowledge of MPS disorders.
- Strong self-awareness, with insight into their own leadership style and impact on others.
- Emotional resilience, able to sustain performance while supporting a community facing life limiting conditions.
- A collaborative and empowering leadership style, able to build trust, delegate effectively and help individuals across the organisation flourish.
- Genuine passion for the Society's mission, with a family and member-first ethos.
- Confidence to build relationships across a wide range of stakeholders, from beneficiaries and Trustees to politicians, media and pharmaceutical partners.
- A proactive, positive approach, comfortable reacting to change and organising their own work to meet deadlines.
- Confidence speaking publicly on behalf of the organisation and the people it represents.

Requirements

Essential requirements

- Eligibility to work in the UK.
- This is an essential car user post. The applicant must hold a current UK driver’s licence, with no more than 6 points and be able and willing to drive UK wide as required.
- **Disclosure & Barring Check (DBS)**

  The MPS Society is a charity that provides a range of care, support and activities for children and adults at risk throughout the UK. This is provided through our dedicated support and advocacy service, telephone helpline, clinical research, online activities and forums, annual events, patient expert meetings, focus groups and conferences. MPS staff, Trustees and volunteers may be asked to be involved in the delivery of its regulated services and activities.

  This post is exempt under the Rehabilitation of Offenders Act 1974. Due to the sensitive nature of the duties undertaking, the post holder will be expected to undertake an enhanced DBS check as part of the recruitment process and for this to be reviewed on a regular basis.

Role specific requirements

	Essential	Desirable
Education / Qualifications		
Degree level educated or equivalent		✓
Experience of		
Senior management or organisational leadership within the Charity or third sector	✓	
Working with committees or Boards	✓	
Income generation / fundraising	✓	
Skills, knowledge and abilities		
Expertise in preparing organisational strategic / business plans	✓	
Experience of setting and working within organisational budgets	✓	
Knowledge of common, third sector, management and HR policies	✓	
Ability to motivate staff and react positively to change	✓	
Ability to organise own work to meet deadlines	✓	
Proactive, positive approach to ensure the needs of the business are met	✓	
Confidence to build effective relationships with beneficiaries, employees, Trustees, the Senior Leadership Team, politicians, media, pharmaceutical partners and clinical experts.	✓	
Ability to speak publicly with confidence on behalf of the organisation and its beneficiaries	✓	
Knowledge of the rare disease landscape, including NHS, pharma, HCPs, NICE, HTA/HST and ABPI contexts.	✓	
Excellent communication skills, with a proven ability to convey complex scientific and clinical information to diverse audiences, including healthcare professionals, patients, families, and other stakeholders with limited knowledge of mucopolysaccharidoses (MPS) disorders.	✓	

Strong business and financial acumen, with the confidence to make informed financial decisions in support of charitable impact and long-term sustainability.	✓	
Ability to use technology, digital channels and innovation to improve communication, engagement, fundraising and organisational effectiveness.	✓	
Ability to think strategically over a 5–10-year horizon and translate goals into practical delivery plans, clear measures and effective organisational follow-through.	✓	
Motivation and behaviours		
Passionate about MPS Society's mission and aims with a family/member-first ethos	✓	
The CEO must be able to demonstrate strong degrees of emotional resilience.	✓	
Collaborative and empowering leadership style, with the ability to build trust, delegate effectively, work in partnership with others and enable individuals across the organisation to flourish.	✓	

Applications

Applications should be made to hr@mpssociety.org.uk.

Please include your CV with a supporting statement of no more than 800 words. Your supporting statement should include an answer to the question below:

The MPS Society supports individuals and families affected by mucopolysaccharidoses (MPS) and related disorders. What interests you about coming to work in this area, and what motivates you to contribute to supporting individuals and families affected by these conditions?

Closing date for applications:

We have an initial closing date of 25th September 2026.