



**multiple system  
atrophy trust**

## Chief Executive Officer

Appointment Brief  
September 2026

**Nick Shanks**

Director, Harris Hill Ltd

07766 538575

[nick.shanks@harrishill.co.uk](mailto:nick.shanks@harrishill.co.uk)

[www.harrishill.co.uk](http://www.harrishill.co.uk)

**HarrisHill**  
Executive Search



# Welcome from Chair of Trustees



Thank you for your interest in becoming the Chief Executive Officer for the Multiple System Atrophy Trust.

We are a relatively young organisation, now in our 30th year. Since our inception we have developed a range of services and support backed up by an evidence base through our MSA Needs Surveys. This development has only been possible through the commitment of our MSA community, both in terms of engagement and fundraising (we receive no Government funding). However, the MSA Trust is unlike any other organisation I have been involved with. There is a genuine connection from our staff to our cause and this is demonstrated day in day out in how they go the extra mile for those we serve (and in supporting one another).

MSA is a rare neurological disease affecting about 4,500 people in the UK and Ireland. It is progressive, leading to increasing disability and premature death. Most people, including health and care professionals, have little knowledge of the condition or experience in the care of people living with it. We at the MSA Trust are here to provide the information, support and hope that people with MSA and their families require, to help them cope with the effects of the disease and allow them to live as fully as possible.

As you would imagine, supporting people with the complex needs caused by such a devastating condition is challenging, both for those affected and for our staff. Because our staff work directly with people affected by MSA in different ways, we prioritise giving them the pastoral care they need.

As the sole organisation focussing on such a rare neurological disease, we look outwards to amplify our voice through collaboration with other groups involved in neurological care. Together we can advocate for the development and improvement of services – both in health and social care – so that the needs of people with MSA can be addressed and improved.

In addition, we support the search for the cause and treatment of the disease, and the associated symptoms and issues people face. The Trust is an important player in the research into these areas, including basic research on the disease itself. We are seen as a respected sponsor of research, both in the UK and internationally.

The Trust is in a strong position in all these areas, with our amazing, committed staff and with the support of fundraising, companies, health services and research groups. We are looking for a CEO with the experience, enthusiasm and vision to take the Trust forward into a world where, although we may face uncertainty and challenge, we can take advantage of the great opportunities to develop research, care and support led by the engagement of those we serve.

We welcome your application.

**Professor David Oliver**  
**Chair**

# About us

The Multiple System Atrophy Trust is the UK and Ireland's leading charity supporting people affected by multiple system atrophy (MSA) – a rare neurological disease with no known cause or cure.

We are here to support everyone affected by MSA including people diagnosed with MSA, carers, family members and friends, and healthcare professionals. We do this by offering a range of support services, free of charge, to our MSA community.

The Social Welfare Specialist service the Trust provides supports people with non-medical needs including welfare benefits and advocacy. A vast number of MSA Support Groups are held around the UK and Ireland, including a virtual offering. Currently the Trust produces over 50 different MSA information resources, from guides to webinars, supporting people to understand MSA. We hold the PIF TICK accreditation for our materials. This is just an overview of our services and we provide much more, a lot of which is detailed on our website - [www.msatrust.org.uk](http://www.msatrust.org.uk)

A vital part of the Trust's services is its professional team provided by our MSA Health Care Specialists. Together they support people affected by MSA across the UK and Ireland. The specialist nursing service is organised into eight regionally based MSA Health Care Specialists. Each specialist is responsible for supporting people affected by MSA within their geographical area, working alongside local health and social care professionals.

## OUR VISION

The Trust's Vision is a world free of MSA. Our Mission is to find the cause and, ultimately, cure for MSA.

Until that day, we will do all we can to support people affected by MSA and to strive to ensure that they are not alone on their individual journeys.

## OUR HISTORY

Our Founder, Sarah Matheson: Sarah was diagnosed with multiple system atrophy (MSA) in 1993 and was fortunate from the outset to be under the care of specialists who recognised the symptoms and monitored her condition carefully.

However, Sarah was dismayed by the lack of available information about MSA. She felt this affected her ability to understand the disease and fully participate in her own management and care decisions. She sometimes felt isolated because of the general ignorance about the condition.

In 1997 the Sarah Matheson Trust became a registered charity. Sarah died in 1999. In 2010 the charity was renamed Multiple System Atrophy Trust and its work continues in her memory.

# The MSA Trust focuses on four key areas:



## 1. PROVIDING DIRECT SUPPORT:

We offer information and support to people living with MSA, as well as their carers, families and friends. This includes access to MSA Health Care Specialists, telephone and email support, social welfare information, and regional in-person and online support groups.

## 2. PROVIDING INFORMATION AND EDUCATION:

We produce guides, factsheets and other resources explaining MSA, how to manage its symptoms and support for adapting to life with this progressive condition. We also provide training and specialist information for health and social care professionals, helping improve understanding and care.

## 3. FUNDING RESEARCH:

The Trust is the principal UK funder of MSA research, supporting studies aimed at understanding the causes of MSA, developing treatments, improving diagnosis and care, and ultimately finding a cure.

## 4. RAISING AWARENESS AND ADVOCATING FOR PEOPLE WITH MSA:

We work to increase awareness among healthcare professionals and the wider public, while campaigning and advocating on behalf of people affected by the condition.

Please follow the link to a video explaining more about our work:

[https://vimeo.com/1190452539/fb2a9a5f08?&login=true#\\_=\\_](https://vimeo.com/1190452539/fb2a9a5f08?&login=true#_=_)

## Lindsey's story



“When I was diagnosed with Multiple System Atrophy, everything changed. The biggest shift came when I had to leave my job. My role was high-stress, and it quickly became clear that the pressure was worsening my symptoms. Stepping away from work wasn’t just a career change, it was a loss of identity, routine, and purpose.

“Since the diagnosis, fear has become a constant companion. I worry about what the future holds, especially for my husband and son. One of the hardest parts is knowing that my life may be shorter than it should be, and the thought of leaving them too soon is heartbreaking. That emotional weight is heavy. Physically, I’ve had to give up things I loved; climbing hills, cycling for miles. Learning to accept my limitations and adapt has been incredibly hard.

“Before my consultant mentioned MSA, I had never even heard of it. Even now, I don’t fully understand the condition and part of me is still in denial. It’s terrifying. The unknowns, the progression, the impact; it’s a lot to take in.

“I feel angry. Angry that my life is changing in ways I never imagined. It feels like a bereavement; grieving the life I had, the things I loved doing, and the person I used to be. The emotions are overwhelming and constant.

“In the midst of all this, the MSA Trust has been a lifeline. The factsheets have been a godsend, clear, informative, and always there when I need them, even in the middle of the night. My Nurse Specialist, Katie Rigg, has been incredibly supportive. I honestly don’t know what I’d do without her.

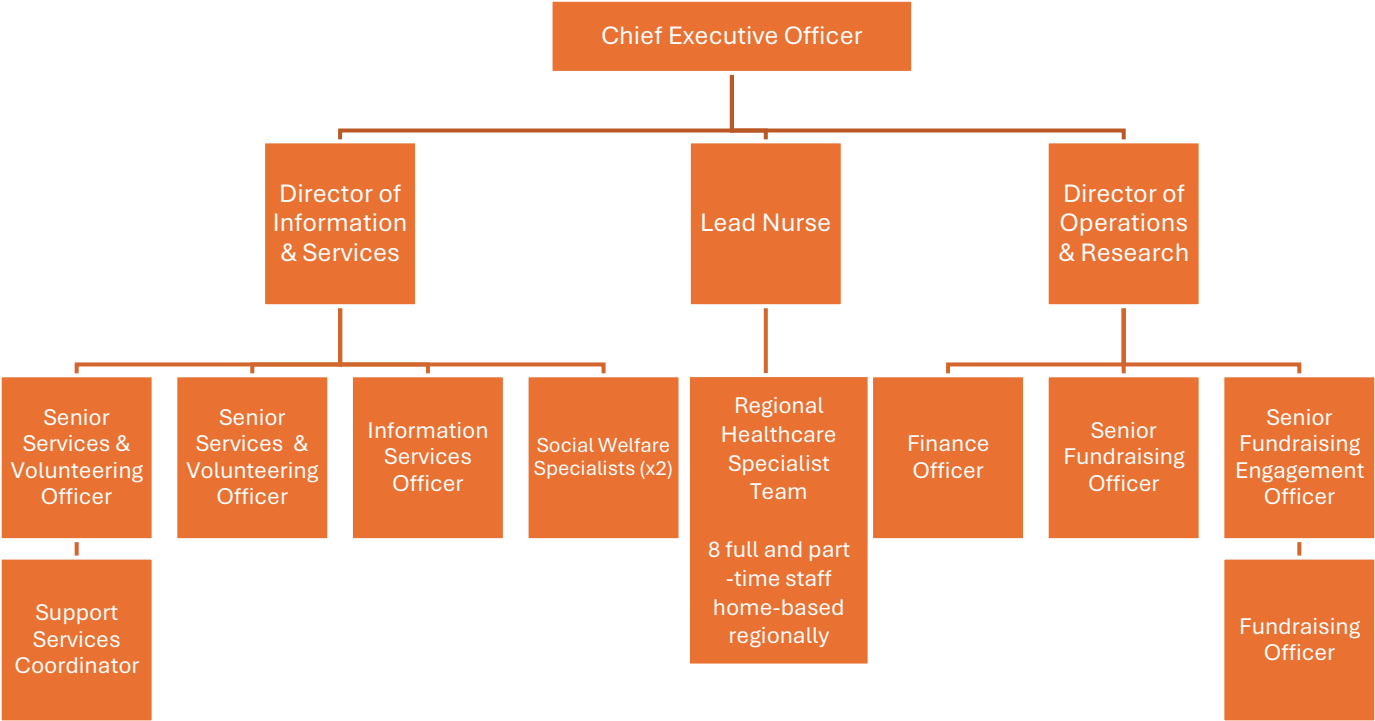
“The support group has also been invaluable. It’s not just for me - it’s a place where my husband and son can talk, ask questions, and feel supported too. That means everything.

“The Trust is more than just an organisation; it’s a source of comfort, knowledge, and connection. I can turn to it anytime, and that constant availability is so important when living with something as unpredictable as MSA.

“Through it all, I am deeply grateful for my husband and son. Their love and presence keep me going. MSA is still so unknown. Even my GP didn’t understand it and had to reach out to Katie for guidance. That’s why the MSA Trust needs more funding - so they can continue their vital work in research, education, and support.

“People with MSA rely on the Trust, and without it, I would feel completely lost and alone.”

# Organisation chart



## MSA Health Care Specialists Support

**139**

Support  
Groups  
attended

**34**

Teaching  
sessions  
delivered

**133**

MSA Clinic  
consultations

They continue to

- ✓ provide expert symptom management, emotional support and practical guidance at Support Groups
- ✓ work collaboratively with local clinicians at MSA clinic consultations
- ✓ improve care quality and raise awareness through health and care professionals training events

**We hosted  
89 in-person  
Support Groups,  
an increase of  
14%**

We continue to provide access to safe and supportive meetings – sometimes the only place where a person with MSA can meet someone else on a similar journey as them.



**91%**

of People with MSA feel the Trust's varied range of support services has provided them with useful information about living with MSA.

**70%**

of people with MSA says the Trust has enabled them to access support networks from other organisations.

**84%**

of people with MSA feel more supported as a consequence of engaging with the MSA Trust

Of those who had an MSA Health Care Specialist in attendance at their clinic appointment,

**96%**

said it was beneficial to them.



*"We were given a pack of information when we registered which has been so useful. They (MSA Trust) have also hosted in-person meetings which has helped us meet other sufferers. They have signposted us to where to obtain grants and just recently have agreed to fund voice banking.... we would be lost without the trust."*



In-person support groups reach up to **71%** of carers and **67%** of family members not living with someone with MSA, making them one of the most impactful community services.



The MSA Trust website reaches over 4 in 5 people with MSA (**82%**), reinforcing its role as a key information source across the whole community



The MSA News Magazine is the single most used service, accessed by **80%** of people with MSA and **86%** of carers

# £480,548

## Research expenditure 2025-26

Invested across 3 research centres and 5 active large grants, funding science at the frontier of MSA understanding - from biomarkers and early diagnosis to care quality and clinical trial readiness.

# 5

Large  
research  
grants  
currently  
funded

# 3

Research  
centres  
supported

# 3

Clinical  
research  
fellows  
funded  
to date

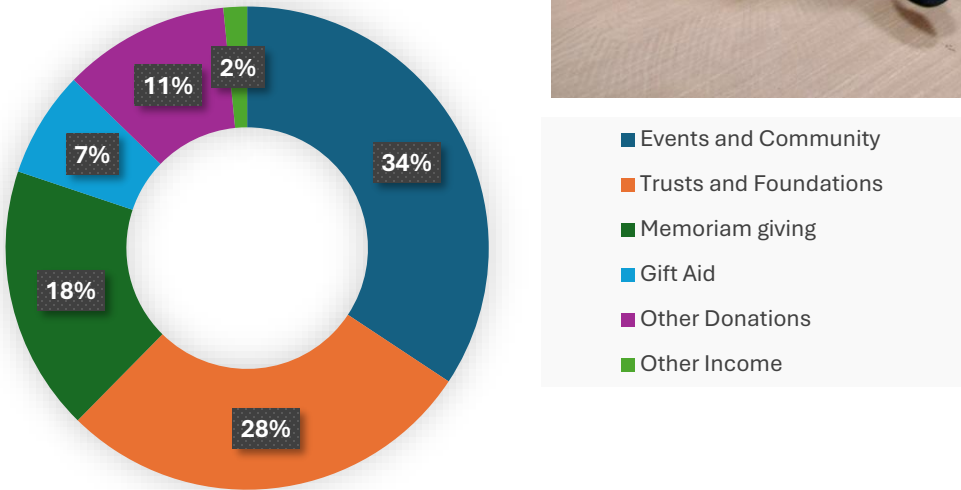
# MSA Trust

## Operational Income and Expenditure

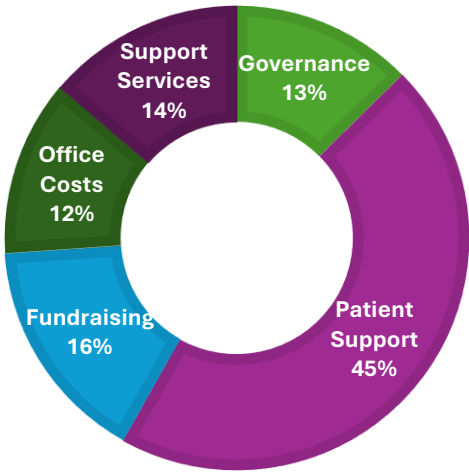
### 2025-26



MSA Trust Operational Income 2025-26  
TOTAL = £1,028,710  
(Full accounts and annual report will be published in Autumn 2026)



MSA TRUST OPERATIONAL  
EXPENDITURE 2025-26  
TOTAL= £1,188,480



- Governance
- Patient Support
- Fundraising
- Office Costs
- Support Services

# Job description



| JOB TITLE   | CHIEF EXECUTIVE OFFICER     |
|-------------|-----------------------------|
| Reports to: | MSA Trust Board of Trustees |
| Salary:     | Circa £70,000 p.a.          |
| Location:   | London (hybrid)             |

## ABOUT THE ROLE

The CEO role at the Multiple System Atrophy (MSA) Trust will play a critical role in running the MSA Trust, the only UK and Ireland charity devoted solely to researching the cause and ultimately the cure of MSA; and delivering a range of impactful national services for people affected by MSA and those that support them.

The postholder will provide strategic leadership for the charity, working with the Board of Trustees to deliver the Trust's vision, mission and strategy. They will be accountable for organisational performance, financial sustainability, governance, research impact, service development and external influence, ensuring that the Trust delivers meaningful outcomes for people affected by MSA and their families.

The postholder will provide strategic direction, operational support and be instrumental in ensuring collaboration and synergy across the Trust's services and projects amongst Health and Care Professionals, Statutory and voluntary sectors where possible. This needs-led approach will in turn inform and direct the Trust's policy and campaigning work.

## KEY RESPONSIBILITIES

The CEO will lead the charity forward in its next stage of development and must be able to demonstrate exceptional leadership skills, strong financial and operational management capability, along with clear empathy with the cause. The CEO will have overall accountability for organisational performance and delivery through the leadership of the Senior Management Team. The responsibilities will include, but are not limited to:

## STRATEGY

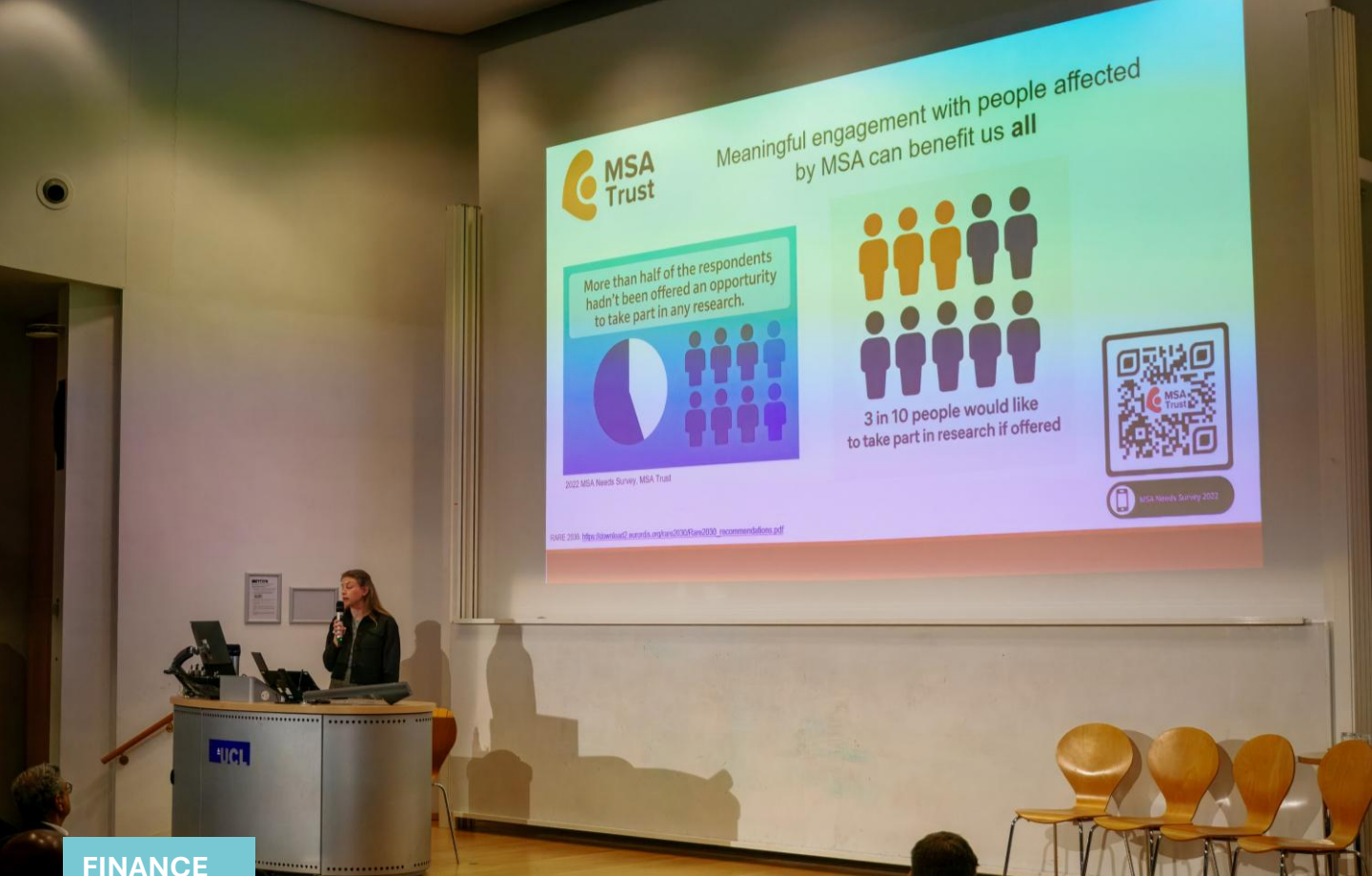
- Formulate the Trust's strategic plan and vision in conjunction with Trustees.
- Lead the development and implementation of future organisational strategies and ensure the Trust remains responsive to emerging opportunities, challenges and the changing needs of people affected by MSA.
- Ensure the voice and experiences of people affected by MSA remain at the centre of the Trust's strategy, service development, research priorities and influencing activity.

## GOVERNANCE & ADMINISTRATION

- Lead the development of high-quality Board and Committee papers to support informed decision making by Trustees.
- Ensure adherence to Charity Commission guidelines and other regulations to protect the charity's integrity.
- Establish an effective framework and leadership capacity aligned with the charity's strategic goals.
- Maintain robust data protection and information security frameworks to safeguard sensitive information.
- Proactively identify and manage organisational risks.
- Maintain appropriate systems of internal control to prevent fraud and ensure accurate reporting.
- Hold executive accountability for compliance with charity law, employment law, health and safety law, data protection and other regulatory requirements and foster a culture of accountability.
- Assume overall responsibility for nurturing a strong safeguarding culture, ensuring effective policies, practices and mechanisms are in place to protect vulnerable individuals and uphold the charity's reputation.

## PUBLIC PROFILE

- Provide strategic leadership for the Trust's communications and digital development.
- Raise the profile of MSA within the NHS and broader medical community.
- Act as the principal ambassador and spokesperson for the Trust.
- Develop strategic relationships with statutory services, relevant government departments, elected representatives, regulators, researchers and partner organisations.
- Influence within the Governmental sector and national and local voluntary networks that support shared ambitions for the neurology sector.
- Develop relationships with other neurological/rare disease associations and charities, in the UK and abroad.
- Engage with key stakeholders to influence improvements in support for people affected by MSA.



## FINANCE

- Be accountable for the charity's income generation strategy and long-term financial sustainability.
- Lead the annual budgeting process and development of business plans, in conjunction with the Finance sub-committee (FSC).
- Lead the annual reporting process and other statutory filings, in conjunction with auditors and FSC.
- Ensure robust financial management, performance reporting and risk management systems are in place.

## HR

- Input into recruitment across the organisation including at induction.
- Lead, motivate and support the senior management team and ensure effective people management practices across the organisation, including workforce planning and legal compliance; appraisal and supervision.
- Foster an inclusive, supportive and high-performing organisational culture, including pastoral care.

## RESEARCH

- Provide strategic leadership for the Trust's research programme and partnerships, oversee our Research strategy and the grant-making process.
- Facilitate the positioning of the Trust as a recognised and influential partner in the co-ordination and development of MSA research activity globally.
- Develop strategic relationships with researchers, research institutions, industry partners and funders.
- Ensure research informs service development, policy and influencing activity.

# Person specification



## ESSENTIAL:

### Education and Qualifications

- Degree-level qualification or equivalent professional leadership background.

### Experience

- Substantial senior management experience, including reporting directly to or working closely with a Board of Directors/Trustees.
- Proven record of developing and executing strategic plans that drive organizational growth or successful transformation.
- Demonstrated financial acumen with experience managing budgets, P&L (Profit and Loss), and fiscal governance.

### Knowledge and Skills

- Comprehensive understanding of corporate governance, compliance, safeguarding and legal responsibilities.
- High-level emotional intelligence with the ability to build, inspire, and manage high-performing executive teams.
- Exceptional communication, public speaking, and stakeholder engagement skills.

### Personal Attributes

- Unimpeachable integrity, ethical judgment, and accountability.
- Strong entrepreneurial mindset combined with strategic resilience under pressure.
- Visionary leadership style geared toward long-term organisational success.

## DESIRABLE:

- Post-graduate qualification (such as an MBA or Master's degree) or specialized executive leadership training.
- Experience operating within the non-profit sector

**Summary:** This is a senior executive leadership role suited to an experienced strategic leader who can drive organisational performance, build partnerships, lead a multidisciplinary team, oversee financial and governance responsibilities, and champion improved support and research for people living with MSA. Experience of operating within a charity would be very desirable

# Terms of Appointment

| Job title       | Chief Executive Officer                                                                                                                                                                                                                                                                                                                                                                                 |
|-----------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Reports to:     | MSA Trust Board of Trustees                                                                                                                                                                                                                                                                                                                                                                             |
| Salary:         | Circa £70,000 p.a.                                                                                                                                                                                                                                                                                                                                                                                      |
| Location:       | London, N1 with hybrid working in place                                                                                                                                                                                                                                                                                                                                                                 |
| Hours of work:  | 35 hours per week<br>Full-time hours 9-5pm<br>Evening and weekend work sometimes required                                                                                                                                                                                                                                                                                                               |
| Contract:       | Permanent / Full time                                                                                                                                                                                                                                                                                                                                                                                   |
| Annual leave:   | 36 days per year including bank holidays, rising to a total of 39 after 2 years                                                                                                                                                                                                                                                                                                                         |
| Pension:        | 6% employer pension contribution                                                                                                                                                                                                                                                                                                                                                                        |
| Other benefits: | <ul style="list-style-type: none"><li>• Death in Service</li><li>• Salary Sacrifice</li><li>• Long Service Sabbaticals</li><li>• Additional day off for Birthday</li><li>• Eye Tests and Help towards glasses costs</li><li>• Paid time off to attend an appointment to give blood</li><li>• Volunteering</li><li>• Flexible Working Policy</li><li>• Hybrid Working</li><li>• Working Abroad</li></ul> |

The MSA Trust is committed to safeguarding and promoting the welfare of vulnerable adults and young people/children and expects all staff and volunteers to share this commitment. Pre-employment checks include an enhanced disclosure and barring service check as a requirement of this post. Our Safeguarding Policy is available on our website, and we encourage applicants to review it before applying.

# How to apply



## If you would like to apply, please send the following:

- An up-to-date CV
- A Supporting Statement (no more than 2 x A4 pages) outlining why you are interested in becoming Chief Executive Officer and relevant experience for the role.

Please submit your completed application to [nick.shanks@harrishill.co.uk](mailto:nick.shanks@harrishill.co.uk) by **9am Friday 9 October 2026**.

## DATES FOR YOUR DIARY:

|                                       |                           |
|---------------------------------------|---------------------------|
| <b>Closing date for applications:</b> | 9am Friday 9 October 2026 |
| <b>First interviews (via Teams):</b>  | w/c 26 October 2026       |
| <b>Second interviews (in person):</b> | w/c 2 November 2026       |

Please could you also let us know if you will require any special provision should you be called forward for interview.

Please state in your application if you have any commitments during the interview period that may coincide with these dates.

# Advertisement

## **Harris Hill is delighted to be working with the MSA Trust to recruit its new Chief Executive Officer.**

The Multiple System Atrophy Trust is the UK and Ireland's leading charity supporting people affected by multiple system atrophy (MSA) – a rare neurological disease with no known cause or cure.

We are here to support everyone affected by MSA including people diagnosed with MSA, carers, family members and friends, and healthcare professionals.

We do this by offering a range of support services, information and education, funding research and raising awareness and advocating for people with MSA.

### **As Chief Executive, you will:**

- Lead the charity forward in its next stage of development.
- Demonstrate exceptional leadership skills, strong financial and operational management capability.
- Have a clear empathy with MSA Trust's cause.

If you are inspired and excited by what the MSA Trust does, we'd love to hear from you.

### **Job title: Chief Executive Officer**

Salary: circa £70,000 p.a.

Contract: Permanent / Full-time

Location: London, N1 with hybrid working in place

### **How to apply:**

Please review the Recruitment Pack for further information about the MSA Trust, the CEO position and for details on how to apply.

### **Closing date for applications: 9am Friday 9 October 2026**

Both the MSA Trust and Harris Hill operate an equal opportunity policy and commit to treating all of our candidates and jobseekers fairly. We welcome and encourage applications from everyone regardless of age, disability, sex, gender reassignment, sexual orientation, pregnancy and maternity, race, religion or belief and marriage and civil partnerships.