



## **Job description**

<b>Job title:</b>	Head of Policy and Public Affairs
<b>Job type:</b>	Permanent, 35 hours per week (Full-time)
<b>Responsible to:</b>	Chief Executive
<b>Location:</b>	Remote (Home-based) with easy travel to Westminster
<b>Salary:</b>	£55,000 per annum

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### **Job purpose:**

The Head of Policy and Public Affairs is a new role that will lead the charity's policy and public affairs strategy to build a better life for anyone affected by Huntington's disease. They will report to the Chief Executive and will work across all departments of the charity.

The role will require frequent work in Westminster and Whitehall and elsewhere in the England and Wales. The post holder needs to be a self-starter and comfortable working with the most senior external stakeholders.

The role will develop a credible and comprehensive evidence base and policy recommendations for the Huntington's Disease Association. It will oversee a programme of external stakeholder engagement aimed at meeting our influencing goals and ultimately supporting the charity to achieve its vision of a better life for anyone affected by Huntington's disease.

### **About Huntington's disease and our work:**

The Huntington's Disease Association is the only organisation across England and Wales offering support to people affected by Huntington's disease. Huntington's disease is a life-limiting, genetic disorder that causes the breakdown of nerve cells in the brain. This leads to symptoms affecting three main areas, movement, behaviour and cognition.

The Huntington's Disease Association was established in 1971 as a specialist service to help people and families seriously affected by Huntington's disease. We raise awareness of Huntington's disease across the general public and allied health and social care professionals. We offer practical advice and support, training to health and social care

professionals and fund research into the disease. We want a better life for anyone affected by Huntington's disease.

## **Main duties:**

### **Policy and policy development**

1. Provide a high level of expertise on policy across the organisation and externally, and to lead the team in developing new thinking and solutions on research policy and equitable access to treatments, care, support and opportunities.
2. Lead the Huntington's Disease Association's policy influencing work with key stakeholders across England and Wales.
3. Develop, manage and deliver a substantial programme of high-quality policy analysis and proposals for change.
4. See through, from inception to launch, ground breaking policy publications of the highest quality that have significant influence on government and NHS policy and practice.
5. Line manage the Policy and Public Affairs Manager to ensure they fulfil their duties and responsibilities in accordance with their role description, the policies and procedures of the charity, and within the legislative framework of England and Wales.
6. Manage the team's budget, ensuring the team operates cost effectively in meeting its objectives.
7. Develop and lead a structured programme of policy work that builds our evidence base, identifies the key challenges in the field, and brings forth new, innovative policy ideas and solutions.
8. Work with colleagues across the organisation to ensure there is good co-ordination and communication of policy and public affairs throughout the charity in order to foster a shared understanding of the Huntington's Disease Association's policies and issues.
9. Work across the charity with the to develop campaign ideas with key audiences that deliver the Huntington's Disease Association's strategy.

### **External relations and influencing**

10. Establish and maintain effective collaborative relationships with external stakeholders and identify opportunities and strategies to improve engagement with science leaders, pharmaceutical industry, political and health and care officials, corporate leaders, scientific bodies, donors and other charities.
11. Work closely with colleagues across the charity to ensure that the Huntington's Disease Association's external messaging and activities reflect our policy priorities and positions.

12. Ensure the Huntington's Disease Association is taking opportunities to apply its policy expertise through engagement in external events and conferences and acting as a media spokesperson when appropriate

### **Evidence, impact and analysis**

12. Identify policy areas in which the Huntington's Disease Association is seeking greatest action and develop evidence-based strategies to influence and effect positive change.
13. Work with the communications team to ensure families affected by Huntington's disease are at the heart of the development of the Huntington's Disease Association's policy priorities and positions.
14. Keep abreast of the policy environment to build and maintain a deep understanding of current issues and trends and producing insight and analysis for the charity.

### **Public Affairs and Campaigns**

15. Advise the trustees and Heads of Departments about effective political positioning and campaigns to achieve our goals; working to ensure we are able to successfully influence key Government policy and decisions
16. Build and maintain effective high-level relationships with key decision-makers and opinion formers including in Government and in Parliament.
17. Ensure campaigns are driven by the needs of the Huntington's community, ensuring consultation and co-production throughout.
18. Support the Policy and Public Affairs manager to develop and deliver a public affairs strategy using a range of creative tactics that engage our supporters, create pressure, build momentum and drive forward our influence with Parliament and Government
19. Build and sustain strong strategic partnerships, for example, with other voluntary organisations, think tanks etc to extend the charity's reach and impact

### **Other duties**

1. Attend and contribute to team and charity-wide meetings.
2. Be familiar with and adhere to relevant legislation.
3. Work collaboratively with colleagues from other teams across the organisation.
4. Understand our obligations under the Data Protection Act and Fundraising Codes of Practice about data management and ensure the Huntington's Disease Association acts in accordance with legislation.
5. Respect the confidentiality of all information obtained whilst working for the Huntington's Disease Association.

6. Work in a manner that facilitates inclusion, particularly of people affected by Huntington's disease.
7. Carry out other tasks as directed by your line manager.

### **General:**

All applicants must be able to demonstrate the right to work in the UK.

The post will be subject to a three-month probationary period.

Full details of how we securely handle the data you provide to us as part of the recruitment process can be found in our privacy notice for job applicants on our website - [www.hda.org.uk/privacy-policy](http://www.hda.org.uk/privacy-policy)

This job description is a representative document. Other reasonably similar duties may be allocated from time to time commensurate with the general character of the post and its grading.

Out of pocket expenses including travel and mileage allowances will be paid on receipt of appropriate claim forms and invoices/receipts. There will be an expectation that the post holder will work some evenings and weekends. There may be occasional overnight stays. Time will normally be taken back in lieu of hours worked.

This post is exempt from the provisions of Section 4(2) of the Rehabilitation of Offenders Act 1974 (Exceptions) Order 1975. You are therefore not entitled to withhold information about convictions which for any other purposes are 'spent' under the provisions of the Act. Any failure to disclose such convictions could result in dismissal or disciplinary action by the Huntington's Disease Association. Any information given will be completely confidential and will be considered only in relation to the positions to which the Order applies.

The successful applicant will be required to complete an online enhanced DBS (Disclosure and Barring Service) application prior to joining the Huntington's Disease Association. This will be completed at the expense of the charity.

All staff are responsible for the implementation of the Health and Safety Policy so far as it affects them, their colleagues and others who may be affected by their work. The post holder is also expected to monitor the effectiveness of the health and safety arrangements and systems to promote improvements where necessary.

The post holder will be expected to undertake training and retraining throughout employment in this post and will be expected to discuss and identify their training goals, with their line manager, to develop their knowledge base and ability in their role.

## Personal specification

**Job title:** Head of Policy and Public Affairs

**Organisation:** Huntington's Disease Association

**Date prepared:** December 2023

	Essential or Desirable	How identified
<b>Qualifications</b>		
Educated to degree level or equivalent experience.	E	Application and interview
<b>Experience</b>		
Strong demonstrable experience of influencing Government and public policy at UK, devolved and local level.	E	Application and interview
Experience of delivering high quality, integrated policy and public affairs strategies.	E	Application and interview
Good experience of managing a diverse range of stakeholder audiences in order to support the delivery of influencing plans.	E	Application and interview
Significant experience of developing high quality policy outputs such as briefings, reports and consultation responses.	E	Application and interview
Substantial experience of designing and delivering policy development initiatives.	E	Application and interview
Strong experience of working with people with lived experience to co-produce policy positions.	D	Application and interview
Substantial experience of commissioning a range of qualitative and quantitative	E	Application and interview

evidence to support policy development.		
Proven experience of strategic development and project management, using resources to deliver real impact.	E	Application and interview
Experience of representing the organisation at a senior level with key external audiences, including the media.	E	Application and interview
Strong experience of budget management.	E	Application and interview
Good experience of working in a senior team to develop, deliver and communicate business plans.	E	Application and interview
<b>Knowledge and skills</b>		
A thorough understanding of health and social policy and UK government policy making processes.	E	Application and interview
A good understanding of public affairs/political influencing and the wider political environment in the UK.	E	Application and interview
Excellent research, analytical and information gathering skills	E	Application and interview
Proven leadership and management skills.	E	Application and interview
Ability to manage a complex and diverse workload.	E	Application and interview
Outstanding communication skills – both written and verbal.	E	Application and interview
Collaborative, with excellent interpersonal skills and ability to partner with and influence a range of different audiences.	E	Application and interview