

About the Post

Working closely with the Head of Policy and Public Affairs, you will support the delivery of lobbying, awareness and engagement projects aimed at politicians, civil servants, health professionals and our members.

You will work with colleagues to research, draft, produce and deliver policy briefings and more in depth reports in relevant policy areas. This work will be directly related to campaigning objectives.

The role will also involve working with members to understand their needs and challenges. We seek to ensure all our campaigning is member-led and focussed on outcomes that will improve their lives. The role will include updating members on political developments of relevance.

You will also assist in providing secretariat support to the APPG on Haemophilia and Contaminated Blood.

Key Responsibilities:

Research and project support:

- Conduct background research in support of current projects
- Jointly write reports on challenges facing our members
- Update general policy briefings for Parliamentarians

Support for the APPG on Haemophilia and Contaminated Blood

- Maintain the webpage and membership list for the APPG
- Produce minutes of meetings of the APPG
- Draft correspondence to MPs and Peers on the APPG

External Communications:

- Produce news and blog posts regarding public affairs and policy developments for The Haemophilia Society website
- Use social media to promote public affairs and policy activity

Political Monitoring:

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- Track relevant activity in Westminster and where necessary provide updates to colleagues
- Identify opportunities for briefings and other engagement for MPs

General:

- Be an effective member of the team, recognising, respecting and promoting the different roles and diversity of the individuals in the team and presenting a positive impression of the team and the organisation.
- Work closely with colleagues to ensure the delivery of projects
- Undertake any other tasks that may be requested.
- The role may require some travel around the UK and occasional evening work in relation to parliamentary activities
- This post is subject to DBS clearance and understanding and agreeing to our confidentiality policy.

Person Specification

- A proven interest in UK public affairs.
- An understanding of challenges in health, disability and work policy.
- A strong desire to develop skills and grow knowledge.
- Confident and professional verbal and written communication skills.
- Strong IT skills including use of Word, Excel and PowerPoint.
- Experience of using Wordpress and maintaining a website would be useful
- Good time management skills and the ability to manage workload
- Understanding of equal opportunities, access and inclusion and the ability to incorporate these into all aspects of work.

About the Charity

We are a small charity that makes a huge difference to the lives of people living with genetic bleeding disorders in the UK. Our community look to us for information and support and to represent their voice to government and their clinical teams. We empower our members to live their lives to the full, whether they are parents of a newly diagnosed baby, anxious and uncertain what the future will hold, or have been living with their bleeding disorder their

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whole life and are now looking to ensure their complex needs are met as they reach older age. We have members across the UK.

We campaign and lobby for our members and ensure that our work reflects the range of challenges our members face. Their needs and priorities vary greatly and it is part of our challenge to use our resources as effectively as possible. Despite being a small charity we seek to 'punch above our weight' and leverage opportunities to effect the improvement of care and treatment for people with bleeding disorders.

Our current lobbying work focuses on improving outcomes for people with bleeding disorders, through improved and more personalised care. Our key theme for 2018 is empowerment.

We see particular challenges for our members at first diagnosis as well as during unplanned emergency care and are starting projects on these issues. Many of our members rely on benefits and changes disability benefits are causing uncertainty and reduced support for our members. We also campaign for better support schemes for people affected by contaminated blood products.

Our policy and public affairs work means we are able to influence commissioning decisions and as the secretariat for the APPG on Haemophilia and Contaminated Blood we are able to ensure our community remains at the forefront of parliamentarian's minds. We also see challenges related to access to the best and safest treatment for our members and work with clinicians, the DH, NICE, NHS England and the MHRA on these issues.

Recently the government announced it will hold a public inquiry into the contaminated blood scandal where around 6000 people were infected with HIV, hepatitis and other viruses via their NHS treatment in the 1970s and 80s. Almost everyone treated for a bleeding disorder at this time was infected and so this has had a dramatic impact on our community for many years. We hope the inquiry will find the truth about what happened and lead to compensation and closure for our members, but we know for many it will be a difficult and emotional experience, and we will be actively involved in the process of an inquiry that may last several years.

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www.haemophilia.org.uk