How we plan to use the grant

In applying for this grant, the Haemophilia Society (THS) put forward a detailed plan of patient advocacy in support of the bleeding disorders community.

These plans include:

Outreach and advocacy work

- We want to host around 20 information events for the infected and affected community in the next 12 months, most of which will be held informally in small venues. A new outreach worker (yet to be appointed) will liaise with local groups, campaign groups and THS members to ensure that the community across the UK has access to these events. The aim of the events is to provide bespoke support appropriate to the evolving compensation process. The content will be decided after consultation with our members.
- We have recruited a full-time public affairs manager to ensure that the bleeding disorder community's needs are represented in the UK's political institutions.
- We will support the next generation of people with bleeding disorders through our Newly Diagnosed Weekends, which currently have very large waiting lists, meaning we struggle to meet demand. We hope this grant will enable us to reach more newly diagnosed families in need of support.
- In addition, we are planning a new family education event. This is a much-needed opportunity for parents and children to connect with others at a residential centre and to learn more about the latest treatment and care for people with bleeding disorders.
- Supporting the next generation of patient advocates by boosting our Young Ambassadors programme through training and development.
- Providing ad hoc expert support for the infected blood community as needed, such as on welfare issues, interpreting medical records and tax issues.
- We plan to recruit a policy engagement manager to ensure the interests and needs of people with bleeding disorders are represented at the heart of clinical policy making.

Empowering the patient voice through THS's campaigns and communications

- Working with relevant government departments and healthcare professionals to ensure the recommendations of the Infected Blood inquiry on protecting patient safety are implemented.
- Pioneering change for women and girls with a bleeding disorder based on findings in a report published by THS in July 2025.
- Commissioning research into finding new ways of measuring the effectiveness of haemophilia A treatment, based on new criterion to reflect an altered and improved treatment landscape.
- Supporting people with very rare bleeding disorders who lack treatment options, community and recognition.
- Maintaining political awareness and pressure within Parliament by providing secretariat services to the All Party Parliamentary Group on Haemophilia and Contaminated Blood.
- Supporting the integration of Advanced Therapeutic Medicines and Products (ATMP) into the bleeding disorders treatment landscape. For example, THS is leading a

research project into the implementation of gene therapy for haemophilia B which will produce learnings for future therapies.
- Restructuring THS website to reflect changes in the way our supporters search for and consume information. Streamlining and updating content to provide easier access to support and information.
- Supporting haemophilia centres in improving their services for bleeding disorder patients when required, based on their individual needs.

Investing in the structure to deliver our ambitions

Our plans are dependent on having an expanded staff team to support the new events and services proposed. For any of you who know our staff, you'll already understand how hard they work and you can be confident that their time will be used efficiently and productively to ensure our support is as good as it can be.

The grant will be used to part-support some existing roles that deliver on advocacy and empowering patient voice, including members of our public inquiry team, such as Debra Morgan and Jessica Bomford.

In addition THS is currently recruiting a full-time public affairs manager who will play a pivotal role in supporting and empowering the patient voice. The job will involve liaising with MPs and peers, providing the secretariat for the All Party Parliamentary Group on Haemophilia and Contaminated Blood and ensuring that the needs of our members and the wider infected blood community are understood by decision-makers. The role will also involve robust scrutiny of relevant government policy and liaison with relevant health bodies to ensure the patient voice is at the heart of decision-making.

As mentioned above, we are strengthening our policy work by recruiting a public engagement manager who will steer our work with clinical decision-makers and ensure that we are at the heart of conversations about new treatments and relevant technological and structural changes within the NHS.

THS has just appointed a full-time communications and marketing officer to support the work of the communications team. This role will free up capacity to enable our communications manager to devote more time to infected blood-related content. The communications and marketing officer will support communications across the charity.

We will also recruit a community outreach co-ordinator will organise a series of UK-wide events for the infected blood community.

We anticipate contracting external experts to support our infected blood work, depending on gaps in our knowledge and the way in which the compensation roll-out evolves. This could include expert clinical guidance on interpreting medical notes, specialist financial support, welfare advice or legal interpretation of infected blood-related questions.