



THE
HAEMOPHILIA
SOCIETY



The Haemophilia Society Strategic Plan 2020 – 2022

Registered charity no. 288260 (Scotland SC039732) Company limited by guarantee reg. no. 1763614



Introduction

We are the only UK-wide charity for all those affected by a genetic bleeding disorder; a community of individuals and families, healthcare professionals and supporters.

For 70 years we have campaigned for better treatment, been a source of information and support, and raised the awareness of bleeding disorders.

Our Vision, Mission and Aims

Vision

Anyone affected by a genetic bleeding disorder has the opportunity to live a fulfilled life.

Mission

- Inform
- Advocate
- Empower

Aims

- Everyone affected by a bleeding disorder has equality of opportunity
- Everyone affected by a bleeding disorder has the opportunity to connect with others in the community
- Everyone affected by a bleeding disorder has the knowledge to feel empowered

We do this by:

- Raising awareness about bleeding disorders
- Providing information and support throughout our members lives.
- Influencing and advocating on health and social care policy and access to treatment

More than 32,000 men, women and children in the UK have a diagnosed bleeding disorder, and the number rises every year. Membership of The Haemophilia Society is free and open to all.

Our peer support through local groups around the UK, online community, and members events offer friendship and a listening ear when needed, as well as enabling people to share their views and experiences.

By bringing people together for information and support at events tailored to support members throughout their lives, we amplify their voices to reduce isolation and influence government, welfare and health care policy.

Our community are at the heart of everything we do – we work collaboratively with members and health professionals to ensure we make decisions influenced by their valued input and direction.

As bleeding disorders are rare, many people will never encounter The Haemophilia Society; we are largely invisible beyond the communities we serve. We have to work doubly hard to raise both awareness and understanding of bleeding disorders and vital funds needed to give those affected the services they deserve and need to live the best life they can.

Context

The Haemophilia Society has developed services, events and campaigns as detailed in the 2015 – 2018 Strategy leading to increased member engagement, the development of services focussed on newly diagnosed families, children, young adults and ageing as well as for women with bleeding disorders and people with inhibitors.

We also campaigned alongside other campaign groups for a Public Inquiry into Contaminated (Infected) Blood and for improved benefits support, treatment and care. During 2018 we hosted the World Federation of Hemophilia Congress welcoming over 5000 delegates from over 130 countries worldwide.

Due to the demands of Congress we extended our strategy for an additional year and using the Theory of Change Model we worked with members, partner organisations and stakeholders to develop this strategy during 2018-19.

Haemophilia and Bleeding Disorders treatment has made significant advances in the last 5 years with the biggest change in treatment options for over 20 years. This has led to improved quality of life for many of our community, but an increase in disparity between those with haemophilia and those with other bleeding disorders.

The opening of the Public Inquiry has also brought to the fore the need for ongoing treatment and emotional support for our older members who are living with multiple infections as well as the long-lasting effects of haemophilia; as the first generation of people living to older age with a bleeding disorder.

Our increased services and advocacy activity have enabled us to build stronger relationships with our members, but also highlighted the need to now work differently to ensure we are relevant to a wider range of the community and are accessible in ways that work for them, digitally and more locally.

We have successfully increased our income but demands for our services and events continues to require us to diversify our funding and increase income further to enable us to continue to meet the needs our community during the next few years.

We have also revised and refreshed our Mission, Vision, Aims and Values based on the feedback we received.



Our Values

We are:

- Transparent
- Professional
- Pioneering
- Supportive

Strategic Aims

- To support and engage with the wider bleeding disorders community
- To empower our community and amplify their voices and advocate on their behalf
- To increase our funding and improve our reputation
- To ensure best practice in our governance.

Strategic Aim 1

To support and engage with the wider bleeding disorders community across the UK

- To extend our reach beyond our current members to engage with other members of the bleeding disorder community, including those with mild and moderate bleeding disorders, rarer bleeding disorders and women, as well as people with haemophilia
- To ensure new members feel engaged and part of the community family
- To improve the number of people who are actively engaged with The Society
- To increase the number and activities of local groups
- To improve access to high quality information for the community
- To continue to develop partnerships with professional bodies, partner organisations and haemophilia centres.

Strategic Aim 2

To empower our community, amplify their voices and advocate on their behalf

- To become the 'go to' information hub through for people with bleeding disorders in the UK
- To develop a strong evidence base of the experiences of our community living with a bleeding disorder across the UK
- To continue to advocate for consistency and improvement in treatment standards across UK
- To engage with and support our members to achieve effective advocacy for inclusion and consistency through the Public Inquiry ensuring transparency and openness in our actions
- To establish The Society as a high-level Public Affairs organisation to ensure bleeding disorders remain on the political agenda.



Strategic Aim 3

To increase income and improve our reputation

- To increase our income and diversify the sources
- To listen to our members needs and respond where possible
- To be transparent in our activities and ways of working, learning from challenges to develop as an organisation
- To work collaboratively with partner organisations seizing opportunities that meet our strategic goals
- To increase and improve communications with our members and wider community aiming to become a central hub of information.

Strategic Aim 4

To ensure best practice in our governance

- To demonstrate the standards of the Charity Governance Code
- To practice a system of 'review and develop' in all our activity
- To strive for a diverse board makeup that is representative of our community.

As with all strategic documents, this outlines the difference we want to make with and for our community and organisation. Our annual plans and three-year targets document the detail of our work including how and when we will achieve this. We will report our progress in our members magazine HQ, at our AGM and in our annual report that is published on our website.



THE HAEMOPHILIA SOCIETY

Find the information you need on our website at haemophilia.org.uk, email us at info@haemophilia.org.uk, or give us a call on 020 7939 0780.

Your Society: getting in touch

The Haemophilia Society

52B Borough High Street

London SE1 1XN

Phone: 020 7939 0780

Email: info@haemophilia.org.uk

Web: haemophilia.org.uk



HaemophiliaSocietyUK



HaemoSocUK



thehaemophiliasociety

Registered charity no. 288260 (Scotland SC039732)

Company limited by guarantee reg. no. 1763614

Members of the European Haemophilia Consortium, the World Federation of Hemophilia Chair, NCVO, NICVA, The Genetic Alliance: Clive Smith: clive@haemophilia.org.uk

President: Baroness Meacher

© The Haemophilia Society 2020

