

THE HAEMOPHILIA SOCIETY

# Outline strategy and plan 2015-2018



*For everyone affected by a bleeding disorder*

## Our vision, mission and values

### Our vision:

Wellbeing for everyone with a bleeding disorder.

### Our mission:

For all those affected by bleeding disorders, we will provide information and services, build community and mutual support, influence government, health and welfare policies, including advocating for those impacted by contaminated blood, and involve people in making decisions about their own care.

### Our values:

We relate everything we do to the needs of everyone affected by bleeding disorders, act with integrity, honesty and transparency, make the best use of our resources, and are inclusive and independent.

Through our work, we encourage and advocate for everyone affected by a bleeding disorder to lead fulfilling lives, make informed choices and, through the Society, to support and inspire others.

We do this by providing easy access to knowledge and opportunities to support people to make their own informed decisions.

We work to influence policy and practice so that the management, care and treatment for bleeding disorders is consistent, effective and accessible; and we enable the voices of those with bleeding disorders to be heard through our membership, in NHS and Department of Health forums, and in the wider community.



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**Our vision:**  
**Wellbeing for everyone  
with a bleeding disorder**

**Providing  
needed  
services**

**Influencing  
policy and  
practice**

**Two-fold mission: for everyone affected by a bleeding disorder**

**Enabler: a sustainable and robust organisation**

**Increase  
and  
diversify  
funding**

**Vibrant  
communications**

**Cost-effective and  
efficient resources,  
structure and  
systems**

**Our values:**  
**We relate everything we do to  
the needs of everyone affected by  
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best use of our resources, and are  
inclusive and independent.**



We advance our vision fundamentally in two ways, with key priorities under each:

### **1. We provide a service to everyone affected by a bleeding disorder:**

- Through greater understanding of the needs of our members we will continue to provide knowledge that will support and empower them to make informed decisions and to lead fulfilling lives.
- We will develop and deliver services so that we help a broad range of people affected by bleeding disorders and support them with their differing needs.
- We will build our relationships with members; articulate their voice more effectively; and establish an inclusive and mutually supportive community.

### **2. We reflect informed opinion to influence policy and practice:**

- We aim to increase our profile and ability to improve policy and practice.
- We look to engage the active collaboration of people affected by bleeding disorders in helping their voice to be represented in decisions about their care.
- We aim to make smarter use of our networks and contacts to increase our own knowledge.
- We will share and deploy our knowledge more powerfully by disseminating analysis, research and evidence.

Our mission is supported by a key enabler and related priorities:

### **Enabler: To be a sustainable and robust organisation, in everything we do we will:**

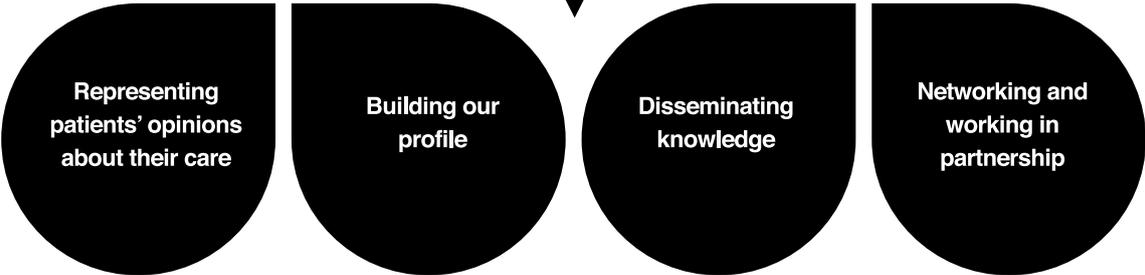
- Present ourselves and our messages through vibrant communications that reflect the effectiveness of the organisation in meeting its mission.
- Aim to increase funding and diversify sources of funding.
- Ensure we have the correct level of resources, structure and business systems to be effective and cost-efficient.





**The Haemophilia Society's members**

**The Haemophilia Society's influence**



## Our seven 'key life stages'

specialised support at every stage of life

### How we will provide a service to everyone affected by a bleeding disorder

- We will develop and deliver services to provide information, support and reduce isolation at seven key life stages. These are:
  - 1 Families with newly diagnosed children.
  - 2 Starting nursery / school.
  - 3 Learning to self treat.
  - 4 Transition from childrens to adult services and treatment compliance.
  - 5 Career choices.
  - 6 Considerations in new relationships and family planning.
  - 7 Ageing and multi-morbidities with bleeding disorders.
- We will develop and deliver services to provide information, support and reduce isolation for those who are:
  - Wanting to stay fit, healthy and active, whatever their age and level of ability.
  - Particularly isolated due to their cultural or family circumstances.
  - Living with or supporting someone with an inhibitor.
  - Affected by contaminated blood.
  - Carriers.
  - Carers.
- We will build our relationships with members via our local groups and new youth ambassador programme, enabling members to articulate their voice more effectively and establish an inclusive and mutually supportive community. This includes recruiting and training community advocates, campaigners and fundraisers.
- We will use the King's Fund Service Design Toolkit to enhance our understanding of the needs of our members at specific points in their lives where they require our services.
- We will seek funding to set up a professional volunteer-run helpline that is quality monitored and enables callers to make informed decisions and to lead fulfilling lives.



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## Our seven 'key life stages'

### How we will reflect informed opinion to influence policy and practice

- We will increase our profile and ability to improve policy and practice via the All Party Parliamentary Group (APPG) on haemophilia and contaminated blood and by working with government in all four nations.
- We will engage members in active collaboration and participation in user involvement opportunities and via our local groups and youth ambassador programmes helping their voice to be represented in decisions about their care.
- We will make use of our networks and contacts to increase our own knowledge.
- We will use the findings of our burden of illness study to share and deploy our knowledge through the analysis, research and evidence we collect.
- We will investigate the potential of facilitating a national patients survey with a research partner.
- We will ensure user representation at all key bleeding disorder, haemophilia centre, NHS and health and social care meeting opportunities.
- We will support and train members to be confident, equal partner user representatives in the haemophilia centre tri-annual audits.

### How we will ensure we are a sustainable and robust organisation, in everything we do

- We will refresh and update our look and feel to ensure vibrant communications that reflect the effectiveness of the organisation in meeting its mission.
- We will increase funding and diversify our funding streams by reaching out to untapped grants and trusts, new corporate partners and increased community fundraising and events opportunities, reaching out to people beyond our own community.
- We will review all our business contracts processes and procedures to ensure we are effective and cost-efficient.
- We will review our staff policies to ensure we are a high quality employer and volunteer organisation leading through best practice.



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### Services

- Support newly diagnosed families through provision of two residential weekends: September 2015 and March 2016.
- Provide support for children and their families through six youth and children's weekends in the summer and one in the autumn; this will include activity weekends, and an arts weekend. All youth activities include siblings as well as those with a diagnosis.
- Work with our members to co-design services for people with Inhibitors.
- Deliver a conference in September on ageing and work with our members to co-design future services.
- Hold information days on Hepatitis C and HIV to bring the community together and provide information and support.
- Hold a Carriers' Conference in January 2016 providing a platform and much-needed support tool for this key sector of our community
- Work with our members in Northern Ireland to identify local need and deliver services to meet this.
- Continue to develop new publications and website information on a range of topics, including dental care, carriers, ageing and inhibitors.
- Refresh the look and feel of the organisation for publications and communications.
- Research the potential for introducing a volunteer-run helpline.

### Membership

- Further engage and interact with current and new members via our events. Introduce phone calls for new members to welcome them to the organisation and identify any needs.
- Continue to develop the website to become the place to go to for information on bleeding disorders.
- Publish two editions of HQ: a special birthday edition to arrive on July 29 and one in December.
- Enhance work being carried out with local groups through a local groups forum to be held in summer 2015 and in summer 2016.
- Launch our Youth Ambassador programme in March and hold a Youth Ambassador day in summer 2015.
- Increased support will be provided for the 2015 Service of Thanksgiving in October.



- July 2015 will be a key month due to The Haemophilia Society's 65th Birthday on 29 July when members will be encouraged to hold their own events across the country.
- Continue to promote and develop Swim Around Britain, engaging as many members as possible in the challenge.
- Develop the member reader panel to enhance all our publications.
- Investigate the possibility of developing a member research advisory panel to comment on and support clinical trial proposals.
- Ensure Raiser's Edge is properly maintained to enable maximum communication with members.

### Networking

- Support the activity of the European Haemophilia Consortium (EHC) and World Federation of Haemophilia (WFH) building relationships to facilitate learning and sharing of good practice.
- Work with the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO), Haemophilia Nurses Association (HNA), physio, dental and lab scientists' professional groups to enhance care and services.
- Work in collaboration with Haemophilia Scotland, Haemophilia Wales and other haemophilia societies across the world to bring a stronger voice to the community.
- Work with the WFH and our contacts to plan for the WFH Congress 2018 as required.
- Be an active member of beneficial alliances and coalitions to maximise our voice with rare diseases.

### Communications

- Continue to update and develop the website, ensuring accuracy and relevant content at all times.
- Seek to raise the profile of the charity and bleeding disorder community via the media and other avenues.
- Ensure Facebook and Twitter remain active and safe places for our community to seek and offer support.
- Build on the Talking Red campaign with an even broader reach, culminating in events on the 20 - 21 June, 2015.
- Develop relationships with our celebrity ambassador, Jack Bridge, and celebrity supporter, Alex Dowsett, to maximum effect for our community and enable them to achieve their ambitions as our supporters.



### Influencing

- Continue to act as Secretariat to the APPG on Haemophilia and Contaminated Blood ensuring best use of the inquiry evidence, as well as encouraging a wider range of subjects and bleeding disorders covered in meetings.
- Support the work of Alistair Burt to bring about a package of support for those affected by contaminated blood.
- Continue to call for access to high quality treatment and services for our community, whenever concerns arise, harnessing the knowledge and skills of our health professional contacts and members.
- Work with and learn from the EHC and WFH to influence policy and practice across the UK.
- Identify key people to influence in all four nations; ensuring people with bleeding disorders remain on the political agenda and healthcare agenda, with reducing inequalities and improving quality of care.
- Be an active member of the clinical reference group (CRG) to positively influence decisions about our community.
- Recruit and train user representatives ready for the haemophilia centre audits.
- Develop a plan to reinvigorate the positive aspects of the Haemophilia Alliance in a format that benefits the community UK-wide and engages health and social care professionals.
- Investigate the potential for a research study on the psychosocial impact of ageing and haemophilia with a research partner.

### Fundraising

- Continued investment in running and challenge events to increase sustainable income and profiling throughout the UK especially within catchment areas of local groups.
- Run a 65th Anniversary campaign of fundraising and profiling events for 2015.
- Increase trust and grant applications and ensure success in applications.
- Develop new corporate partnerships outside our traditional pharma support.
- Increase pharma corporate partnerships.
- Introduce a new World Haemophilia Day event and marketing collateral.
- Introduce a fundraising element to the Talking Red campaign, and seek new corporate support.
- Develop Swim Around Britain, seeking increase sponsorship for the challenge.
- Iceland Trek – Celebrating 65 Years of the Haemophilia Society.
- Integrated Christmas campaign – May onwards.
- Charity Of The Year application for Virgin Money London Marathon 2017-18 onwards.



## Governance

- Review all business contracts ensuring value for money.
- Review financial procedures and write protocols for all financial activity including local groups.
- Review auditors for 2016-17.
- Review staff and volunteer policies.
- Undertake trustee governance training.
- Undertake a trustee skills audit and gap analysis.
- Review data protection procedures and protocols.
- Ensure Raisers's Edge is used effectively and efficiently with high quality data management.
- Review the role and function of the Clinical Advisory Group.
- Deliver a successful and useful AGM and conference for members.
- Recruit a new Chair of the Board in preparation for a handover in 2017.
- Build on the success of this year's AGM and conference to provide an even better event in November 2015 in Leeds.



### Services and membership

- Continue to deliver services undertaken in 2015-16.
- Develop and deliver services as outcome of inhibitor project commenced in 2015.
- Develop and deliver services as outcome of ageing project commenced in 2015.
- Work with members to co-design services for carers.
- Develop a robust volunteer policy and training programme.
- Consult members on service development requirements for future services.
- Recruit a services assistant to help deliver the increased services.
- Host the Buddy Awards.

### Fundraising

- Build on and develop all fundraising events, opportunities and partnerships from previous years, increasing income from each area.
- Introduction of a new national community fundraising product with associated marketing collateral, digital and social media platforms.
- Establish new sustainable Individual Giving and Committed Giving campaigns.
- Introduce a new Donor Journey Programme to include new key life stages cycles: 'from birth to legacy provision – and everything in between'.
- Seek sponsorship for the Buddy Awards.

### Governance, communications, influencing and networking

- Continue to deliver the activities delivered in 2015-16.
- Recruit key positions for WFH Congress 2018 as required.
- Attend WFH Congress in Orlando to promote the 2018 Glasgow Congress.
- Support members as user involvement members of the haemophilia centres tri-annual audit.
- Aim to run a UK-wide bleeding disorder user experience survey with a research body.



### Services and membership

- Continue to deliver services delivered in 2016-17.
- Work with members to identify gaps in service provision for future planning.

### Fundraising

- Build on and develop all fundraising events, opportunities and partnerships from previous years, increasing income from each area.
- Capital-type integrated media campaign – ‘Conference 2018 and Beyond. Creating a Legacy’.
- Recruit an additional fundraiser to support increased activity.

### Governance, communications, influencing and networking

- Continue to deliver the activities delivered in 2016-17.
- Work closely with the WFH in the final preparations for Congress 2018.
- Recruit a project manager to support the WFH congress preparations.
- Host the WFH Congress in Glasgow.





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