


# Haemophilia Society



**THE HAEMOPHILIA SOCIETY**

est. 1950

**Celebrating 67 yrs**


**5597 members**

**3% increase 16-17**

**51% women**

**49% men**

**newborn - 96**



**“** Being able to meet other families and sharing some experiences helped me to deal with certain feelings and experiences I hadn't dealt with before **”**

The Haemophilia Society is the only UK-wide charity for all those affected by genetic bleeding disorders.

We help people to lead fulfilling lives make informed choices and to support and inspire others

### Publications

**3 new publications**

Schools, VWD, Understanding haemophilia

**3 in development**

Rare disorders, Sex, Dental care

### SERVICES 2016-17

<b>3</b> Newly-diagnosed weekends	<b>1</b> Create Arts weekend	<b>1</b> Ageing Conference
<b>1</b> Sports Day	<b>3</b> Youth Weekends	<b>1</b> Global Family Picnic
<b>1</b> HIV Info Day	<b>1</b> Inhibitor Conference	<b>2</b> Workshops for ageing/inhibitors projects

We ran 14 x member events engaging 264 members in 2016-17

### Advocacy & Campaigning

**105 MPs** are members of the APPG supporting the campaign to call for justice over the #contaminatedblood scandal

**14 mentions** of The Haemophilia Society in parliament compared with 4 in the previous 2 years combined

**Our #ContaminatedBlood campaign called for the government to:**

- Answer why people in England stand to be worse off than they are and receive less support than those in Scotland
- Offer HIV and Hep C affected patients affected by the #ContaminatedBlood scandal the dignity they deserve
- Provide at least the same support as Scotland
- Deliver sustainability and security to the community, ensuring no one is worse off in a new scheme

In the 70s and 80s over 4500 people with bleeding disorders were infected by blood-borne viruses including HIV and hep C via treatment with contaminated blood products.

As a community, we raised our voices to say that this must not be ignored or forgotten, and the government must not cut funding for those affected.

### Communications

We launched a new e-newsletter with very positive results

**44.9% OPEN RATE**

**8.7% CLICK RATE**

**3367** Facebook followers (up 6%)

**2787** Twitter followers (up 4%)

**139k** Twitter impressions

**360** Twitter clicks

It is impossible to stress how invaluable the support is of this network even after the event, thanks to the power of social media. Knowing the faces behind the profile pics makes all the difference!

### Governance

**Reduced costs**

- Reviewed and renewed all policies
- Reduced costs on all contracts
- Trustee governance review and new risk assessment process
- Safeguarding and Data Protection training and review

**Risk Assessment**

**Data protection**

**Safeguarding**

### TRAFFIC SOURCES

6.8% other  
99.8% other  
18.2% other  
15.2% other

**46.3%** new visitors  
**53.7%** returning visitors

**107k** unique views

Benefits: MOST READ, News, People's stories

Fundraising

9 Key Events

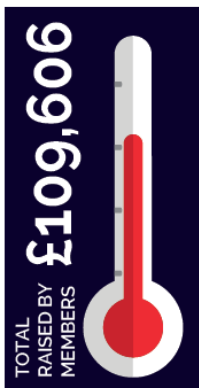
100+ Fundraisers



London Marathon

Our top event was the London Marathon which in a total of £25,500 from 9 runners. One member alone raised nearly £8000!

“ Raising money by wading through cold wet mud still made us smile! ”



Things we are proud of

We are proud to be co-hosts and organisers of the WFH World Congress 2018 held in Glasgow



99% said they would recommend our services to others

We created two new films on Ageing and Living with an Inhibitor which are part of a growing list of resources on our website

“ Reassuring to feel you share an experience with other people in a really lovely environment. But mostly exposure to the excellent guys living with haemophilia and showing us how in real life they manage. worth a million words ”



We held the 2nd Talking Red Week in June and it was great! Lots of people raised loads of funds and awareness

**HQ** We launched a new website which was more cost-efficient

Things we can do better

- Grow and diversify income, expand range and geography of fundraising events for more unrestricted funds
- Increased reach, stronger advocacy for our members, more member-led campaigning.

- More regular and more consistent communication with our members
- Broader membership, better engagement

Liz Carroll,  
Chief Executive, The Haemophilia Society  
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