

E-HQ



THE
HAEMOPHILIA
SOCIETY

Winter 2018

The Haemophilia Society magazine

Welcome

Introducing E-HQ our brand new online magazine! in addition to HQ, this electronic update will keep you informed about our projects and activities and will be produced twice a year in October and March.



With so much going on and with so much planned for the future, we felt that it was important to have more regular communication with our members. We have lots to share and so we have decided to produce two new pieces of communication.

The first, which you may have already seen, is our monthly update that can be viewed on our website. These are a useful, quick round up of what is happening across the organisation; what we are working on and what we are planning for the next month.

The second new communication is E-HQ, which will be a more in-depth look at what we are working on and planning. This will be available online in October and March.

These will be in addition to our bi-annual magazine HQ, which will remain our main piece of communication. Our 28 page, printed magazine will continue to be mailed out to all of our members in June and December.

We hope you will find these new ways to connect useful. Please do email feedback to info@haemophilia.org.uk

Liz Carroll

CEO, The Haemophilia Society

Dates for your diary

17/18 November - Member Conference, AGM and Gala Dinner

5 December - Christmas Carol Service

For everyone affected by a genetic bleeding disorder

haemophilia.org.uk



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News from the fundraising team

Member Conference, Gala Dinner, and Disco 17/18 November 2018

To celebrate our Annual Member Conference, we will also be holding a fabulous gala dinner at the Copthorne Hotel, Birmingham. This event is available to all members, and you can register for a track session (Haemophilia, Von Willebrand, Rare Bleeding Disorders, Womens, Inhibitors and Exercise), and the three-course gala dinner evening via our website at haemophilia.org.uk/who-we-are/agm/

We can't wait to see you there!



Carol Service 5 December 2018

Join us for an evening of carols and mince pies on the 5 December at St Botolph without Bishopsgate. There will be carol singing, guest readers by candlelight, and mulled wine after the service. We look forward to seeing you there and celebrating the festive season!

All welcome. Tickets cost £10 for adults, £5 for children and concessions, and are available to purchase through our website at haemophilia.org.uk/events-page/christmas-carol-service/

Christmas Cards now on sale!

Support The Haemophilia Society in the festive season by purchasing our Christmas cards, now on sale! From packed cards, to animals, birds, Christmas Themes, Fine art, Religious, and much more - there is something for everyone! Follow this link to order yours today at haemophilia.admiralcharitycards.org/



Make a date – 25 November – Road-show in Leeds

The Society's Public Inquiry Team has been out interviewing members and taking statements in the south west and in London. Next month (November) we move north and are holding a meeting on Sunday 25 November in Leeds city centre. At the meeting there will a presentation on the Inquiry so far, what is happening in the future as well as time to answer your questions.

The meeting will be held between 2pm and 6pm (venue to be advised) and more details will follow shortly. If you would like to attend please let us know together with any questions you would like to ask. Email us at publicinquiry@haemophilia.org.uk or call us on 020 7939 0780. For further information, please visit inquiry.haemophilia.org.uk

In other developments, echoing The Society's call for urgent action from the Government to improve payments to those infected with HIV and Hep C, the Chairman of the Inquiry, Sir Brian Langstaff, has written to the Cabinet Office Minister. The Society has also already written to the Prime Minister asking that the issue of compensation be addressed now and, as an interim measure, all those infected in the UK should at the very least be eligible for at least equivalent financial arrangements as exist in Scotland which are generally higher than those in the rest of the country. In his letter Sir Brian asked that 'decisive action' be taken on the issue.

Service of Thanksgiving and Remembrance

On Saturday 27 October, we held our annual service to remember all those who died from contaminated blood products within the bleeding disorders community.

We welcomed around 200 people at St Botolph without Bishopsgate to a moving sermon led by Reverend Richard Donoghue where he spoke about how the start of the inquiry brings hope that the truth will be uncovered.

Names of those to be remembered were read aloud and everyone was invited to light a candle as a way to symbolise and honour a loved one. People also wrote messages that they placed on the altar.

We thank all those who attended this important service and we hope that it offered the opportunity to remember and honour those who died.



Policy and Programmes Update

Treatment

The overriding theme at the European Haemophilia Consortium conference was how the treatment landscape for haemophilia will be changing in the next few years. We have also made changing treatment options for bleeding disorders the focus of our AGM and conference in Birmingham in November.

To ensure that new treatments become available in the UK we work with NICE and the NHS to help make that case. In the last month we have been involved in conversations and evidence gathering to build cases for new treatments such as Coagadex for people with factor X deficiency and Emicizumab for people with haemophilia without inhibitors.

Lads and Dads

We are also looking forward to announcing a new type of event next year. This will be a Residential Two Day, Two Night, Action Weekend for Lads and Dads which will take place for the first time in February 2019. This event will accommodate 10 lads (16+ with a bleeding disorder) and their dads.

The event will be run and led by a team of highly experienced and qualified experts in all manner of outdoor action activities. Our purpose is to create a positive and lasting experience while incorporating activities, education and social opportunities.

Inhibitors

Living with an inhibitor or caring for someone with an inhibitor is an intense and unpredictable experience full of uncertainty alongside the need to be compliant with a rigorous treatment regime. We are planning on holding an inhibitor conference in Spring 2019 for this group of patients, so look out for more news on the details of this event to be released soon.

A Facebook inhibitor group has also been set up to offer a dedicated forum of support and we were also involved with the European Inhibitor Network on “Finding ways for better inclusion of People With Inhibitors in the life of NMO”.



Volunteers

We are reconfiguring our volunteer programme, if you are interested in giving any of your time to support our work, let us know. And finally get in touch with us if you would like to help us develop our programmes, need any support or are interested in attending any events.