

E-HQ



THE
HAEMOPHILIA
SOCIETY

Spring 2019

The Haemophilia Society magazine

Welcome

E-HQ will keep you up to date on our projects and activities and is produced twice a year (October and April). Our printed HQ goes out to all members in July and December and there are monthly updates to look out for too!



We have had a busy few months here at The Society, and this part of the year has seen us successfully run more events than ever!

On Saturday 23 March we held our Big Red London Bridge Walk - walked by 115 members of our community, they raised over £12,000 whilst taking in the London sights across 8 famous bridges. Thank you to all of those who took part.

We also held our very first events tailored to dads and sons and mums and daughters - these events went really well and offered people the chance to bond together whilst having fun and trying new things. More details can be found on page 3.

We were honored to be a part of The Last Tsar exhibition at The Science Museum, which gave us the chance to raise awareness of bleeding disorders within a wider audience. You can read the full article on page 8.

April sees the Infected Blood inquiry resume. Hearings will initially take place in London and then move to Belfast, Leeds, Edinburgh and Cardiff. You can read the full article on page 7.

We hope you find the updates in E-HQ useful. We are always happy to hear from you, so please do email info@haemophilia.org.uk with your feedback.

Liz Carroll

CEO, The Haemophilia Society

For everyone affected by a genetic bleeding disorder

haemophilia.org.uk



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News from the fundraising team

Big Red London Bridge Walk

On 23 March, The Haemophilia Society held our **Big Red London Bridge Walk**, beginning at the Embankment Café and Gardens. Participants weaved through the London sights, across **8 bridges**, raising awareness and funds for the charity.

The Bridge Walk Route took walkers firstly over Waterloo Bridge, along the river Thames past the impressive Tate Modern, then over Millennium Bridge with the fantastic St Paul's Cathedral in front of them, continuing along back over London Bridge, Tower Bridge and the Tower of London, Southwark Bridge and Blackfriars, and then over Westminster Bridge, past Big Ben and the Houses of Parliament, and past the London eye, to return over Hungerford Bridge to the finish line!

We had **115 walkers** taking part in total, a fantastic turn out for such an important cause. Together, our walkers raised over **£12,000** and had a fantastic day, coming together as a community, sharing experiences, and getting involved. Our walkers have worked so hard and we want to say a huge thank you to each and every one of you who took part. We truly could not do what we do without you.

If you would like to register your interest for next year's Bridge Walk, then please email events@haemophilia.org.uk



New events for Lads & Dads and Mums and Daughters a great success!

We held our first residential events for Lads & Dads and Mums & Daughters in the Brecon Beacons National Park in February and March respectively.

The weekends came about following a survey conducted by our Youth Ambassadors who felt that they needed an event that combined activities, education and social opportunities. These events enabled members aged 16–25, with a bleeding disorder, to enjoy an action-packed weekend with their parent at a time those close bonds may be changing.

Both weekends began on Friday afternoon where the groups explored their surroundings and relaxed around the camp fire. Saturday morning for the lads and dads started with a stretch and challenge using various methods of travel, equipment and skills to overcome 'obstacles' set by the training team.

This was followed by an exhilarating (so we are told!) experience of Clay Pigeon Shooting. For the mums and daughters their adventure started with a morning of quad biking across the Brecon Beacons



trails. A combination of adrenaline-fueled action then lead to the calm stillness of unerring accuracy and competition with the challenge of archery.

The group was then taken back to the farm where they shared experiences during a discussion group before heading to Swansea for a cocktail making experience.

The final activity for both groups was an invigorating (i.e. very cold water!!) morning canyoning at the waterfalls of the National Park with a breathtaking white water and rapids ride. This was brilliantly finished off with a 7m jump into a waterfall. We understand the girls were less enthusiastic than the boys with the 7m jump!

Youth Ambassador Matthew said: **“We are a small part of the community but want as many as possible to feel included, we are all connected by a bleeding disorder yet have so much more in common. The opportunity to make friendships that will go further than just Haemophilia Society events is amazing because we start off on a level playing field and it’s more than just another bleeding acquaintance (pardon the pun)”**

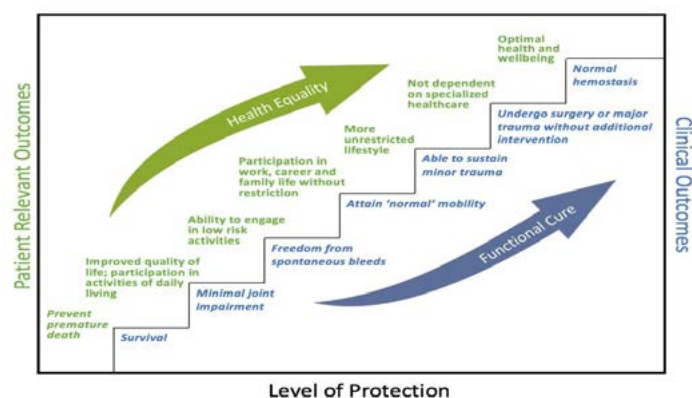


Advocating for Access to New Treatment

This is an exciting time as new treatments and new treatment approaches for bleeding disorders are constantly being developed. However, not all of these new advances are getting approved for use in the UK.

There are a complex set of different routes for new treatments for rare diseases to be approved across the UK. Some new treatments go through a prioritisation process run by NHS England with input from NICE.

We have recently been involved in developing policies for treatments for Haemophilia A, Von Willebrand's and Factor X deficiency. Other products are procured on a UK wide basis through tender exercises run by the Commercial Medicines Unit. This has recently taken place for SHL and EHL factors for Haemophilia B.



New treatments and new models of care can allow people with bleeding disorders to achieve better outcomes

We have seen positive outcomes such as last year's decision to make Emicizumab available to people with haemophilia A and inhibitors. In other cases, such as Extended Half-life products for Haemophilia A and B and Coagadex for Factor X deficiency access has been restricted or delayed.

In light of these challenges in access to new treatments The Haemophilia Society, working with the All Party Group on Haemophilia and Contaminated Blood has launched an Inquiry into the current systems of licensing, procurement, commissioning and prescription of treatments for genetic bleeding disorders in the UK.

It will document the current processes with a view to how these processes impact on the treatments that patients are offered and can be offered by the NHS. We wish to show where the processes are working well and when they are not and make recommendations for how the processes could be changed to improve access to treatments and outcomes for people with bleeding disorders.

The APPG are seeking extensive input from all stakeholders: Government, the NHS, industry, clinicians and people with bleeding disorders and would welcome submissions including documents and data and any other information. Formal submissions and any other evidence can be sent to appg@haemophilia.org.uk

To read a longer article on our work on access to Coagadex for Factor X deficiency visit our site here.

Fundraising in your local community

Please consider fundraising for us in your local community, to support our work and raise awareness of genetic bleeding disorders.

You can hold a regular coffee morning, lunch with friends, a karaoke or quiz night, or even simply set up a standing order! Resources to help you with your fundraising can be found on our website [here](#).

We couldn't do what we do without you, and your fundraising will help us to continue to provide our vital services, such as our Newly Diagnosed Weekends, Youth Camps, advocating for improved treatment and care, and much more.

Sign up today!

We currently have places in RideLondon 100 (cycling event), Great North Run, and the ASICS London 10K (running event). If you are interested in fundraising for us and enjoy sport, or know someone who would like to take part, then please get in touch to receive your application form, at

events@haemophilia.org.uk



Infected Blood Inquiry hearings start this month

At the end of this month [April] the Infected Blood Inquiry resumes and will start to hear the personal testimonies of people infected or affected by the contaminated blood scandal. Hearings will initially take place in London and then move to Belfast, Leeds, Edinburgh and Cardiff.

Last month The Society announced it had appointed new legal advisors, Eversheds Sutherland, which will now represent The Society during the Inquiry. Leading the team is Peter Jones, who set up Eversheds Sutherland's Inquiries and Investigations team more than 20 years ago and has been involved in some of the UK's most prominent public inquiries, including the Shipman Inquiry and the Bloody Sunday Inquiry.

The firm currently represents two core participants in the Grenfell Tower Inquiry. Peter is assisted by Principal Associate, Angharad Shurmer and other members of the team.

The Society has also instructed Katie Gollop of Sergeants' Inn chambers who will act as our Queen's Counsel (QC) during the Inquiry. Katie and the Eversheds Sutherland team are responsible for representing The Society at the Inquiry as well as supporting those of our members who have chosen to be represented by Eversheds Sutherland through the Inquiry process.

www.inquiry.haemophilia.org.uk

Policy and Programmes Update

Inhibitor day

We held an inhibitor information and support day following the survey we did with members who have an inhibitor asking them about their care, treatment support and what they would like from us to navigate the challenges of life with an inhibitor brings. We had 4 key speakers:

1. Jemma Efford, Haemophilia Clinical Nurse Specialist, GOSH talked about new advances in inhibitor management and treatment
2. Trupti Bhandari, Paediatric Haemophilia Physiotherapist, Evelina London Children's Hospital discussed inhibitors and physio support
3. Rajesh Shah, Partnership Advisor, Department for Work and Pensions gave information on applying for PIP and DLA
4. Jim O'Leary, Haemophilia Ireland and European Haemophilia Network representative talked about the work of the inhibitor network for people across Europe.

We also talked about what an inhibitor is and ensured the information we took from the recent survey really does fit with the information people need. There was time in the day to talk and share experiences and find support, which we know is vital for everyone who has or cares for someone with an inhibitor.

Living Well event

We held a great information day in March for our older members where Sarah Bowman the haemophilia specialist social worker from Sheffield haemophilia centre discussed housing as you get older, benefits, ageing well with a bleeding disorder and what is possible with home adjustments if your mobility is reduced.

Debra Pollard, Lead Nurse at The Royal Free Haemophilia Centre talked about vein access as joints fuse and veins become more fragile and how your haemophilia centre and GP can support you to ensure your treatment doesn't suffer.

During the afternoon Cathy Harrison, Specialist Nurse at the Sheffield Haemophilia Centre also talked about red flags and when you should seek help such as shortness of breath, chest pain, severe headache, skin changes and altered vision.



The final speaker of the day was Lesley Carter a Senior Health Influencing Manager at Age UK talking about emotional

wellbeing and how to talk about difficult topics. The day concluded with a discussion about our aging care pack that is being developed following a member survey about the issues you would like the Society to focus on in supporting you as members.

The pack was well received, and we gained some useful feedback for developing the information we had begun to work on.

This pack will be available in mid-summer. We concluded the day with an update on the public inquiry to ensure members were aware of recent developments and hearing dates coming up.

Local Groups forum

On Sunday 24 March our local group officers came together with staff and trustees at The Society to look at the role of local groups, what works, what doesn't, and how The Society can better support the fabulous volunteers who give so much of their time to support other members in their local area.

Each group also shared some of the events they run so they could inspire others or discuss the challenges of volunteering across some big areas of the UK. Local groups are spread across the UK and currently run events in the following areas.

Yorkshire

Tayside

Bournemouth

London and South

Lincolnshire Group

Grampian

Bristol and South West

Local groups are a perfect way to meet others locally, have fun together as a family and find informal support from people who understand life with a bleeding disorder. Each group is slightly different, but are all focussed on their community (some big, some not so big), but the welcome is big, wherever you are.



Some of the events we heard about were Dragon boat racing, sponsored cycles, the Nippy Dipper (a dip in the North Sea on Boxing day) trips to The Science museum, a panto and a farm full of ziplines and zorbing as well as guest speakers about treatment developments.



Get in touch if you would like to join your local group or even talk about setting one up where you live!

The Last Tsar

The Science Museum invited The Haemophilia Society to have a drop in stand at their recent 'Lates' event. Lates are when the museum opens to the public in the evening for a special event related to a particular exhibition.

This event was themed around Russia and had a range of activities including the chance to try out your skills at making a Faberge egg, screen print a Russian revolution poster, try out the Vodka bar as well as listening to expert speakers such as forensic scientist Peter Gill; who spoke at our own event about developing DNA techniques enabling him to identify the bones as belonging to the Last Tsars.

Guests also had the opportunity to learn about the Russian railway and nursing in Russia. There was also an orchestra playing beautiful classical Russian music. Over 3,000 people attended the event and lots visited our stand to learn about haemophilia, our work and the connection between haemophilia B and the Romanov Family.

We were questioned on genetics, clot formation, treatment developments and life with a bleeding disorder. We were also able to help people understand the practical side of living with haemophilia by taking along some demonstration kits of treatment.

People learnt how to find a vein, mix treatment (fake, not the real stuff!) and generally understand far better what the



practical side of prophylaxis really means day to day when trying to get ready for work or school.

No needles were allowed so guests missed out on the whole experience, but for many this really brought home how even if you are well, and don't have joint damage haemophilia can impact your life.

We were also able to talk about the Public Inquiry and met someone who had family members affected who hadn't heard about the inquiry so were able to help them find information and support.

Of course while we were there we took the opportunity to talk about other bleeding disorders and our Talking Red campaign for women with bleeding disorders.

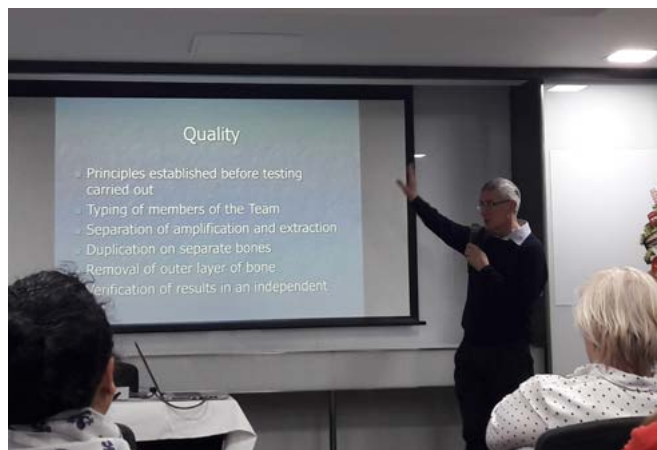
Sadly, our star guest with haemophilia B wasn't able to attend at the last moment, but we hope we did you proud!

With 3 hours of non-stop visitors to the stand we were very busy myth busting and

raising awareness. As is often the case, most people had heard of haemophilia, but thought you cut yourself and bled all over the walls in a cartoon style event, rather than the reality of everyday life with haemophilia, so it was a perfect opportunity to educate and inform members of the public we wouldn't usually get to reach.

There was also a very special moment being in the museum when it was closed to the public, with just a few people who were there to exhibit before the public arrived, definitely a calm before the storm moment.

As a team we often get asked to do unusual things and it was a huge privilege to work with The Science Museum and team of experts to help bring this exhibition together.



When you work for a charity you never know where it will take you, sometimes good, sometimes challenging, but I think all of us that attended would say this was a very privileged moment we will remember for a long time.

UPCOMING EVENTS - MORE TBC

April

17 - World Haemophilia Day
28 - London Marathon

May

24-26 - First European
Conference on Women and
Bleeding Disorders

June

7-9 - Newly Diagnosed
Weekend, Eleveden Centre
Parcs

22 - Talking Red Event,
Belfast

29 - Talking Red Event,
Birmingham

July

21 - Asics London 10k
28 - World Hepatitis Day
Ageing Event TBC
Inhibitor Event TBC

August

4 - Prudential Ride London
100
7-11 - Youth Camp, Surrey

September

8 - Great North Run
20-22 - Newly Diagnosed
Weekend, Dublin

21 - Serpentine swim

October

26 - Service of remembrance
and thanksgiving
Ageing Event TBC
Inhibitor Event TBC

4-6 - EHC Conference, Skopje

November

16-17 Member conference &
AGM, Liverpool
Newly Diagnosed Weekend
TBC

22-24 - EHC - New

Technologies, Athens

28 - 1 Dec EHC Inhibitor

Summit, Barretstown, Ireland

December

4 - Christmas carol service

1 - World AIDS Day

January 2020

VWD Information Event TBC

February

Newly Diagnosed Weekend
TBC

March

Talking Red Event TBC

Local Group Forum TBC

Ageing Event TBC

Inhibitor Event TBC

Newly Diagnosed Family weekend

In February we held another one of our fantastic newly diagnosed family weekends at Sherwood Forest Center Parcs.

Our amazing speakers at the weekend included a registrar, physio, nurse, psychotherapist, trustees and youth ambassadors.

We also had a lovely family that had previously attended our newly diagnosed family weekends join us for a port demonstration, this was really special.

They reassured the nine newly diagnosed families who attended, that if they ever felt overwhelmed and needed support to remember that they are not alone.

We will be having another newly diagnosed family weekend in June at Elveden Centre Parcs and another in September in Dublin (exact location to be finalised) if you have a newly diagnosed child please get in touch with us. All of our planned events can be found at www.haemophilia.org.uk/events



We are here to support you in anyway we can. Please remember newly diagnosed family weekends are for all bleeding disorders, irrelevant of their severity.

To find out more, please email services@haemophilia.org.uk



Our publications

Whether you or someone in your family has been recently diagnosed, you have been living with a bleeding disorder for many years, or you simply want to find out more, our range of publications offers reliable information for you and your family.

Written by clinical specialists and reviewed by health professionals and people affected by bleeding disorders, all our publications are free and delivered throughout the UK.

We have recently updated the following resources that can all be found [here](#).

- PIP factsheet 1 - making a claim
- PIP factsheet 2 - assessment process
- Disability Living Allowance for children with bleeding disorders
- Understanding Von Willebrand Disease