



Monthly Update

Latest news from The Haemophilia Society

Get a spring in your step at The Big Red London Bridge Walk!

We are gearing up for our Big Red London Bridge Walk this month and we already have lots of fantastic supporters signed up to take on this family-friendly challenge to help raise funds and awareness of genetic bleeding disorders.

Thinking of joining us?

The route takes you across eight bridges, across ten miles. It's all-age, all ability and there is no minimum sponsorship so join us for as little or as long as you can, and make it a family affair.

HOWEVER— Raise over £150 and you will be entered into a prize draw...

Registration is just £5 per person, and we'll send you a welcome pack with fundraising advice, sponsorship form and t-shirt!

On the day you will get a cool map and fun things to do as you weave your way through the iconic sights of London!

Registration is simple, just visit <https://bit.ly/2QX1DkB> to book your place, or drop us an email at fundraising@haemophilia.org.uk for more details.

UPCOMING EVENTS

March

- 8 - International Women's Day
- 16 - Living Well Conference
- 23 - The Big Red London Bridge Walk
- 28 - Inhibitor Information and Support

April

- 17 - World Haemophilia Day
- 28 - London Marathon

May

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

June

- 22 - Talking Red Conference, Belfast
- 29 - Talking Red Conference, Birmingham

July

- 21 - Asics London 10k

Also inside: Great North Run | RideLondon 100 | Lads and Dads weekend | Update from the public inquiry | Newly Diagnosed Family Weekend |

For everyone affected by a genetic bleeding disorder

News from the fundraising team

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! 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.



Challenge Events

If you are currently considering a challenge, such as giving something up, or a sporting event, then please consider getting sponsored by friends and family for The Haemophilia Society! We would love to hear from you, so please get in touch at fundraising@haemophilia.org.uk

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



International Women's Day is coming up on 8 March!

If you would like to raise awareness of genetic bleeding disorders in women, please fundraise for us! Paint your little fingernail red, and ask people to sponsor it!

The more the sponsorship, the longer you paint it for! This means that when people ask why you have one fingernail painted red, you can tell them all about how women also have bleeding disorders.

Policy and Programmes Update

New treatment for Von Willebrand's

There is a new treatment for people with VWD which is going through the process of being considered for potential use in the UK. For the first time there is a licensed recombinant VWF product, that is a replacement factor that isn't sourced from human blood plasma.

The Haemophilia Society has been part of the NICE and NHS England working group that has evaluated the evidence in favour of the treatment and advocated for why this treatment should be made available to people with VWD in the UK.

The proposed treatment policy will go to an NHS England clinical panel and we will find out later this year whether or not it will be commissioned for use instead of plasma derived factors for eligible patients.

Lads and Dads weekend

Our first Lads and Dads weekend took place on 15-17 February and proved to be a great success.

Friday afternoon arrival allowed the group to settle in and explore their surroundings followed by chilling around the farms camp fire. Saturday morning activities started with stretch and challenge, followed by an exhilarating experience of Clay Pigeon Shooting, in the beautiful Brecon Beacons National Park.

The final activity on Sunday was an invigorating morning canyoning at the

waterfalls and rivers of the National Park for an exhilarating white water and rapids ride.

If you would like to find out more about our planned events, please email services@haemophilia.org.uk



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, if you have a newly diagnosed child please get in touch with us.

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

New legal team for inquiry

The Haemophilia Society has appointed a new legal team to represent it at the Infected Blood Inquiry. Eversheds Sutherland, a UK-wide organisation with branches in England, Scotland and Wales, has in-depth experience of how public inquiries in the UK work.

The team will be led by Peter Jones, who has been a partner in Eversheds Sutherland for more than 30 years. Eversheds and Sutherland's Inquiries and Investigations Team has provided and led teams of lawyers for inquiries such as the Mid Staffordshire NHS Foundation Trust Inquiry and The Shipman Inquiry and currently represents two core participants in the Grenfell Tower Inquiry.

Eversheds Sutherland replaces Malcomson Law as The Society's legal representatives.

