



Regular Update

Latest news from The Haemophilia Society

New VWD treatment – what do you think?

Please help by giving us some feedback on the first ever artificially made treatment for adults with von Willebrand Disease.

NHS England is looking at evidence which could give the go-ahead to a new treatment called vonicog alpha. It would be used to treat adults for treating bleeding complications or given before surgery for preventing bleeding.

Vonicog Alpha is the first product for VWD which is artificially made, rather than taken from human blood. Recombinant treatments are already available to people living with haemophilia A and haemophilia B.

Vonicog alpha works in the body in the same way as von Willebrand factor made by the body itself, by replacing the protein needed to stop bleeding that is missing or not working.

Your views and treatment experiences are really important in helping NHS England decide whether this treatment should be rolled out across the NHS.

If you have VWD please fill in the survey below to have your say on this new treatment.

www.surveymonkey.co.uk/r/DY7H293

UPCOMING EVENTS

October

9 – Family Day - Edinburgh Zoo

11-13 – Newly Diagnosed Weekend, Nottingham

18 – Family Day - Edinburgh Zoo

25 – Family Day - Paradise Wildlife Park, Hertfordshire

28 – Family Day - The Deep (aquarium), Hull

26 – Service of Remembrance and Thanksgiving

29 – Family day at Techniquet, Cardiff

31 – Family day at Belfast Zoo, Belfast

November

16-17 – Member conference and AGM, Liverpool

December

4 – Christmas Carol Service

Also inside: Charity Golf Day | Inca Trail to Machu Picchu | Online Shop
| Update from the public inquiry | Book now for our Member Conference!

For everyone affected by a genetic bleeding disorder

News from the fundraising team

Our fundraisers going the extra mile

Thank you to our fabulous fundraisers over the past month! From marathons and school fetes, to cycle challenges and golf days, our community fundraisers have been busy raising awareness of genetic bleeding disorders.

Some of these fabulous fundraisers included:

Charity Golf day

The Pytchley Golf Lodge held a charity golf day and raised £2,135.57 for The Haemophilia Society.

A massive thank you to The Pytchley Golf Lodge for hosting a great fundraising event and for their support!



Inca Trail Trek to Machu Picchu

Our fabulous member Josh Taylor-Rose, who has haemophilia A, recently embarked on a 6-day trek to Machu Picchu to raise money and awareness of bleeding disorders.

Josh went through the Inca Trail to one of the Seven Wonders of the World and completed the challenge in 5 long days raising over £1,000 along the way!

He said: "With help from The Haemophilia Society, I have been able to lead a 'normal' life. I hope that by completing this trek, I can do my bit by making people more aware of Haemophilia, and who the society is, as well as raising some money at the same time for a great cause."



Online shop

Choose from our new range of merchandise, and support all those with a genetic bleeding disorder across the UK!

With a Talking Red event planned for March 2020, we need to start preparing!

Grab yourself a Talking Red nail varnish from our store now!



Christmas Cards coming Soon!

Show your support this year and buy your festive cards from The Haemophilia Society.

Our beautiful designs would be a welcome addition to any home with funds going directly to The Haemophilia Society.

Cards will be available to order online from October at www.haemophilia.shop

To purchase items from our online shop, please go to: www.haemophilia.shop

Great North Run

On Sunday 8 September, our fabulous runners took part in the Great North Run and did a great job raising awareness of genetic bleeding disorders.

We would like to thank Clare and Thomas for representing us and for all their hard work!



THE HAEMOPHILIA SOCIETY

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For everyone affected by a genetic bleeding disorder
Contact us at info@haemophilia.org.uk or 020 7939 0780
Charity no. 288260 (England & Wales) SC039732 (Scotland) UK company 1763614

HaemophiliaSocietyUK
HaemoSocUK
thehaemophiliasociety
Registered with FUNDRAISING REGULATOR

Fundraise for us!

We are always on the look out for new fundraisers and there are lots of ways you can get involved.

Check out our fundraising page for ideas and information on how you can help us to raise awareness and much needed funds to support our work throughout the UK.

www.haemophilia.org.uk/get-involved/fundraising/



Infected Blood Inquiry hearings re-start

The Infected Blood Inquiry will resume this month [Oct] to hear more personal testimonies from those infected and affected by the contaminated blood scandal.

Sitting at Fleetbank House in London, the Inquiry will hear a further three weeks of individual witness statements before moving on to expert witnesses in February 2020.

The personal testimony hearings will take place from 8-11 October, 15-18 October and 29 October – 1 November. Anyone is welcome to attend the hearings. To do so you can register online with the Inquiry on www.infectedbloodinquiry.org.uk/hearings or you can call the Inquiry team on **0808 169 1377**.

If you are infected or affected it is possible to claim back any reasonable travel costs. Full guidance on expenses is available here: www.infectedbloodinquiry.org.uk Please click on the 'Expenses Guidance' tab

From 24 February 2020 the Inquiry will hear from members of its expert groups.

They will give evidence about clinical knowledge of haemophilia and other bleeding disorders, hepatitis C and HIV as well as the psychosocial impact of these infections.

We know that coming to the hearings can be very difficult, but many people have also told us of the comfort they felt from being with others who had been through similar experiences.

If you are attending and would like support from The Society, please let us know so that a member of our public inquiry team can meet you at the hearings. Contact us on publicinquiry@haemophilia.org.uk

You can keep up to date with what's happening at the Inquiry by watching the live feed of the hearings via Youtube or from regular posts on our public inquiry Facebook page and our dedicated Twitter feed [@HaemoSocUK_PI](https://twitter.com/HaemoSocUK_PI)

Book now for our free member conference and AGM

#Empower #Educate #Advocate



Following the success of last years mini-congress, we will be hosting our Annual Member Conference this year in Liverpool on 16/17 November.

Enjoy sessions on a wide range of relevant topics, meet others with bleeding disorders and find out the results of trustee elections for 2019.

Members can choose from our eight specific tracks including: Severe Haemophilia, Mild & Moderate Haemophilia, Emotional Wellbeing, Von Willebrand, Newly Diagnosed, Rare Bleeding Disorders, Ageing and Womens.

You can view and download the programme and decide which sessions you would like to attend here www.haemophilia.org.uk/wp-content/uploads/2019/08/Draft-conference-agenda-programme-2019.pdf

All sessions are completely free.

A **FREE** Crèche & activities for children are provided throughout the weekend.

For more information about the day and to book your sessions, please see www.haemophilia.org.uk/who-we-are/conference/