

HQ



THE
HAEMOPHILIA
SOCIETY

The Haemophilia Society magazine
Summer 2021



Inside: Working with Healthcare at Home to find solutions
| Looking forward to your AGM and Bleeding Disorders Forum
| Inspiring Yorkshire – news from our local group

For everyone affected by a genetic bleeding disorder



LESS FEAR, **MORE HOPE**

Living with a rare blood disorder is **more** than regular infusions.

It's about a caregiver learning to recognize the signs of a bleed in a young child.

It's struggling with mobility after years of enduring the peaks and troughs of factor.

It's facing the challenge of maintaining venous access after decades of infusions.

It's about the chronic fear that comes with living with a chronic disease.

Patients and caregivers are our focus at Sigilon. You have given us the courage to advance our programs and to pioneer a new category of medicine, **Shielded Living Therapeutics™**.

It's time to replace chronic fear with **hope**.

For more information about our programs in rare blood disorders, please visit www.sigilon.com

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From the CEO

This issue introduces two of our amazing Ambassadors – Sunni Maini our new VWD Ambassador and Josh Taylor-Rose one of our Youth Ambassadors, who reports on the EHC's Youth Leadership workshop.

The Public Inquiry team provide updates on the evidence from the latest hearings. The spotlight on former pupils of Treloar's was featured by many media outlets including BBC News and the Today programme and Clive Smith was interviewed by both the BBC and Australian broadcaster ABC.

The harrowing and emotional evidence coincided with the publication of the draft Terms of Reference for the review of the potential compensation framework. THS will be responding and continue to call for not only financial recompense but also accountability and equitable access to comprehensive care for the whole Bleeding Disorders Community.

The Women's Working Group has been developing a symptom tracker to support better diagnosis for women with bleeding disorders, which will be launched in October as part of our refreshed identity and communications strategy, which we look forward to sharing later in 2021.

This summer the 36 Fitness Challenge continues and we invite you to take part in Buddies Who Brunch to support the community. As events begin to open up I look forward to meeting families at the Newly Diagnosed Weekend and the participants at Youth Camp in July and being able to meet far more of our members and supporters in person at last.

Enjoy this issue of HQ!



Kate Burt,
Chief Executive

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News

A round-up of the latest news, services and events

Sunni Maini becomes our new Von Willebrand Disease (VWD) Ambassador

“By becoming the Society’s new VWD Ambassador, I really hope to be able to give something back”, says Sunny Maini, 37. “I want to give people affected by bleeding disorders hope that by overcoming their fears, there is no impossible journey.”

Sunny, who lives in Hampshire with his wife, has had a successful career as a headhunter in London for 15 years, and has also worked in the music industry. He was appointed as our VWD Ambassador at the beginning of this year.



Sunny was diagnosed with Severe VWD Type 3 as a young infant. He explains, “Being a man with my condition is really rare, and I’m quite an anomaly, even for the bleeding disorder community! To be honest, my parents struggled to grasp what the condition meant, and how to manage it. Coming from an Indian background, there was a lot of stigma associated with

my condition, and it was kept hidden as much as possible.

“But, despite all the challenges, I’ve always tried to keep a positive attitude and not let VWD hold me back or define me. At school I eventually became the captain of the football and cricket teams. It can be easy to become a bit reclusive and filled with fear when you have a bleeding disorder, and it’s important to share how hard it can be sometimes, but it’s also really important to tell people that there is hope and there is so much to be achieved.

“As our new ambassador, I’m already enjoying representing our members at two international forums; the European Haemophilia Consortium and the World Federation of Haemophilia (WFH). The WFH is publishing the first internationally agreed guidelines for best practice treatment and care for people with VWD. It’s a call to action to make sure that as people we all get the care we need, wherever you happen to live. It’s a big challenge but I’m looking forward to it!”



EHC’s October conference goes online

The European Haemophilia Consortium’s (EHC) annual scientific conference is a good opportunity to find out more about future treatments, and how they might impact on day-to-day care, among other topics. The conference, this year which is being held virtually, commences Sunday 3 October 2021. It is open to all, and the registration fee is 15 Euros for people with a bleeding disorder.

The EHC is an international non-profit organisation representing 47 national patients’ organisations of people with rare bleeding disorders across Europe. The week-long EHC conference offers plenty of content which you can dip-into according to your interests, beginning with an opening event on Sunday 3 October at 19.15 CEST, followed by a symposium and networking event. The conference’s scientific programme will then run from Monday 4 to Friday 8 October 2021 - more details can be found at www.ehc.eu/events/ehc-conference-2021/



Ever thought about being a Trustee for The Haemophilia Society?

The Society's board of trustees meets six times each year to give strategic direction to our work.

Trustees are volunteers who draw on personal experience of either living with a bleeding disorder, or wider knowledge and expertise, for example in charity governance, fundraising, finance, communication, advocacy, understanding of the NHS or government relations.

Trustees are responsible for governance and oversight at the Society. As a smaller charity, they make a real difference to what we do.

The Haemophilia Society is committed to creating a diverse environment and encourages applicants from all backgrounds without regard to race, colour, religion, gender, gender identity or expression, sexual orientation, disability or age.

Members will soon be receiving nomination papers. If you would like to consider standing for election, or to find out more, please contact Clive Smith, chair of trustees by phone **020 7949 0780** or email **clive@haemophilia.org.uk**

Member Joanne Nicholls explains the role of our recently formed Women's Working Group

The purpose of the sub-committee, which reports to the Society's board and is led by Dr Kate Khair, is to make sure that the interests of women and girls with bleeding disorders are represented at the highest levels, as well as within the Society.

Joanne Nicholls, 44, of Coventry joined the WWG:

"There are about ten of us in the WWG, and we meet quarterly. Some of us are women with bleeding disorders, while some are parents to females affected. As an advisory group we scrutinise the Society's work and represent the views of women with bleeding disorders. We also help shape agendas, read through articles and take part in surveys.

"I hope by being a part of this group, by the time my daughter reaches adulthood there will be a greater understanding of Women with bleeding disorders in both healthcare and the wider community".

Recent topics include preparing for menarche, and fertility and bleeding disorders. We have been involved in the creation of a new symptom tracker for women, and we are also

planning for next March's Talking Red event, to help raise the profile and care of females with bleeding disorders.

"I've enjoyed getting involved with the group. It's not too time-consuming and contributes to an area that is still poorly understood."

Do we have your correct email address?

Keeping you in touch with news and views from the bleeding disorders community is so important, and the most efficient and cost effective way for us to do this is by email.

If you have received emails from us, then rest assured that we have your details. If you are not sure that we have email details for you, please contact us at **info@haemophilia.org.uk** or telephone **020 7939 0780** so we can check that we have all your correct information.

If you have opted to only receive information from us by post, then you do not need to do anything. We will continue to keep in touch with you this way. Please do remember to let us know if you change address, though!



Be in with the chance to win

£25,000

Play our weekly lottery,
powered by **unity**

Sign-up today at haemophilia.org.uk/lottery



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THS Giveaway!

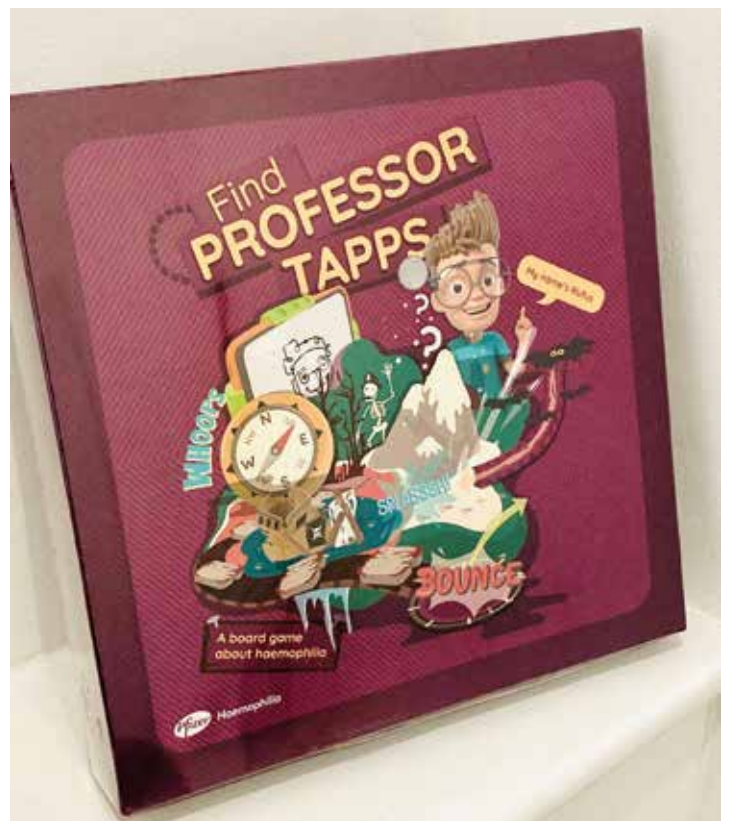
We're giving away five copies of our board game *Find Professor Tapps* – which teaches kids all about haemophilia.

All you need to do to be entered in the draw is:

Follow [@thehaemophiliassociety](https://www.instagram.com/thehaemophiliassociety) on Instagram.

Tag a friend! Each tag counts as an entry, so the more friends you tag, the more chances you have of winning.

Winners will be announced on 15 August.



Meeting and learning from our European peers

Youth Ambassador, Josh Taylor-Rose



The European Haemophilia Consortium Youth Leadership Workshop, was held virtually this year for the second time due to the COVID-19 pandemic between 23-25 April.

I was grateful to The Haemophilia Society for arranging me to attend this engaging weekend.

EHC works hard to invest in patient advocacy and developing leadership skills for the future. This is what excited me the most about the weekend ahead as it was an opportunity to network with other representatives from different NMOs (National Member Organisations) throughout Europe; in the hope that I would take something from their experiences and bring them back to the UK.

The weekend did not disappoint, sharing a range of experiences from different bleeding communities throughout Europe. It was a real eye-opener to see that with today's youth working together, with creativity, commitment and passion, the future looks really promising for all with bleeding disorders, in contrast to a bleaker view which many unfortunately had to face head on during the 1970s and 80s.

Additionally, the weekend was filled with so much positivity and I hope to keep in touch with some of the country representatives, as these networks will help bring about a positive culture to all involved with the bleeding community throughout the UK.

One of the focuses during the workshop was looking at what your own NMO does well, and what they could do better in the future. What was great to see was that each country has their own merits, for example it was admirable talking to the representative from Switzerland and learning that he is on the board of trustees for the Swiss NMO.

This shows great forward thinking, rather than having an organisation that predominantly makes decisions based on the past, which can sometimes blur the lines of what an NMO is trying to achieve as an organisation.

This is something I would like to see the UK Haemophilia Society try to achieve in the next five years or so, as young blood can help drive this NMO's future, especially when it comes to strengthening the THS voice and augmenting the impact we have through the bleeding community.

These sorts of weekends/workshops are an invaluable opportunity. The Society benefits from these relationships as they are key to innovating our future by enabling, maintaining and growing an active engagement and partnership throughout Europe with the different NMOs.

If you ever are presented with the opportunity to engage in such a workshop, grab it with both hands as the knowledge the attendees and speakers demonstrated throughout the weekend will stay with me for a long time.

Sacrifice and perseverance of campaigners highlighted at Infected Blood Inquiry

Campaign work across the UK to try to achieve justice for those infected and affected by the contaminated blood scandal over four decades has been recognised at the Infected Blood Inquiry.

Campaigners took centre stage in a week of hearings to tell inquiry chair, Sir Brian Langstaff, about their extensive research, political lobbying and sheer determination to make sure the issue was not swept under the carpet by politicians. All had made huge personal sacrifices to pursue their campaign work.

Bruce Norval, infected with hepatitis C as a child, presented research about the role of military vaccines and their history of transferring viruses.

Former chair of the Birchgrove group, Rob James, described his work as a patient activist to improve specialist care.

Jason Evans, whose father died as a result of the scandal, founded the Factor 8 campaign group following the crushing disappointment of the Penrose Inquiry in 2015. He has made thousands of Freedom of Information requests to unearth key documents, many of them blocked by government bodies.

The heads of Haemophilia Scotland, Wales and Northern Ireland described the importance of devolution in their successful efforts to get answers and increased support.

Tribute was paid to the campaign work of those infected who died before having the chance to give evidence themselves, such as brothers Haydn and Gareth Lewis and Steve Dymond.

Lynne Kelly, chair of Haemophilia Wales, said:

“This campaign has truly been fought on the shoulders of giants. They fought the lack of transparency, accountability and willingness to engage for over 30 years and we will not forget them or their perseverance.”

Former staff and trustees from The Haemophilia Society give evidence

The campaign work of The Haemophilia Society (THS) in pushing for recompense for those infected with HIV and hepatitis C was also examined by the inquiry.

Former trustee Simon Taylor, who is co-infected, defended THS's decision to make a “moral” argument rather than push for court action in 1987 because he said people with HIV were ill and dying and needed help urgently. The first government payment of £10m was seen by THS as a “foot in the door”, but it was “totally insufficient”, he said.

Karin Pappenheim, CEO of THS from 1998-2004, said there was a constant “tension” between providing services for people with bleeding disorders and their families and campaigning for financial support for people infected with hepatitis C.

The charity campaigned on this issue from 1995, but it was not successful until 2004, when the Skipton Fund was introduced. There were questions within THS about how long it could sustain what proved to be an expensive campaign.

Treloar's pupils seen as "objects for research and study" by clinicians

Boys with haemophilia who were infected with HIV and hepatitis C while pupils at Treloar's College told the Infected Blood Inquiry they were often given no support in dealing with the devastating impact of their deadly viruses.

The inquiry was told that the boys' parents were not involved in their son's treatment in any detail with some pupils left to tell them about their HIV infection themselves.

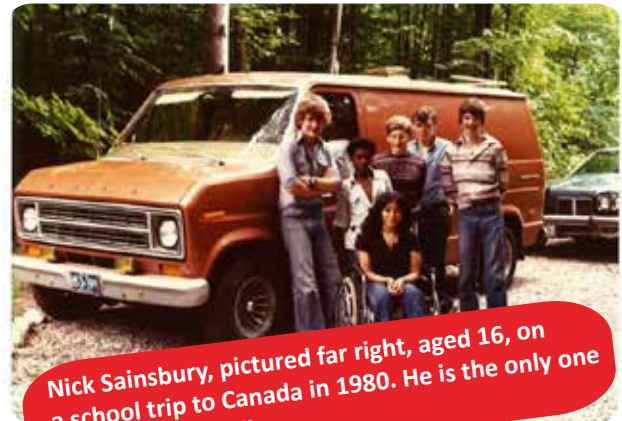
Campaigners believe that in the 1970s and 80s about 120 boys with haemophilia attended Treloar's, a boarding school for children with physical disabilities in Hampshire. It is thought that 72 former pupils have now died as a result of their infections.

Former pupils told the inquiry about their 'survivor's guilt' as the small band of those still alive to tell their story continues to dwindle and how their camaraderie had helped them get through the bleakest of times.

Inquiry investigations also raised the shocking prospect that some boys with haemophilia had been recruited to the school specifically to be researched upon. Inquiry counsel, Jenni Richards QC, said that a long "pattern of studies" over many years at the school may have led to a mindset among clinicians that the boys were first and foremost "objects for research and study" rather than "individual patients".

Nick Sainsbury was 11 when he became a pupil at Treloar's College in 1974, leaving his family 250 miles away at their home in Hull.

He told the inquiry that the school failed to keep his parents informed about his wellbeing, including details about his treatment for



Nick Sainsbury, pictured far right, aged 16, on a school trip to Canada in 1980. He is the only one of the boys still alive.

haemophilia as well as about persistent problems with bullying.

His family tried to shield him from his diagnosis, but in 1988 he learnt he was HIV positive and later that he had hepatitis C. Of the stigma he faced, Nick told the inquiry:

"They called us ticking time bombs... We were just people who had been given a treatment that was supposed to enhance our lives. It was killing us. And we were treated by society as if we were evil."

Since giving his evidence, he has received more than 70 messages of support and, for the first time in over a year, felt well enough to go out for a walk.

Nick said: "I said what I've been waiting to say for 40 years. It has given me a real lift."

He now hopes the inquiry will uncover "full and frank" details of policy and decision making by politicians in the 70s and 80s.

Compensation breakthrough for contaminated blood victims

Compensation for those infected and affected by the contaminated blood scandal will be paid if the Infected Blood Inquiry recommends it, according to a former government minister.

Matt Hancock, then Health Secretary, told the inquiry in May he accepted the government had a moral responsibility to support those impacted by the scandal.

He said: "If the inquiry's recommendations point to compensation, then of course we will pay compensation."

The inquiry had already looked at a letter from Penny Mordaunt MP, the minister who sponsors the inquiry, to Chancellor Rishi Sunak written in September 2020 in which she said it was "inevitable" that the inquiry would recommend "substantial compensation" is paid. She said preparations for this should begin immediately.

Ms Mordaunt, who attended the inquiry in June to hear evidence from former Treloar's pupil Lee Stay and talk to participants, went on to announce an independent review of compensation schemes.

Led by Sir Robert Francis QC, the study of compensation schemes will recommend a compensation framework to the government by February 2022 after consultation with the community and other organisations.

Current and former health ministers of Northern Ireland, Scotland and Wales also gave evidence to the inquiry.



They agreed that paying compensation was "inevitable" and that both devolved and UK governments had a moral responsibility to act. Vaughan Gething, Minister for Health in Wales 2016-2021 told the inquiry: "I think it's undeniable that people have good reason to be angry and upset about what had happened and the fact that they're still having to argue and fight their case."

The inquiry was told that funding uncertainty from Westminster made it difficult for devolved governments to guarantee long-term funding of support schemes, which added to the anxiety of those receiving the payments.

Asked directly about this, Mr Hancock said: "I would absolutely give a commitment to anybody receiving a payment, any of the beneficiaries infected or affected, that I would expect that to continue for their lifetime."

Ms Mordaunt emphasised that regular support payments would not be impacted by the compensation framework. She said of Sir Robert's study: "It is not there to remove support, it is there to do something different."



Clive Smith, chair of The Haemophilia Society, said although there was a long way to go, the announcement of the compensation review was an “important breakthrough”. He added:

“Victims of the contaminated blood scandal have been waiting almost 40 years for any government to acknowledge liability and offer compensation for the devastation and loss that this NHS treatment disaster caused. This is the closest any government has come to that admission.”

Compensation study wants your views



Sir Robert Francis QC will meet with those infected and affected as a key part of his role to look at options for a compensation framework for those impacted by the contaminated blood scandal.

The appointment of Sir Robert, 71, who recently retired from regular practice, was made in May by the Paymaster General, the Right Hon Penny Mordaunt MP. He will report

back to her by February 2022 so decisions can be made before the Infected Blood Inquiry makes its final report.

Sir Robert is a barrister who specialised in medical law, including medical and mental health treatment and capacity issues, professional discipline, and claims for damages in clinical negligence cases. He chaired the two Mid Staffordshire NHS Foundation Trust inquiries and has considerable experience of working on public inquiries.

After engagement with the community, the scope of the compensation study - known as its terms of reference - will be finalised over the summer. After that, Sir Robert will consult with those infected and affected and will also look at compensation schemes in other countries, such as Ireland.

The Haemophilia Society will be holding meetings with our members in the autumn to ensure that your views are represented. Join us for the first meeting about the compensation framework review on Monday 27 September at 6pm.

You can join the meeting using this link:
<https://us02web.zoom.us/j/86985084474?pwd=VUc2QlNYd1djaDg1UUdqOXZrUGg5dz09>

You can also contact Sir Robert directly with your views at ibcompframeworkstudy@cabinetoffice.gov.uk or: Infected Blood Compensation Study, Room 408, Cabinet Office, 70 Whitehall, London, SW1A 2AS.

You can follow the inquiry through THS's dedicated Twitter feed or join our closed Facebook Page. Read a weekly summary of inquiry evidence on our website. Contact our team at publicinquiry@haemophilia.org.uk with any questions.

Exploring the benefits and boundaries of being physically active

We've spoken to some members of our community about their experiences of leading an active and healthy lifestyle.

The summer is certainly looking brighter, with lockdown restrictions easing and a full summer of sport ahead of us – with the Euros, Olympics, Paralympics, and Wimbledon all set to return after a year's hiatus.

To make the most of the sunshine, many people will be getting back outside and boosting their physical activity, whether they are continuing a new fitness regime started during lockdown or getting back in the habit of regular exercise. Serotonin levels will certainly be on the rise.

Staying active and healthy is vital when you have a bleeding disorder. But there are still concerns around what boundaries there may be to physical activity.

We spoke to some of our members and youth ambassadors about their experiences with living an active lifestyle with a bleeding disorder.

Here's to a summer of more activity, and physical and mental wellbeing.



“The biggest misconception I find is that when parents are told to keep on top of their children’s medication plan, they straightaway believe part of this task involves wrapping them in cotton wool. The best thing a parent can do for their child with a bleeding disorder is to encourage all sports. Leading an active life is a lot easier if people enjoy the sports or exercise they are completing.”

Being active is so important for so many reasons; having a good mental state, feeling in good physical shape, and having a good work life balance, to name a few.”

Josh, Youth Ambassador



“Keeping active and taking part in an online Get Moving class for people with mobility issues, and the encouragement from the trainers has been life changing for me, along with an attitude of changing ‘I can’t do it to I can do it’!!!!

Keeping moving helps with stiff and sore joints and at 70 years young; bring it on!”
Lynne, THS Member





"I don't like to let my condition control me; I like to control it!"



"From a very young age I have always been sporty and wanting to be physically active.

I'm sure when I told my parents at the tender age of two that I really would like to ride ponies, that their hearts must have been in their mouths.

My parents have always had a fear of me becoming injured from falling off or hurt from being on the ground with the horses.

But despite this they have only ever been my biggest supporters! My mother being Factor 8 and Factor 11 deficient knows the full risk for me but again has never discouraged my riding.

A lot of people have been shocked, we have always had comments from others saying "should you really be doing that? Isn't there something safer you could do" but overall people are impressed.

I have never met another Haemophiliac rider, but I hope to meet one, one day! I don't like to let my condition control me; I like to control it!"
Rebekah, THS Member



"When I first started being active and wanting to be healthier my doctors were worried about me potentially having an increase of bleeds. We worked together to create a care plan for the increased activity to make sure I wouldn't suffer from any more bleeds.

I was never encouraged not to be active.

When I can I like to go the gym, I set some time aside for myself so I can go and work out the stresses of that week.

It is incredibly important to be active both physically and mentally, not to mention it's fun as well when you find the sport or activity that you love. For me it's dancing, and I can't wait to get back into a studio."

Jay, Youth Ambassador

"It's fun when you find the sport or activity that you love"





Helping you get active this summer

Many sports and physical activities are safe for people with bleeding disorders, and through our Summer Appeal we want to ensure that our community knows that.

It is inspiring to read of the experiences of some members of our community and how they ensure that they are physically and mentally active. Of course, different people have different experiences and not everyone can easily determine what kind of activity is right for them. Nor does everyone have access to the relevant advice or information on how to maintain an active lifestyle with a bleeding disorder.

The Haemophilia Society has recently launched its Summer Appeal, in which we would like to encourage the community to get together and get active, while also addressing parents' and young people's concerns around participating in exercise and sport with a bleeding disorder.

“We want to ensure that everyone in our community has the opportunity to take part in sports and other physical activities.”

Will you show your support during this summer of sports?

If you would like to find out more information about or support our Summer Appeal, please visit haemophilia.org.uk/get-involved/summer-appeal



Healthcare at Home patient and parent forum working to find solutions

When home deliveries of treatment and equipment for people with bleeding disorders in England were severely disrupted last year, the work of supplier Healthcare at Home came under the spotlight.

What emerged were long-running problems including delivery of the wrong equipment, treatment arriving in the wrong dosage sizes or not arriving at all. An IT failure brought the problem to a head.

After listening to patients and members, The Haemophilia Society stepped in and a patient and parent forum was set up to address the problems. The forum meets four times a year and is made up of five patient or parent representatives, Healthcare at Home and The Haemophilia Society.

Lisa Steadman is a member of the forum. Her son has severe haemophilia A and the family has been receiving treatment through Healthcare at Home for over four years.

Their deliveries have been beset by problems, including being sent the wrong treatment dosages, incorrect ancillary items as well as the wrong quantities of items ordered, causing either shortfalls or concerns about what to do with excess stock.

Lisa said: *“Being responsible for my son’s healthcare can be stressful enough, without having to deal with the consequences of not having the right treatment and trying to correct the issues.*

“Being on the forum has given me the chance to speak on behalf of other families experiencing the same issues and ensure that



they are being addressed. I feel we have been listened to and our views respected.”

Joanne Nicholls’ daughter has Type 3 von Willebrand Disease and is on prophylaxis using a port. Over the last three years Joanne says Healthcare at Home’s service has been “terrible” with ancillary items often missing or wrong.

Joanne said: *“It’s been really stressful and has had a big impact on our lives. When I joined the forum I was initially just glad to have the chance to vent, but I was impressed by how they listened and I do think they are making changes which will work. In a small way, I feel I’ve helped to make a difference”*

As a result of the forum, Healthcare at Home has developed a new ancillary form using standardised language to avoid confusion over terminology and introduced a different system of handling complaints through specially trained staff.

Healthcare At Home Becomes Sciensus

This month, Healthcare at Home changed its name to Sciensus. Although the name has changed, its team remains the same. You can find out more information at hah.co.uk/shapeofthings/

Looking ahead to a successful and sustainable future

The Haemophilia Society is looking to improve the way we work to support the bleeding disorders community.

This year, The Society is renewing its purpose and redefining its strategic goals. As we emerge into a post-pandemic world, the coming months will be critical in terms of how we rebuild the organisation and challenge the conventions of how we have operated in the past.

We are developing a clear strategy for how we will achieve this and deliver an ambitious growth plan over the next three years.

As we embark on this journey, it is more important than ever that we set ourselves up for success and bring a step change in how we engage with our members and the community.

Therefore, a key aspect for the success of our strategy is to relook at our communications and identity and evolve it in a way which reflects our future vision for The Society and reaffirms our purpose as the UK-wide charity for bleeding disorders.

If you have been to our website recently, you will have seen that some of this work has already begun. On 20 April we launched a new-look and easier-to navigate site. The refreshed, brightly coloured website reflects a shift to being more accessible and relevant for our community.



With new dropdown menus, it is now easier to find the information that you are looking for, whether it is the latest news, resources or ways to get involved. We have also developed more user-friendly event sign-up forms on the site and improved our fundraising section.

This is just the first phase of our plan to make the website more accessible to the needs of our community, with additional features being developed over the coming months, so keep an eye out for more improvements.

Our work continues

Over the next few months, we will also be working with partner organisations, ambassadors, Trustees and some of our members to examine and review our brand identity as a patient organisation. We have organised a members review panel who we will be consulting with as our strategy develops, alongside our other stakeholders.

As the work continues, we will share updates on how we progress and hope that all of you will feel that our new strategy truly represents the bleeding disorders community and you as our valued members and supporters.

Your 2021 AGM and member's Bleeding Disorders Forum

We're looking forward to welcoming you to this year's combined Annual General Meeting (AGM) and Bleeding Disorders Forum on Saturday 20 November 2021.

This year the event is being held in London, at the Holiday Inn in Regent's Park. Due to the changing Covid 19 situation, it is possible that, due to Government restrictions, attendance in person may be limited and pre-registrations will be necessary. For this reason, we are also giving members the option to attend the event live online.

Whether you join us online or in person, you'll be able to hear from Chair of Trustees, Clive Smith, and CEO, Kate Burt, at the AGM during the morning session (10.00am – 11.15am). There will also be an opportunity to ask questions.

The afternoon session, called the Bleeding Disorders Forum, replaces our more usual Member's Conference, which we have adapted into a more succinct session better suited to the current pandemic climate. Running from 11.30am until 5pm, the Bleeding Disorders Forum might be shorter than our usual member's conference, but it will still pack a considerable punch.

Topics for discussion will include Talking Red – 10 Principles of Care, new therapies, mental health, and patient empowerment – the power of your voice. There will be lots of opportunity to join the conversation during the sessions, and also during our lunchtime breakout sessions, either in person or virtually.



We will share a detailed agenda and speaker details at haemophilia.org.uk once finalised.

Information on how to pre-register for the event - either in person or online - will be sent out to all members in late summer.

Modernising how we vote

This year we are looking to modernise the way that members are invited to vote for new Society trustees. Currently, posting all members AGM and trustee nomination information, followed later by trustee voting forms, is a considerable environmental and financial cost.

This year we will invite you to vote for your chosen trustee online, unless you specifically tell us you would like to receive voting forms in the post.

We very much look forward to seeing you – virtually or in person - at the combined AGM and Bleeding Disorders Forum in November, but if you have any questions in the meantime, please don't hesitate to email us at info@haemophilia.org.uk or telephone **020 7939 0780**.

Still going strong after Racing Around the World

Continuing on from their successful fundraiser in the spring, the Yorkshire Group have a fun year ahead.

Following on from the incredible Race Around the World, Bleeding Yorkshire have a series of activities and events lined up for 2021 - aiming to have something for everyone and continuing to grow their community.

Anne, from the Yorkshire Group says;



“Saturday 26 June found the Bleeding Yorkshire community out and about on their bikes. A Bring your Bike along session at the Brownlee Cycling centre was a huge success!

From First Timers to Tour de Yorkshires - a lot of fun and in-person connections were made. Thank you to all who attended.

Next up is our Yorkshire Day family picnic and mini-Olympics at Temple Newsam Park on Sunday 1 August. Bring your outdoor games, any sports equipment, picnic blanket and food for a fun afternoon in a glorious outdoor setting celebrating Yorkshire Day!

Dependent on government Covid guidelines, further events to include Get Golfing, Laser Tag, Escape Room and Climbing Wall to name but a few!



In keeping with the group’s great Yorkshire tradition (COVID-19 permitting) our Christmas Party will be taking place on Sunday 4 December at John Charles Centre for Sport with fun, food, bar and games. All are welcome!”

Let's Brunch!

Hold a Buddies who Brunch event, connect with friends, have fun and raise vital funds for The Haemophilia Society.

Brunch is a great excuse to catch up with friends, family or colleagues to raise awareness, support people in your community and raise money while enjoying some tasty treats. You can host your brunch at home, or meet up outdoors.

In our fundraising pack you will find everything you need to organise a brunch to remember. Contents include three delicious food recipes, bunting, stickers, social media frames and quiz sheets.

We have also set up a Facebook group where you can connect with other 'brunchers', share tips, recipes and experiences, compare your delicious masterpieces and post the best pictures from your event.

And because everyone loves a challenge, we invite you to join in our **Red Velvet Pancake Challenge**. During your event, why not create a pancake stack using our red velvet pancake recipe then measure the stack with a ruler or tape measure and see how high you can go!

Join our 'Buddies Who Brunch' Facebook group and share it's height with a photo, and include the hashtag **#RedPancakeChallenge**.

See haemophilia.org.uk/events/events-calendar/buddies-who-brunch/ for the Red Velvet Pancake recipe.

No challenge is complete without a prize so we will reward the tallest, most fun and innovative pancake stacks with goodies from our merchandise range.



And last but not least, anyone who signs up to our brunch will get 30% discount on branded aprons and mugs in our online shop.

What are you waiting for?

Email lina@haemophilia.org.uk to get your exclusive fundraising pack today!



Fundraising update

We really appreciate your continuous support through this difficult year and helping us be there for every person with a bleeding disorder. Your support has been greatly appreciated and has made a massive difference to our community. If you would like to take on a fundraising challenge, set up a fundraiser or get involved in any other way, please email fundraising@haemophilia.org.uk or head to our website.

36 Fitness Challenge

With lockdown finally coming to an end and warmer weather on its way, we launched The 36 Fitness Challenge to encourage members of our society to stay/get fit while helping us raise awareness of genetic bleeding disorders and vital funds that will help us support every person affected.

We based the challenge around the number 36 to mark the more than 36,000 men, women and children in the UK that have a diagnosed bleeding disorder.

Our favourite part of this challenge was seeing all the different ideas our members came up with.

To lead by example, THS staff and trustees took part in the challenge, doing everything from running or skipping rope, to walking and climbing stairs.

The Warren family were one family who took part in the challenge. They set a goal to each run 36km in the space of

36 hours, with their daughters Leah and Ella both covering 3.6km of walking in that time too.

They completed their challenge in just 24 hours and raised an incredible £1,005.68. Leah and Ella celebrated the success of their challenge with a well-deserved ice cream.

Another lovely supporter, Samantha Grant, put together a team of 16 friends and family members to tackle the challenge.

They picked different activities, from walking to knitting, squats to cycling, giving up chocolate or TV to press ups and star jumps.

Not only did they do a fantastic job raising awareness of bleeding disorders wearing by our t-shirts, but they also raised an amazing £1,512 for The Haemophilia Society.

Thank you to everyone who has shown their support!



Ultra Challenges

Are you looking for a new challenge to get in shape, re-energise, and raise funds for The Society?

We have teamed up with Ultra Challenges, who organise walking and running events across the UK.

Wyatt Ko, whose grandad and two of his cousins have haemophilia, took on the Jurassic coast challenge, walking 100km continuously and raised an impressive amount of £780 for The Society.

Kim Timms, also decided to tackle one of the Ultra Challenges to support our community. She did both the Winter and Summer Ultra walk and raised a remarkable £721!

To see the full list of Ultra Challenges and choose your adventure head to their website:
ultrachallenge.com/



Big Red Bridge Walk

Our traditional Big Red Bridge Walk was just one of the many mass participation events in 2020 that had to be cancelled due to the global pandemic.

With everything finally opening up again we thought it would be a wonderful opportunity to meet up in person and continue the tradition of our Big Red Bridge Walk!

Some of our wonderful supporters; Valerie Watson, Eileen Ross, and Hilary and Geoffrey Yarnall from the Lincolnshire local group, could not be stopped by the pandemic, and organised their own virtual bridge walks in the past year.

With the success of those events, we've decided to keep both formats to create a hybrid event.

You can join us on a 10 mile walk across eight London

bridges on October 9 (if the COVID restrictions will allow us to do so), or organise your own local bridge walk and we will send you all the fundraising materials and support you may need.

There is no minimum sponsorship or registration fee, and we will reward everyone who raises £150 or over with an item from our exciting merchandise selection.

To register your interest, visit the events calendar on our website or email lina@haemophilia.org.uk – we cannot wait to see you again!



Talking Red Event

5 March 2022

Park Inn by Radisson, York

Thousands of women struggle with common symptoms – such as heavy periods and frequent bruising – unaware that they can ask to be tested for a bleeding disorder.

Living with a bleeding disorder can be challenging to manage and affects relationships, education and work.

It can be lonely living with a condition that some people find hard to talk about.

No woman should go through this alone. Our yearly event, Talking Red, brings people together to share knowledge and experience to empower women to get the treatment and care they need.

Confirmed Speakers

* Diana Mansour, Consultant in Community Gynaecology and Reproductive Health Care and Head of Sexual Health Services in Newcastle

* Rezan Abdul-Kadir, Consultant Obstetrician and Gynaecologist with a specialist interest in bleeding disorders at Royal Free Hospital, London. She is a member of the Medical and Scientific Advisory Group for the European Haemophilia Consortium and also served on the Women with Inherited Bleeding Disorders Committee of the World Federation of Hemophilia.

Registration for this event will open in the autumn.

Empowering
Women

Sharing
Knowledge

Dispelling
Myths

To find out more about **Talking Red** please email info@haemophilia.org.uk or call us on 020 7939 078



THE
HAEMOPHILIA
SOCIETY



#TalkingRed
2022

Something for everyone – from learning to awareness raising and fundraising. Do join us!

2021

Fundraising events

- 21 August** Virtual Prudential RideLondon, London
- 12 Sept** Great North Run, Newcastle
- 18 Sept** Sepentine Swim, London
- 3 Oct** London Marathon, London
- 9 Oct** London Bridge Walk, London

Member events

- 17-19 Sept** Newly Diagnosed Weekend, Manchester
- 30 Oct** Service of Thanksgiving and Remembrance, London/virtual
- 20 Nov** AGM/information day, London/virtual
- 8 Dec** Christmas carol service, London/virtual

2022

- 5 March** Talking Red event, York
- July TBC** Newly Diagnosed Weekend, (North)
- 27 – 31 July** Youth Camp, Surrey
- 14-16 Oct** Newly Diagnosed Weekend, Essex

Awareness days

- 7 Sept** Youth Mental Health Day
- 10 Oct** World Mental Health Day
- 19 Nov** International Men's Day

2022

- 1–7 Feb** Children's Mental Health Week
- 8 March** International Women's Day
- 7 April** World Health Day
- 17 April** World Haemophilia Day
- 1-7 June** Volunteers Week



Please note: due to the uncertainty around COVID-19 restrictions, all events are subject to change so that we always adhere to the latest government guidelines.

To find out more about any of these upcoming events, please contact info@haemophilia.org.uk



THE HAEMOPHILIA SOCIETY

“We really appreciate the help we’ve had from The Society. My daughter absolutely loved youth camp. For the first time in her lifetime I could be fully relaxed, knowing she was having a great time and that everyone around her understood about her bleeding disorder.”

Parent of child who attended Youth Camp.

Find the information you need on our website at haemophilia.org.uk, email us at info@haemophilia.org.uk, or give us a call on **020 7939 0780**.

Your Society: getting in touch:

The Haemophilia Society
52b Borough High Street
London SE1 1XN

Phone: 020 7939 0780

Email: info@haemophilia.org.uk

Web: haemophilia.org.uk

 [HaemophiliaSocietyUK](https://www.facebook.com/HaemophiliaSocietyUK)

 [HaemoSocUK](https://twitter.com/HaemoSocUK)

 [thehaemophiliasociety](https://www.instagram.com/thehaemophiliasociety)

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Members of the European Haemophilia Consortium and
the World Federation of Hemophilia

President: Baroness Meacher

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Front cover image courtesy of the Moon family - members of Yorkshire Local Group

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