

E-HQ



THE
HAEMOPHILIA
SOCIETY

Autumn 2020

The Haemophilia Society e-magazine

Welcome

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 April.



Welcome to the October 2020 issue of E-HQ. I am delighted to have joined The Haemophilia Society team and to have the opportunity to work with the whole community to deliver an even greater impact.

In my first weeks at The Society I have been fortunate to have virtually attended the EHC and WFH Conferences.

Having the opportunity to hear from people with bleeding disorders across the world has been inspiring and underlined to me what a unique community we are here to support. The current pandemic has affected every major economy in the world and every industry, including charities.

We are facing unprecedented challenges, but as we emerge into a world that is different

from the one in which we lived pre-pandemic we also have a unique opportunity to redesign the way we work and challenge the conventions about what is possible in our approach to supporter engagement and collaboration across our community.

Through global influencing, national innovation and far greater impacts locally we can bring together people and ideas to do extraordinary things and resolve the challenges we face today to deliver a different tomorrow.

I look forward to working with and for you.

Best wishes,

Kate Burt
CEO, The Haemophilia Society

For everyone affected by a genetic bleeding disorder

haemophilia.org.uk



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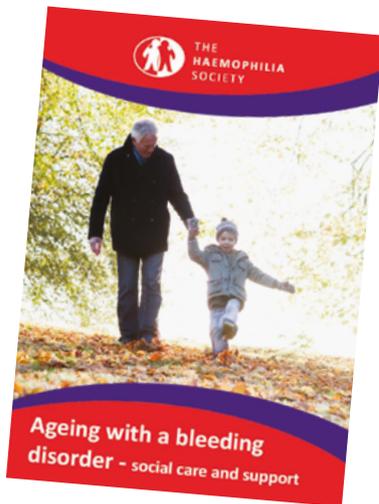
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New publications now available online

We have just published two new booklets offering information and support to our members young and old.

The booklets *'Ageing with a bleeding disorder – social care and support'* and *'Bleeding disorders and school'* are now available to read and download from our website.



'Ageing with a bleeding disorder' looks at what support is available for our older members and how to access it.

This includes most aspects of social care such as specialist housing, home adaptations and what's involved in a care needs assessment. There's also information for carers.

The booklet looks at what extra care may be needed by people with bleeding disorders and offers a step-by-step guide on how to get more help.



Our booklet *'Bleeding disorders and school'* is full of practical tips and information about how to make the transition to school as smooth as possible. This can be starting school for the first time or making the move to secondary school where parents often feel they have less control over the care their children receive.

It's important to build up relationships of trust with school, and this booklet offers practical advice about how to do this.

It also give advice about vaccinations, Physical Education and school trips, which often cause particular concern to parents.

Nicola, and her teenage daughter Tegan, who both have Haemophilia C, had to adopt a new approach when Tegan started at secondary school a few years ago and became a lot more independent. Nicola has used this experience of ensuring Tegan got the care and understanding she needed at school to help The Society put this booklet together.

Nicola said: “Friendship groups are so important and if you have to miss school a lot because of your bleeding disorder you quickly get left behind by your peers. Tegan loves school and has wonderful friends and I wanted to do everything I could to make school manageable and enjoyable for her.

“It hasn’t always been easy, but we have built up a great relationship with the school’s first aider and other staff who have been a great support.”

Youth Resilience During COVID-19 – Staying Strong Together!

Youth ambassador Jess Page joined almost 100 young people with bleeding disorders from around the world to discuss resilience during Covid-19.

Jess was one of three people chosen to address the webinar, organised by the World Federation of Hemophilia (WFH), and spoke about her connection with The Society and how the charity has had to adapt its support as a result of the pandemic.

The other speakers, from Honduras and Mauritius also described their experiences, including changes to treatment and communications difficulties in communicating due to poor internet access.

Jess said: “It was genuinely interesting to hear everyone’s experiences and to appreciate that, although it’s been tough in the UK, others around the world have had a lot more to deal with. One person said he’d had his prophylaxis stopped as a result of Covid-19, which was shocking.”

Our *‘Bleeding disorders and school’* and *‘Ageing with a bleeding disorder – social care and support’* booklets have become the first of our publications to be translated into Arabic, Polish and Urdu online. We hope to translate other key resources into a number of different languages to meet the needs of our members, funding permitting.

All of our information booklets can be found [here](#).



The WFH felt the event, which was designed to provide health and wellness strategies for young people with bleeding disorders, was so successful that it hopes to organise other similar webinars.

Following the event, Jess received a number of positive comments from people taking part who said they found her talk ‘inspiring’.

Jess said: “A lot of young people with a bleeding disorder are missing out on social connections and the contact with their centre, so it was great to connect and remind yourself that you’re not alone and that we can still all support each other.”

Find out more about Newly Diagnosed Weekends



Our Newly Diagnosed Weekends (NDW) are free events which support parents who have recently found out their child has a bleeding disorder.

We bring together experts in bleeding disorders care to share knowledge and experiences so that families get the help they need to ensure their child gets the best care.

We haven't been able to hold NDWs recently because of Covid-19 restrictions, but we hope to get this event running again early next year, as we know how valuable they are to families.

Our NDW events are open to any family who has a child aged 0 to six that has been recently diagnosed with a bleeding disorder, such as haemophilia or von

Willebrand disease. Families attending must be members of The Haemophilia Society, which is free to join.

We invite 10 – 15 families per event and over the course of the weekend you will meet a range of people involved in bleeding disorders care, including:

- bleeding disorders consultant
- play specialist
- clinical nurse specialist
- young people living with a bleeding disorder
- psychotherapist
- physiotherapist
- staff from The Haemophilia Society

Some sessions involve talks and presentations which give everyone the chance to ask questions and find out what



they need to know. Other sessions are more practical, such as showing how to give an injection or how to support a needle phobic child.

‘Children of all ages played together happily. They were able to see that they’re not the only ones with this condition, and could feel the same as everyone else.’

There are also break-out sessions allowing parents to talk together or to ask professionals about a specific issue. The Society’s Youth Ambassadors attend to talk about the reality of living life with a bleeding disorder.

Parents tell us that the NDW made them feel less isolated and more informed about their child’s condition. Everyone takes away something different, but we hope you’ll achieve some of the following:

- better understanding of your child’s condition
- meet parents in a similar situation
- gain an insight into adult life with a bleeding disorder
- get practical tips on helping young

- children through treatment
- explore your feelings about having a child with a bleeding disorder
- meet bleeding disorder healthcare experts
- in an informal setting
- space to focus on your family and how best to deal with the bleeding disorder



‘The weekend was an intensive lesson in the history of haemophilia, current and future treatments, and UK treatment centres. My favourite part was the mums’ meeting, where we could express our feelings without guilt, or worry about being criticised or judged.’

We offer a free creche operated by staff with experience of dealing with children with bleeding disorders which is open to all children. This is a whole family event and we welcome all children, including siblings without a bleeding disorder. Our NDWs are free, including meals and accommodation.

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

William McKeown - Access and Service Improvement Ambassador

Hello all! It has been fantastic to come on board with UKHS as an Access and Service Improvement Ambassador. I have been doing lots of work with Haemophilia NI over the past 3 years and this additional role will no doubt be complimentary to the work I have already doing as a patient advocate.



But, “what is an ‘Access and Service Improvement Ambassador?’ and, “Why would you want to do it?”, I hear you ask! Good Questions!

Firstly the ‘why?’

I am 29 and have Severe Haemophilia A. I have been on prophylaxis since I was 5 years old and have access to excellent treatment through the Haemophilia Comprehensive Care Centre in Belfast.

As a result, I enjoy a good quality of life, I work as a doctor specialising in Care of the Elderly medicine. In my free time, my wife Ruth and I enjoy running, sailing and hill-walking.

Unfortunately, I know all too well that not everyone with a bleeding disorder can speak to having had such quality of care and quality of life. It is the existence of this basic inequality that has motivated to me to take on this new role helping to empower our community.

So, what is an ‘Access and Service Improvement Ambassador’?

As a new role, the exact answer to this question is still to be decided! Fundamentally, I want to ensure there is strong patient input into decisions about how care for people with bleeding disorders is organised in the UK.

This includes having ambitious and world leading treatment guidelines and access to the best care regardless of postcode.

I want to ensure there is informed patient choice when it comes to treatment decisions and that patients have access to the best treatments for them, including the right products and comprehensive multi-disciplinary care (such as physiotherapy, occupational therapy and psychotherapy).

I also want to work with the pharmaceutical industry to make sure safe, effective and better treatments are developed in partnership with patients. So, there is lots of work to do and I am looking forward to getting stuck in!



Ross Bennett - Youth Ambassador

Hi, I'm Ross Bennett and I have severe Haemophilia B. I was diagnosed at the age of 3. I have recently finished my Masters at the University of Aberdeen in Strategic Studies and Energy Security.



I have lived abroad in India and the Falkland Islands in recent years. I have also had the privilege of working in Borneo and most recently the USA.

I've lived a slightly different life to most haemophiliacs as I went to boarding school aged 7 so have been managing it since then.

Due to being at school, university and living abroad it has been very difficult for me to be involved with the society.

Now, is the time that I can join The society and upon looking at the Youth Ambassadors I realised no one had Haemophilia B and felt this role needed to be covered so applied to become a Youth Ambassador.

The work the society does is also something I wanted to be involved with as it looks a fun and rewarding experience.

I hope to get a number of things out of the role including trying to continue to move haemophilia forward in the coming years.

I also want to meet haemophiliacs and discuss the different experiences that we have all had and hopefully help people that have questions or difficulties.

In my spare time, I love to play and watch sport. I play baseball and cricket for clubs and have spent my time at university playing baseball across the UK.

I also enjoy cycling and running for general fitness. I enjoy going to Lords in the summer to watch cricket and look forward to things returning to normal and being able to return to stadiums.

I look forward to meeting you all once we are allowed to do so.



Infected Blood Inquiry quizzes clinicians

Investigations at the Infected Blood Inquiry have now turned to the role and knowledge of key clinicians at haemophilia centres around the UK.

The evidence, where possible, is being given in person, but some consultants are taking part remotely using a video link.

In addition, Jenni Richards QC, counsel to the inquiry, has given presentations about Cardiff Haemophilia Centre – with specific focus on its influential former director Professor Arthur Bloom – Oxford Haemophilia Centre and St Thomas’ Haemophilia Centre.

Ms Richards has presented a series of letters, minutes from meetings of the UK Haemophilia Centre Directors’ Organisation, medical journal articles, publications from The Haemophilia Society and media reports to establish what was known, firstly about the long-term impact of non A, non B hepatitis (now known as hepatitis C) in the 1970s and, later, about the emerging knowledge of AIDS as cases were reported in America from 1981.

Dr Mark Winter, director of Kent Haemophilia Centre from 1983 – 2011, was the first clinician to give evidence. He described the “hardest decision of my life” to switch his patients to unlicensed heat treated US factor in early 1984, amid criticism from some other haemophilia specialists at the time.



Yet in October 1984, Dr Winter realised that his decision was “probably irrelevant” as of the 31 patients tested for HIV, all but one was positive, almost half of which were children.

He said: ***“You knew from that moment that whatever part of the haemophilia community you were in.... life would never, ever be the same again.”*** He said, on reflection, his patients were probably already infected before he began using heat treated products.

He accepted that by 1979 the long-term risks of non A non B hepatitis were well known among clinicians and that until 1985-6 any regularly treated haemophilia patient was “extraordinarily likely” to contract the virus. Dr Winter said he did not believe this could have been avoided.

Dr Brian Colvin, director of the Royal London’s Haemophilia Centre from 1977-2007, said he was unaware that some centres were using heat treated product in early 1984. He said that as more became

known about the risks of factor product, there was never a move by haemophilia centre directors to return to mass treating using cryoprecipitate. He said cryo was “old hat” and would have meant “going backwards” in haemophilia care.

Clinicians will continue to be the focus of the inquiry’s hearings until January 2021. After that the inquiry will look at evidence of The Haemophilia Society’s role in the scandal, followed by an investigation of the Trusts and Schemes created to support victims of contaminated blood.

The inquiry is operating under strict social distancing rules which means a much smaller number of people are present for the hearings. Sir Brian Langstaff, chair of the inquiry, now stays apart from people attending the inquiry. He said he would miss the chats he had enjoyed during breaks in previous inquiry hearings.

Keep up to date with the inquiry through The Haemophilia Society

We provide regular updates when the inquiry is sitting. You can follow us on Twitter on @HaemoSocUK_PI or join our private Facebook Statutory Public Inquiry page. We also publish a weekly summary of the evidence on our website which you can find [here](#). Click [here](#) for the latest timetable of inquiry hearings.

Campaign for equal support payments across UK

The Haemophilia Society, along with many other campaigners, has been lobbying UK governments to increase support payments so that victims of the contaminated blood scandal receive the same level of support, regardless of where they live.

Until recently, the infected blood support schemes in England, Scotland, Northern Ireland and Wales all had different payment levels. These can vary by thousands of pounds a year.

In August, in response to campaigning by The Haemophilia Society, Haemophilia NI and Friends and Families of Haemophilia NI, the Northern Ireland Executive announced an uplift to match payments made in England. It also confirmed that this will be an on-going increase.

This uplift means that payments made to claimants of Wales Infected Blood Support Scheme are now the lowest in the UK. In September, The Society wrote to health minister Vaughan Gething, asking him to increase support payments as a matter of urgency. A reply from his department said it was working with other UK governments “towards achieving parity across the UK schemes”.

There are also different payments for widows and bereaved partners across the UK which we believe must be levelled up to properly support those left behind. Some groups, such as bereaved parents and children, have never received any financial support and The Society calls for them to be included in the scheme.

News from the fundraising team

We are so grateful to all of our supporters who have continued to fundraise for us during this difficult time. Here are some of the ways you can get involved!

Instagram Takeover

If you follow us on Instagram, you might've noticed that our Youth Ambassador have taken charge of the platform. They've covered various topics, from mental health, travel, working, tattoos, family, sports etc and answered any questions you've had for them.

In case you've missed some of the content, you can still watch it in our highlights. There is something for everyone, so give us a follow via [this link](#).

The Haemophilia Society's Christmas Cards

Because it's never too early for the Christmas spirit... Get ahead of the crowd this year when it comes to your Christmas card list. Explore our magical range of festive Christmas cards and spread your merry wishes with more of a meaning this year.

All Christmas cards come in packs of 10 with envelopes and cost £5.99 per pack. Due to new Coronavirus restrictions we are still working from home and all orders will be sent out once a week.

To order your pack today head to [our shop](#). or send us an email at fundraising@haemophilia.org.uk

Raffle in aid of The Haemophilia Society

Jaguar Enthusiasts' Club has kindly donated this incredible Jaguar to be raffled in aid of The Haemophilia Society.

To win this beautiful, 2014 Jaguar XK Signature special edition which is finished in Italian Racing Red with Ivory/Charcoal leather interior, all you have to do is purchase tickets at a mere £2 each (complete book of 10 tickets costs £20).

Buy your tickets online at: www.jec.org.uk/ raffle or call 0117 969 8186.

JAGUAR ENTHUSIASTS' CLUB SUPPORTING THE HAEMOPHILIA SOCIETY



RAFFLE TICKETS JUST **£2** ALL PROCEEDS GO TO THE HAEMOPHILIA SOCIETY



WIN THIS JAGUAR XK
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The draw will take place at the Summer Jaguar Festival, Blenheim Palace on 16 May 2021.

Virtual Bridge Walk

Even when we can't see each other face to face, we still create a sense of community and support online.

Help us continue the tradition in these difficult times and sign up to our Big Red Virtual Bridge Walk.

We have created a Facebook group for all walkers where you can share pictures, videos, updates and experiences, and help us be there for every member of our community. For more info email fundraising@haemophilia.org.uk or visit our [events page](#) on our website.



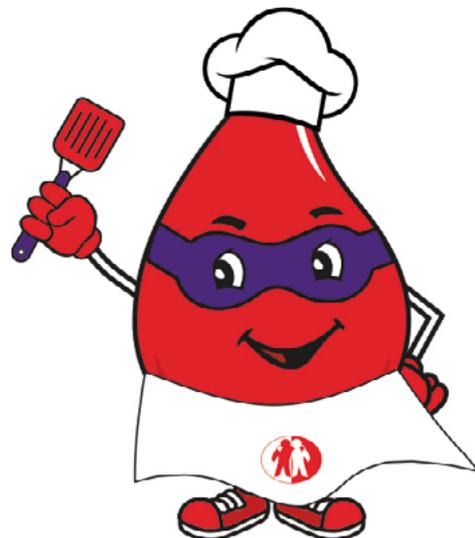
Buddies Who Brunch exclusive fundraising packs



Brunch is always a good idea, especially when it's for a good cause. So why not host a virtual Buddies who Brunch? Connect with friends, have fun and raise vital funds for The Haemophilia Society.

Order your exclusive limited-edition fundraising pack which includes quiz sheets, recipes, stickers, bunting, fundraising guide, social media frames, sponsorship form and more!

To get your guide drop us an email at fundraising@haemophilia.org.uk and for more info head to our [website](#).



Triathlon Triumph!

Patricia Bell marked her retirement, after 40 years of working as a haemophilia nurse, by taking on Winchester Triathlon. Patricia raised an impressive £1,400 for The Haemophilia Society – and wrote this poem about her experiences - well done Patricia and thank you!

TryTri

In September 2016, a day sunny and fine
I swam around The Serpentine
To fundraise for the Haemophilia Society
A cause which is so dear to me.

To celebrate my nursing retirement
I recently signed up for another event,
The Winchester Sprint Triathlon
Which I thought looked really rather fun,
So, What of myself did I personally ask?
What constituted my goal - my task?

A swim in a pool, just 16 lengths
I could easily do that - it's one of my
strengths,
Then onto my bike for a 22k ride
around the Hampshire countryside
Described as undulating! Don't be silly
in truth it turned out rather hilly.
Then the bit I didn't like the best
A 5k run in a running vest.

I wanted to attract publicity
and grab attention deservedly
So how did I make myself characteristic
Easy. A tutu, hair ribbon and the reddest
lipstick
not the done thing when you go in
transition



but I'd laid out my kit, it was all in position.
I parked my bike put on my fancy dress
I think I looked good...well more or less.

I waved when cheered in Romsey Road
at the cars that passed, they watched when
slowed.
So, all in all, a happy day
My family encouraging, when I came their
way

Finally - My advice to anyone is swim, run
pedal
If you wish to win a Triathlon medal.

Trish Bell
October 2020

I raised £800 and over £1,000 with Giftaid.
Thank you to those who sponsored me.
Would I do it again? You bet!

Newly Diagnosed Virtual Event

Saturday 31 October 9.30am-5pm



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Due to ongoing Covid-19 restrictions we are now running this event virtually.

This event aims to support parents of a child recently diagnosed with a bleeding disorder. We bring together experts to share knowledge and experiences, so families get the help they need to ensure their child gets the best care.

Our Newly Diagnosed events are very informal. Our sessions include presentations and Q&A's, giving everyone the chance to ask questions and find out what they need to know.

Over the course of the day you will meet a range of people involved in the care of bleeding disorders e.g. doctor, nurse, physiotherapist, play specialist, psychotherapist and our Youth Ambassadors.

Everyone is welcome, we hope you can join us!

Register here: <https://col.eventsair.com/nwd/ndw2020/Site/Register>

Contact us: 020 7939 0780 or at info@haemophilia.org.uk

Annual General Meeting and Member conference



THE
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Saturday 14 November from 10am

Virtual

We have been monitoring COVID-19 government advice closely and will now host our Annual General Meeting and member conference virtually only to ensure the safety of all.

We had hoped that a limited number of members would have been able to attend in person, but this is no longer possible at this time.

Details about how you can join this virtual event will be sent out in the coming weeks.

Topics that will be covered include; gene therapy, ageing with a bleeding disorder, physio during Covid-19, EHL and Non replacement therapies, Talking Red and VWD.

All sessions will be filmed and will be available after the event and we hope to offer further opportunities for updates in 2021.

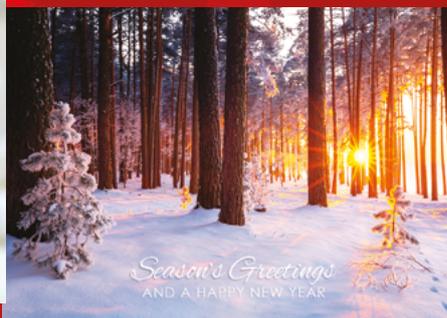
Visit haemophilia.org.uk/events-page/annual-member-conference-2020/
or contact us on 020 7939 0780 or at events@haemophilia.org.uk



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Christmas Cards On Sale!

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



Cards are now available to purchase from
haemophilia.org.uk/shop!

For everyone affected by a genetic bleeding disorder

Contact us at info@haemophilia.org.uk or 020 7939 0780

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