

HQ

The Haemophilia Society magazine
Winter 2020

70 years of support



THE
HAEMOPHILIA
SOCIETY



Inside: Sarah's story: My bleeding disorder diagnosis at 52
| Teen GB baseball star: 'haemophilia is just this thing I have'
| Infected Blood Inquiry: special report | Our first-ever virtual conference

For everyone affected by a genetic bleeding disorder



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Christmas Cards On Sale!

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festive cards from The Haemophilia Society



Cards are now available to purchase from
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For everyone affected by a genetic bleeding disorder

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From the CEO

As the year draws to a close there are glimmers of light as lockdowns ease and vaccines are on the horizon. When the history of the Pandemic is written and the extraordinary transformation in how people have had to live, work and communicate analysed it will show that the most profound changes have come about through technology and science, developed in academia but delivered at scale by industry.

This is also true for the bleeding disorder community, as was discussed in brilliant sessions at our recent conference including Gene Therapy, EHLs, Ageing with BDs, Non-Factor Replacements.

There is more on the AGM and conference in HQ together with updates from the Public Inquiry, the launch of the APPG report, news from our Youth Ambassadors and many inspiring stories from across the community.

As we look forward to 2021, we will be sharing plans that we outlined at the conference. These include a renewed engagement strategy with haemophilia centres, our members and supporters and a commitment to build a national network of local groups.

We want to grow and diversify our income and build a stronger profile - making the case for a clear, influential voice for everyone with a bleeding disorder in the UK.

Thank you to everyone in the community who has been so welcoming and shared their views on how we become a more powerful organisation to support the bleeding disorder community.

I look forward to working with you in 2021. Have a very happy festive season and New Year.



Kate Burt,
Chief Executive

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First-ever virtual conference is a success

Our first ever virtual conference and AGM was full of inspiring personal stories and top-level presentations from the UK's leading experts in bleeding disorders.

Best of all, every session is available to watch again on our website so no one has to miss out.

In a busy day, our new CEO, Kate Burt, outlined her plans for The Society, putting supporter engagement at the top of her priority list. She said it was important that The Society gives all members "a voice and a choice" in their treatment and care. Chair, Clive Smith talked about The Society's activities over the last year and praised the generosity of members which has been so vital in helping our work continue since the challenge of COVID-19 struck.

As always, the conference was split into several sessions to make sure the discussion topics covered a wide range of relevant issues.

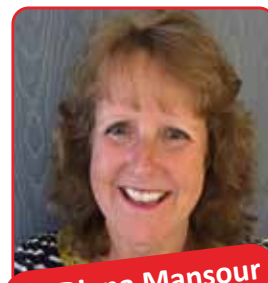
We are very grateful to so many top clinicians for joining us, sharing their expertise and answering questions – in particular Dr Charles Percy, Dr Steve Austin, Dr Pratima Chowdary, specialist haemophilia nurse Debra Pollard, Professor Mike Laffan, Dr Diana Mansour, Dr Susi Shapiro and specialist haemophilia physiotherapist Paul McLaughlin.

At lunchtime there was a chance to chat to the trustees in a dedicated meeting room and also to drop in our Youth Ambassadors who were discussing all kinds of issues, including how to ensure our younger members are engaged and kept in touch with others of a similar age.

Our feedback on the event has been very positive. One participant said: *"I found it very relaxing in my own home, and easier than having to travel. Also, I could nip in and out*



Dr Charles Percy



Dr Diana Mansour



Paul McLaughlin



Dr Susi Shapiro

of different things and pick up on what was relevant to us as a family."

Trustee Conan McIlwrath, who hosted a session on ageing with a bleeding disorder with Dr Shapiro, said: *"The conference was as close to the real experience as I think humanly or maybe virtually possible. It was fantastic to watch the knowledgeable speakers and nice to see people getting involved with many questions coming in from the floor."*

Although we hope next year's conference will take place in person, there's no doubt that hosting it virtually has given us some fresh ideas about how to widen access to this popular and hugely informative event. We're already looking forward seeing you all at a bigger and better conference next year.

'Mum cried when I told her I might be cured of haemophilia'

One of the conference highlights was hearing first hand from severe haemophiliacs Paul and Elliot about the impact of gene therapy on their lives.

Both men took part in one of the first gene therapy trials at the Royal Free Hospital in September 2018 and now have consistent factor levels of about 40 per cent. Neither have had any treatment since their infusions.

Paul, 55, who has severe haemophilia A and cleared hepatitis C in 2003, said the experience had been "life changing" for him and his family. He said: ***"It made my mum cry. She said she didn't think she would live to see the day when I would have the opportunity to be cured of haemophilia."***

Elliot, 27, who has severe haemophilia B, said his new factor levels were "insane" and added: ***"I don't think about my haemophilia much anymore. I'd 100 per cent do it all again."***

They talked about side effects, including having to take steroids which can trigger severe sleeplessness and weight gain. They also had to attend frequent follow-up visits at their haemophilia centre.

Paul said he struggled emotionally following his successful therapy. He said: ***"I'd always been 'Paul the haemophiliac'. I felt I'd lost my identity and I just couldn't handle it."***

Two years on, both men have nothing but praise for the results of gene therapy. Paul commented: ***"I haven't had any treatment since September 2018. I can't stop smiling."***

Chances to diagnose girls with bleeding disorders are being missed

Young women and girls who have very heavy periods should be tested for bleeding disorders, but lack of awareness among the medical profession often means diagnoses are missed, a leading gynaecologist told the conference.

Dr Diana Mansour, consultant in community gynaecology and reproductive healthcare in Newcastle, led a discussion on managing bleeding disorders in girls and young women.

She said that 20 per cent of adolescent girls who experience heavy menstrual bleeding – sometimes right from their first period – will have a bleeding disorder, as will a third of those admitted to hospital as a result of heavy periods. Yet chances to diagnose girls and young women early are being missed – and not just by GPs, but also inexperienced haematologists and gynaecologists.

Of the girls with heavy menstrual bleeding who are diagnosed with a bleeding disorder, the majority – 60 per cent – will have a type of von Willebrand disease. Other disorders include platelet function defects, thrombocytopenia and low factor levels.

Dr Mansour stated that many GPs were unaware of the complexity of testing for a bleeding disorder and were not referring their patients to get the help they needed. She also said that there needed to be more specialist services linking gynaecology and haematology.

News

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

Invitation to participate in online study to understand your preferences for novel haemophilia therapies

Look out for an opportunity for you to participate in research which will be used to inform healthcare decision-making in the future. This important research will examine the preferences of people with haemophilia for hypothetical haemophilia treatment options (including gene therapy) to understand the relative importance and value of novel treatment characteristics. This research will be undertaken via an online survey in partnership with The Haemophilia Society.

Aim: To examine the preferences of people with haemophilia for novel haemophilia therapies

Eligible: Adults (18 years or older) with moderate or severe haemophilia A or B

Duration: Approximately 40-minute online survey, including an educational video about gene therapy

Remuneration: £30 Amazon voucher will be provided for your participation

Information on how to take part will be in the news section of our website and posted via social media.

NICE review of evaluation methods

The National Institute for Health and Care Excellence (NICE) is undertaking a review of its evaluation methods and processes in response to the evolving and increasingly complex treatment landscape.

The purpose of the review is to optimise NICE for the future, support the expansion and acceleration of patient access, and to simplify the health technology evaluation process. With stage one of the review now complete, NICE published the first consultation setting out proposed reforms and the case for change on 6 November 2020. This consultation period will run for six weeks, closing on 18 December 2020, with NICE encouraging feedback from industry and patient groups.

One of our aims would be to ensure the patient voice is embedded in the way NICE evaluate new treatments and that they take into account the wider social impacts of living with long-term conditions.



Hemo Heroes app launched



This newly launched app has been specifically designed to help children aged four years and older to learn about and manage their hemophilia.

Main features include:

- Users can name their own hero who has haemophilia.
- They must keep their hero healthy and happy by following the tips provided in order to receive 'Prophy Energy Points'.
- Users can navigate their hero around five rooms, with activities to do in each.
- Energy points can then be used in exchange for prizes from the shop.

Hemo Heroes can be downloaded from Google Play. Pfizer supported the development of this app.

WFH VWD representative on working group

We are seeking someone living with VWD to represent The Haemophilia Society and the UK VWD community on the WFH VWD working group.

This will involve attending virtual meetings and feeding back actions and information from this group to The Society, being part of the Global Call To Action on VWD.

If you are interested, you can find more information at: www.wfh.org/en/our-work-global/vwd-initiative-program

Please email debra@haemophilia.org.uk outlining why you would like to be part of this group and to find out more information.

Have you caught up with our Bleeding Matters Live! series yet?

We've been getting together online to discuss a range of issues linked to living with a bleeding disorder. Whether it be chats about treatment, girls' bleeding disorders, virtual consultations or a new perspective on the contaminated blood scandal – we've been talking about it all.

The webinars have encouraged members to swap notes on their experiences – such as using emicizumab, standard

half-life or extended half-life and find out more about how treatment is commissioned.

If you missed our webinars first time round, don't worry – they're on our website in the resources section. Look out for more in the Bleeding Matters Live! series in the future. If you've got ideas for a topic that you think will get everyone talking please email info@haemophilia.org.uk

HQ goes digital!

As a charity it is vital that we carefully consider how we spend our funds so that we can continue to support our community.

It is for this reason that we have decided to produce HQ magazine electronically as its main method of delivery from next year. This will mean a significant cost saving per year.

We will, however, continue to send printed copies to members who have opted out of email. If you have opted into email but did not receive the Autumn issue of E-HQ magazine then let us know your correct email address via info@haemophilia.org.uk

We want to keep in touch with all of our members, so if you think we do not have the correct contact details for you please do let us know by email or phone.

Trustees announced at AGM

At our recent AGM we announced the results of our trustee election.

We are so pleased to share that Sonia O'Hara has been re-elected and will continue in her role with The Society.

Sonia said: 'Absolutely delighted, humbled and thankful to all members of The Haemophilia Society who voted for me to remain as trustee on their board for another three years. It is an honour to serve the bleeding disorders community'

We also welcomed our new trustee Anna Geffert to the board. Anna who has severe vWD, brings a wealth of experience in PR, communications and fundraising.

Anna said: "I want to support The Society and its members to ensure the amazing work you do across the board continues and we are able to keep pushing to find better treatments and even cures, leaving a positive legacy for my children and their children to come."

Congratulations to Sonia and Anna – we look forward to working together!

Bleeding Matters Live!





THE
HAEMOPHILIA
SOCIETY

in collaboration with a pharmaceutical
company would value your input into the

BLEEDING DISORDERS PATIENT EXPERIENCE SURVEY

What are we doing?

The Bleeding Disorders Patient Experience Survey is a nationwide patient survey that is looking to gain a true understanding of the patient experience and will help inform improvements in care for patients with bleeding disorders today and in the future.

How can you get involved?

People living with bleeding disorders across the country are invited to complete this survey to share their experiences across burden of illness, treatment, lifestyle and personal goals.

To complete the survey please visit:
myonlinesurvey.co.uk/HPES20CO/

It should take approximately half an hour to complete and will ask questions about your bleeding disorder and access to care, as well as the impact of COVID-19.

What will the information be used for?

The responses will be confidential and anonymous, and no personal information or individual responses will be passed on to any other organisations. The data gathered will enable us to identify where patients with bleeding disorders feel their care has changed for the better, whilst also highlighting their priority areas for improvement. The responses will help to advocate for improvements in care nationally for people with bleeding disorders.

This flyer and survey have been developed and funded by a pharmaceutical company in collaboration with The Haemophilia Society. The survey is being delivered by Quality Health, who have been commissioned by the pharmaceutical company. The name of pharmaceutical company will be disclosed following completion of the survey.

Job Code: C-ANPROM/UK//3497 | Date of Preparation: October 2020

Focus on Infected Blood Inquiry

In February 2021 the Infected Blood Inquiry will look at the role of The Haemophilia Society during the contaminated blood scandal of the 1970s and 80s and beyond. For those who haven't been following this issue, here's a guide to The Infected Blood Inquiry and the contaminated blood scandal.

What happened?

In the 1970s and 1980s, 4,689 people with haemophilia and other bleeding disorders were infected with HIV and hepatitis viruses through the use of contaminated clotting factors. Since then more than 3,000 people have died and of the 1,243 people infected with HIV, less than 250 are still alive.

People with haemophilia and their families were subjected to appalling abuse and discrimination in the 1980s as a result of ignorance about the HIV virus. Many victims continue to keep their infection secret today.

Why was the haemophilia community hit so hard?

The new treatment for haemophilia in the 1970s was factor concentrate. This was produced by pooling human blood plasma from up to 40,000 donors and concentrating it to extract the clotting factor. Just one contaminated sample could infect the entire batch. Each dose could infect a person with HIV and hepatitis C.

A shortage of UK-produced factor concentrate meant it was imported from the United States, which used blood from high-risk paid donors such as prisoners and drug addicts.

What is the Infected Blood Inquiry?

The inquiry was set up in 2017 to look into the circumstances in which men, women and children were given contaminated blood and blood products through NHS treatment since 1970. It is due to publish its report in 2022.

Why is The Haemophilia Society's role being examined by the inquiry?

The inquiry is taking evidence from those infected and affected as well as clinicians, organisations and politicians who were involved in decision making or influential at the time of the scandal. The Society welcomes this scrutiny and has cooperated fully with the inquiry's investigation.

What can we expect from The Society's evidence?

It is likely that witnesses will be asked to talk about the charity's actions and advice during this period and its support for those infected from the 1990s to the present day.

Why has The Society apologised for the advice it gave?

During the scandal The Society issued statements reassuring members that the new factor treatments were safe and to continue using them. This advice was based on independent, expert medical opinion which we now know to be wrong and extremely damaging to our community. We have apologised unreservedly for our actions and deeply regret the hurt, pain and anger this has caused. We hope the inquiry will give us another opportunity to express this regret.

'We'll do all we can to help the inquiry get to the truth.' – read Chair Clive Smith's pledge to members on page 12.

Inquiry continues to hear evidence through lockdown

Infected Blood Inquiry hearings will not be knocked off course by the COVID-19 pandemic, its Chair Sir Brian Langstaff has stressed.

Clinicians from haemophilia centres are continuing to giving evidence to the inquiry – although for now this has to be done using a video link.

Although the inquiry team was forced to make changes to proceedings as a result of tighter lockdown rules introduced in November, Sir Brian insisted that the hearings continued as timetabled.

Sir Brian said: ***“Many people have been waiting years for the answers this inquiry is tasked with delivering. The inquiry’s work is too important to wait.”***

Members of the public, including those infected and affected, cannot attend the hearings in person until restrictions are lifted.

Questioning of the clinicians has been led by Jenni Richards QC, counsel to the inquiry, who has been probing what individual clinicians knew about the long-term impact of non-A non-B hepatitis in the 1970s, the emerging risk of HIV/AIDS and opinion then and now about how much information and choice of treatment patients should have been given. The questioning has also looked at the introduction of recombinant (synthetic) products, new risks of vCJD, as well as financial and emotional support for those infected.

The first clinician to give evidence was Dr Mark Winter, former director of Kent Haemophilia Centre, who described “the hardest decision of his life” to switch his patients to unlicensed American heat treated products in May 1984. He talked about the moment when, in October that year, his patients were tested and 30 – all

but one – were HIV positive. Dr Winter said: ***“You knew from that moment that whatever part of the haemophilia community you were in life would never, ever be the same again.”***

The inquiry has also heard from former directors of haemophilia centres at the Royal Free, Manchester Royal Infirmary, Royal London, Bradford, Birmingham and Sheffield as well as presentations on influential clinicians who have since died, such as Professors Arthur Bloom of Cardiff Haemophilia Centre, Professor Charles Rizza of Oxford Haemophilia Centre and Professor Geoff Savidge of St Thomas’ Haemophilia Centre.

One clinician, Professor Liakat Parapia, former director of Bradford Haemophilia Centre, broke down in tears at the end of his evidence. He told the inquiry that he felt he was to blame, albeit unwittingly, for infecting his patients.

Professor Christine Lee, former director of the Royal Free’s haemophilia centre, said awarding compensation was “the wrong thing to do”. She told the inquiry: ***“It suggests liability and I truly believe that people at that time were doing what they thought was the best.”***

The inquiry will continue to hear evidence from clinicians until mid-January 2021. The role of The Haemophilia Society will then be investigated in early February, followed by a look at trusts and schemes set up to help victims of contaminated blood. The inquiry will also spend a week of hearings looking at Treloar school in March.

Quotes from clinicians at the latest inquiry hearings

If you were a haemophiliac patient in Britain and you'd had factor VIII once, it was extraordinarily likely that you would have hepatitis C. I do not believe hepatitis C was avoidable in regularly treated patients.

Dr Mark Winter, former director of Kent Haemophilia Centre, on the risks of contracting hepatitis C in the 1970s and 80s

It was a radical proposal, but it didn't make its way on to my desk. With hindsight... I'm sure it would have had some impact.

Prof Edward Tuddenham, former director of the Royal Free's haemophilia centre, on a call to withdraw US blood products from the UK in May 1983

Without knowing it, I'm responsible for infecting them [his patients]... All I can say is I'm sorry.

Prof Liakat Parapia, former director of Bradford Haemophilia Centre

I don't want people to think I'm a hard, unsympathetic person, because I'm not. These people were part of my life... It was the saddest tragedy of all, but I think to suggest culpability is wrong.

Prof Christine Lee, former director of the Royal Free's haemophilia centre

I'm ashamed to say I'm not sure I would have had the strength of character to go against the prevailing view.

Prof Ian Franklin, former director of Birmingham Haemophilia Centre, on whether he would have stopped factor concentrate if he'd joined before 1983

We'll do all we can to help the inquiry get to the truth

“For the Infected Blood Inquiry to deliver truth and justice, it must shine a light into every corner of every organisation that played a part in our community in the 1970s and 80s – and that includes The Haemophilia Society.

In February 2021, the inquiry will look at the role of The Society before, during and after the contaminated blood scandal and I, along with everyone here at the charity, welcome this scrutiny. We have waived legal privilege, meaning the inquiry has absolutely all the evidence The Society has. We have held nothing back in assisting the inquiry in its work.

We do not yet know who the inquiry will call to be a witness or what evidence will be examined – that is the choice of the inquiry, not The Society - but I give you my guarantee that today's Haemophilia Society will do all it can to help the inquiry get to the truth.

As a board of trustees all with a connection to the bleeding disorders community, we are as anxious to uncover the truth as you all.

As one of three brothers, all with severe haemophilia A, I have grown up in the shadow of the contaminated blood scandal. Like many of you, I have lost friends and peers to this treatment disaster that should never have happened and for which no one has ever been held accountable.

Having attended the inquiry in person in London, Leeds and Edinburgh and watched online the evidence from Belfast and Cardiff, I've seen the courage, determination and pain

of our community in ensuring our story is told to the world.

I know that some members are angry and disappointed by actions taken by The Society in the past. Some felt unsupported and believe The Society should have done more to help them.

We cannot undo the past, but we will respond openly and honestly to criticism – no matter how difficult it is to hear.

For the inquiry to deliver justice, we need to know what happened. We need to ensure people affected and infected have the financial support and security they are entitled to, without having to go cap in hand for money which, by rights, should already be theirs. Justice means making sure this never, ever happens again and that individuals and organisations are held accountable for their actions.

Perhaps then, and only then, can we begin to look to the future and start to heal the wounds that have divided us as a community for far too long.”

Clive Smith, Chair of the board of trustees,
The Haemophilia Society



Supporting excellent global care

Improving care for people with bleeding disorders around the world is an issue The Haemophilia Society is passionate about.

The importance of global support for our community was brought home to us when we hosted the World Federation of Hemophilia (WFH) World Congress in Glasgow in 2018.

Using money we earnt from hosting the congress, The Society pledged £45,000 over three years to the WFH's Cornerstone Initiative which provides basic care for people living with bleeding disorders in countries where little or no treatment exists.

So, how is this money being spent? In 2019 our contribution to the Cornerstone project helped people with bleeding disorders in Bangladesh, Benin, Malawi, Mozambique, Myanmar, Tadjikistan and Togo.

Some of the projects have had a dramatic impact. For example, advances in training have seen a 90 per cent increase in the number of patients identified by The Hemophilia Society of Bangladesh and, thanks to training by WFH volunteers, the country's professional healthcare community can now accurately screen for inhibitors.

In Benin, the Cornerstone project helped the Association Béninoise des Hémophiles to build a strong volunteer base and develop an action plan. The organisation then met with the Minister of Health to pass on information and communicate patient needs.

Volunteers from the South Africa Hemophilia Foundation joined forces to train 40 nurses from all 10 regions of Malawi while a volunteer from the Kenya Hemophilia Association trained 14 lab practitioners



in diagnostic techniques. This has helped to overcome difficulties in outreach and diagnosis work in Malawi.

The Hemophilia Society of Tadjikistan was able to use help from the Cornerstone project to train more than 40 healthcare professionals and lay members in advocacy and factor usage. The Society was then able to meet with the Ministry of Health to push for state support.

A spokesman for the WFH's Cornerstone project said: "The improvements we are making in patient care, access to treatment and local leadership via the Cornerstone Initiative are only possible due to the support of the global bleeding disorders community. We thank you for sharing our belief that every person with a bleeding disorder deserves access to care, regardless of where they live."

"The road to basic care for people living with bleeding disorders in developing nations is arduous, but we are making great strides. This would not be possible without you. Thank you!"

Haemophilia no barrier to Alex's baseball dreams

When Alex Deacon started playing baseball with a toy bat his dad brought home from a trip to America, no one imagined that one day he'd be competing for his country.

But at 17, Alex, who has severe haemophilia A, is one of the top young baseball players in Britain and dreams of continuing to play his sport in the United States.

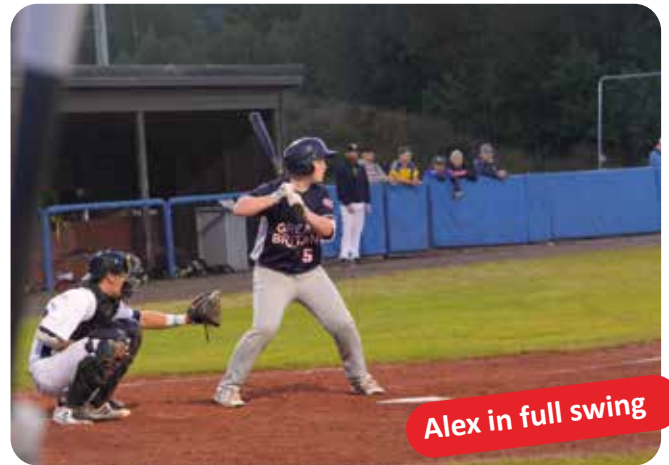
Alex says his haemophilia has never stopped him getting involved in sport and he encourages everyone to find their own favourite activity.

He told us: *"I'd say to anyone interested in baseball to give it a go, but it doesn't have to be baseball, it is just anything that you really enjoy. It just makes you happy every time you do it - it's where you feel comfortable. The cherry on top is when you play well."*

The team spirit, fun and friendliness of the baseball community have kept him interested in the sport from the age of six. Alex played in several leagues before being selected at the age of 13 to compete in the under 15 squad and now the under 18 team. He has played in the European Qualifiers three times and says the thrill of playing for team GB never gets old.

Alex said: *"The best part is when you go out on the field when the line ups are being announced. You sing the national anthem whilst wearing your country's name on your chest. It's a really good feeling. You get chills every time."*

Alex and his teammates are now waiting to hear where and when next year's European Qualifiers will take place. Although he's been



very lucky in avoiding injury in his career so far, this year he suffered a sprained ankle which has hampered his training.

In taking up baseball, Alex's parents discussed the risks with his haemophilia team who have supported him through his playing career, as have coaching staff. From the age of 10 he was put on trials for the extended half-life product Esperoct which he takes twice a week.

Alex remembers sitting down with the entire coaching staff to tell them about haemophilia.

He said: *"They know about my haemophilia, but it's not in the front part of their minds, although they are wary of it. The coaches don't stop you from doing anything because of it, which is the most reassuring part. They get you stuck in with everyone else."*

For Alex, haemophilia is *"just this thing that I have", which he is happy to talk about to his team mates and anyone else.* He said: *"They don't think of me differently because I have it. They think of me as the guy that goes out and plays."*

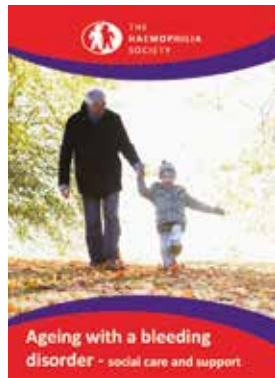
If you want to follow Alex's progress or are interested in baseball, he and three friends have started a podcast – Ducks Across The Pond – about their sport at www.ducksacrossthepond.co.uk Twitter @ducksacross

New publications launched

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 publications offer reliable information for you and your family. We have a number of new booklets this year which are free and delivered throughout the UK.

Ageing with a bleeding disorder – social care and support

Designed to help our ageing members to plan their specific needs as they reach older age. Elderly people with bleeding disorders may have chronic joint damage that brings about falls and fractures, so it's important to get the right care and support either at home or in residential care. Social care can be complicated, but we hope that this booklet will simplify the process and give you several paths to choose from.



Bleeding disorders and school

An overview of important points to bear in mind when managing a child with a bleeding disorder. It is not a complete guide; the relationship between the school and the parents is paramount.



This booklet aims to help teachers and parents create a healthy, happy and safe school environment for children with bleeding disorders. This will ensure that the school, the child and the parents feel confident and supported in managing any difficulties that may arise.

New for 2021 – newly updated Understanding haemophilia booklet

An overview of haemophilia with information on diagnosis, treating and living with this condition. If you or your child have recently been diagnosed with haemophilia you may be feeling quite overwhelmed. Remember, you are not alone and many families are facing the same concerns and issues. This booklet aims to give you a better understanding of living with haemophilia and answer your concerns.



Booklets in other languages

As a small charity, The Haemophilia Society does not have the funding to translate all of our resources. However, we are working to translate more of our resources and will update our website when they become available. We are in the process of translating other booklets into Polish, Arabic and Urdu.

For our younger community, three booklets endorsed by The Haemophilia Society:

Adam the adventurer, Adam and his woodland walk and Adam goes to school.

Join Adam and his friends on his quest to learn more about haemophilia, treatment and managing haemophilia at school.

All of our booklets are available to download or order free of charge from our website.

UKHCDO patient representative – Paul Sartain

This role is just one example of The Society's representation on UKHCDO committees for over 20 years.



I have been The Haemophilia Society's patient representative on the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) Data Analysis Group (DAG) since its

inception in 2017 and initial advertisement by The Society seeking volunteers.

The DAG is held monthly and comprises medical professionals responsible for the care of people with bleeding disorders, statisticians, NHD staff, and the patient representative. Its purpose is to review and decide on requests for analysis and/or data from the National Haemophilia Database (NHD) – predominantly statistical in nature.

The NHD was established in 1968 and has evolved over time with the information it holds, and is currently populated from two sources:

- haemophilia centres
- patients via Haemtrack home therapy recording system (2008 and onwards).

On the world stage, the NHD was 'pioneering' at its inception and has been used as a template by other countries too.

NHD data is used to look for any trends in treatment over time and especially to identify any safety issues that might come up. An important use of the data is to inform commissioners of healthcare to ensure that adequate funding is in place. Pharmaceutical

companies also request aggregated data to help them with post marketing surveillance e.g. of inhibitor formation or to plan UK supplies.

The Patient Representative role is:

- To ensure adherence to the principles of confidentiality and ethical use of patient information.
- To provide insight to a request from a person with a bleeding disorder perspective.
- The opportunity to influence the types of analysis that could be undertaken.
- To provide input to changes of policy and/or patient information documentation, e.g. NHD patient record report explanatory notes.

Discussions can be quite in depth and where clarification or concerns are identified then originators (of requests) are informed appropriately.

On a personal level it has been a steep learning curve and given me a far greater awareness of the complexities of providing care for those of us with a bleeding disorder.

It has also emphasised our individual responsibility for accurate and timely recording of personal treatment records via Haemtrack to ensure the 'statistical piece' of the overall jigsaw picture of our current and future treatment needs is the best it can be.

Further information about the UKHCDO and the NHD can be found at www.ukhcdo.org/

Getting smart about where medicines we use come from

William McKeown – Access and Service Improvement Ambassador, highlights the key messages he took from the EUPATI expert patient workshop.



I just wanted to share some recent reflections on my attendance at the EUPATI (European Patients' Academy on Therapeutic Innovation) expert patient workshop.

This was originally billed as a face-to-face course in sunny Madrid. Unfortunately, due to the COVID-19 pandemic the event had to be rescheduled as a four-day Zoom call in drizzly Northern Ireland. Woe is me!

Beforehand, a week on Zoom sounded rather grim in principle. However, I could not have been more wrong and as it turned out, it was a fascinating and uplifting experience for all who participated. Over 60 patients from across Europe converged on the conference virtually.

Multiple disease areas including cancer, rare genetic disorders and paediatric conditions were represented. I was struck by how the spectre of diseases can actually unite and bring together patients from far and wide.

I unquestionably met patients from other disease areas who I will be staying in contact with for years to come.

We had four days of expert talks on multiple areas of medicine development and regulation. Try not to yawn! The truth is these processes are absolutely critical for patients to access the right treatments.

Having good quality clinical trials to develop medicines, that ensure safety of new products, is something which people with haemophilia need as we enter the brave new world of gene therapies and non-replacement therapies (such as emicizumab).

I think the take home message is that we as a bleeding disorder community need to 'get smart' about where the medicines we inject ourselves with come from.

We need to improve scientific and regulatory literacy in our community so that we as patients can hold to account the pharmaceutical companies, governments, scientists and regulators who are developing and approving the safe therapies that we need.

We simply cannot leave it all to our health professionals and politicians to speak on our behalf. We need to speak for ourselves.

If you want to learn more about these issues please feel free to get in touch with UKHS, ask your doctor or use the excellent patient resources on the EUPATI website (<https://eupati.eu/resources/publications/>).



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Visit haemophilia.org.uk/get-involved/leaving-a-legacy-in-your-will/
or contact us on 020 7939 0780 or at info@haemophilia.org.uk

MPs push for improvements in treatment and care

A group of MPs has published a detailed review of the standards of care and access to treatment for people with bleeding disorders in the UK

The APPG on Haemophilia and Contaminated Blood is a group of MPs and members of the House of Lords who campaign with and on behalf of people with bleeding disorders in parliament. They are led by Labour MP Dame Diana Johnson and Conservative MP Sir Peter Bottomley.

In April 2019 the APPG launched an inquiry and call for evidence to understand to what extent people with bleeding disorders are getting the best care and what barriers there are to improving outcomes.

The final report, published this November, made 19 recommendations which fell into three main themes.

“Despite big steps forward in the treatments available to people with bleeding disorders, most are still seeing their lives held back by their condition.”

Dame Diana Johnson MP

First while the report looked in detail at drug approvals and commissioning, access to treatment goes beyond just provision of drugs; it includes proper care from a multidisciplinary team of professionals.

As a result of a lack of resources wider holistic needs are being ignored by treaters across the UK and not all patients are seeing genuine comprehensive care. The peer review of haemophilia centres published earlier this year confirmed the scale of this problem with only half of centres having sufficient physiotherapy provision and less than a third providing dedicated psychological or social worker support.

As a result, the UK seems to have fallen behind other comparator countries in outcomes for people with bleeding disorders.

Second, there is an inequity in access to treatment for many people. Women particularly seem to have greater difficulties in accessing treatment and appear to see disproportionate delays in diagnosis and referral to care. And rarer bleeding disorders such as FX deficiency and Factor XIII deficiency have had or continue to have delays in approval of newer treatments.

Finally, throughout the report we see a lack of informed and collaborative decision making between patients and clinicians. Most people with bleeding disorders did not feel particularly involved in decisions about their treatment with less than half feeling able to influence their choice to treatment. The inquiry saw a system where commissioners’ desire to drive down costs was unduly influencing prescribing decisions at the cost of patient choice.

In addition to their latest work on Access to Treatment, the MPs have previously secured debates in the House of Commons on contaminated blood products and were instrumental in the campaign for a public inquiry.

To read more about their work or to download the full report visit haemophilia.org.uk/APPG

‘Diagnosis with von Willebrand disease literally saved my life’

The challenges of late diagnosis and a lack of specialist clinics for women and girls with bleeding disorders must be addressed if equality of care is to become a reality, MPs and health professionals have been told

Dr Jo Traunter, a trustee of The Haemophilia Society, who has type 2 von Willebrand disease, said women were subjected to ‘disproportionate delays in diagnosis and referral to care.’

She was speaking at the launch of a report into access to treatment and care for people with bleeding disorders in the UK. As reported on p19, the launch of the All Party Parliamentary Group on Haemophilia and Contaminated Blood’s report featured personal stories from people living with bleeding disorders as well as healthcare professionals.

Jo told the meeting that she was diagnosed with vWD at the age of 36, just before the birth of her third child. The birth was difficult and Jo believes she would have died if her bleeding disorder had not been known.

She said: **“Diagnosis literally saved my life and I will not be alone. How many women have suffered unnecessary severe bleeding or even die because of a lack of diagnosis?”**

Jo, who is also a vWD ambassador to the European Haemophilia Consortium (EHC), said two of her three children have also been diagnosed with the condition. Her daughter must travel hundreds of miles to a specialist clinic in London to get the help she needs to manage her vWD.



She highlighted the huge differences in care across the UK for women with bleeding disorders.

Jo said: **“Equity in care and support should be available to all and not be limited to those who are able to successfully navigate the primary care system.”**

Although Jo experienced repeated bleeds and extensive bruising as a child, doctors never tested her for a bleeding disorder. On one trip to A&E doctors were so concerned by her bruising that social services were involved.

It was only the long memory of an anaesthetist who remembered Jo’s prolonged bleeding from childbirth nine years previously that triggered her life-saving diagnosis.

Jo said that since diagnosis she’s become aware of a difference in treatment options for women with bleeding disorders compared to men and was also critical of the lack of specialist care.

She concluded: **“Early diagnosis and appropriate treatment options, together with access to specialist support in clinics such as gynaecology and psychology are essential. These services should not be confined to certain regions and trusts; access to such clinics are fundamental to the treatment of women with bleeding disorders.”**

'Mine was a lonely diagnosis'

Sarah was 52 when she was diagnosed with a rare type of von Willebrand disease

She had suffered a lifetime of unexplained painful injuries, experienced three very frightening haemorrhages and, for the previous decade, debilitatingly heavy periods.

Yet, when her diagnosis finally came, she struggled with the news.

Sarah said: *"All through my childhood I'd been told not to make a fuss, not to be the child that cried wolf, because if I did no one would believe me when I was 'really' injured. After a while I stopped making a fuss and ended up putting up with so much.*

"So, to find out that I have had a bleeding disorder my whole life and treatment was available was difficult. I struggled."

A 'lightbulb moment' came very recently when she twisted her ankle and received treatment at her haemophilia centre. She said: *"For the first time I felt the pain of the injury and then the relief that you get when you have factor and your blood starts to work as it should. I had never felt that before."*

Sarah finds it hard to accept that so many chances to diagnose her condition – type 2n vWD – were missed. Her bleeding disorder means that although her blood initially clots, it can't sustain a clot, so her bleeds and haemorrhages happened a week or so after surgery. Not one doctor treating her haemorrhages suggested a bleeding disorder might be the cause.

Traumatized by poor and insensitive treatment following her last haemorrhage, Sarah refused to attend hospital again.

Sarah struggled with her diagnosis



Her periods became unmanageable, she had to set an alarm hourly to change her pads at night and she dreaded dealing with embarrassing leaks at work.

No one knew what she was going through, she said: *"This was deeply personal and it involved blood – not really dinner table conversation. I kept it to myself."*

It was only a medical crisis that forced her back to hospital and, after confessing her terror about surgery to a consultant, a clotting test was done, leading to her vWD diagnosis.

Still very new to her condition, Sarah has turned to Talking Red, The Haemophilia Society's campaign to raise awareness, share knowledge and bring together women with a bleeding disorder.

She said: *"Mine was a lonely diagnosis – I didn't know anyone with any type of bleeding disorder and I still don't fully understand how to deal with my condition."*

I want to be part of the Talking Red community so I can learn from others and if I can do anything that will help others in the same situation that would be tremendous."

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 events@haemophilia.org.uk or head to our website.

Jaguar raffle

Jaguar Enthusiasts' Club has this year chosen us to be their charity of choice and kindly donated an incredible Jaguar to be raffled in our aid.

To get your ticket go online at: www.jec.org.uk/raffle or call 0117 969 8186.

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 buy tickets at £2 each (complete book of 10 tickets costs £20).

The winner will also receive a £500 voucher for JEC's insurance partner, Peter James Insurance.

Your money will be supporting The Haemophilia Society with our vital work.

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



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Every penny counts – order our new flat-pack collection boxes today!

Every penny counts, especially in these unprecedented times when we don't know when we will be allowed to go back to normality and run our fundraising events again.

We have designed new flat-pack collection boxes that you can order from our website and help us collect spare pennies and pounds to be put towards our work.

We appreciate that times are hard for everyone but any small change lying around your house or office will eventually add up and help us to continue

running our free services. To make it more fun you can even use it as a swear jar, collect only coins of a certain value or set yourself a goal of how much you will put in the box weekly or monthly.

When the box is full, all you need to do is just deposit money directly into our bank account and drop us a note to let us know so we can thank you!

Any contribution however big or small, will make a difference and help us be there for our bleeding community during these difficult times.



Charitable Travel – for charity, not for profit

We are happy to announce that we have partnered up with Charitable Travel.

Charitable Travel is a registered social enterprise and a financially protected travel agency, whose purpose and mission is to help you with your holiday plans and at the same time support the great work that UK-based charities deliver around the world.

When you book a holiday or cruise with Charitable Travel, they sacrifice travel agency commission so you can make a free five percent donation to The Haemophilia Society through their dedicated JustGiving page at **charitable.travel/haemophilia-society** for no extra cost.

Magnet Offer and The Haemophilia Society

You can now turn your fridge into a wall of art while supporting The Haemophilia Society at no extra cost!

For only £9.99, including the delivery, you will receive 10 personalised photo fridge magnets with pictures you choose from your social media, which make a great Christmas

present or a stocking filler for your loved ones, while over 50 per cent of the cost will be donated directly to our Society.

Head to the Magnet Offer website and design a perfect present while supporting The Haemophilia Society.
www.magnetoffer.com/home



Ultra challenge: 100km Jurassic Coast trek

Despite the pandemic, some of our amazing supporters are embarking on difficult challenges to raise vital funds for our charity, which needs support now more than ever.

One of the most exciting challenges is probably a 100km Jurassic Coast trek, organised with Ultra Challenges, that one of our incredible supporters, Wyatt Ko, is taking on for us. Wyatt said:

"I am going to be taking on the Jurassic Coast challenge, walking 100km continuously. I'm fundraising for The Haemophilia Society to help raise money to support families affected

with bleeding disorders. My grandad and two of my cousins have moderate haemophilia A.

Cassius is 16 and Jonny is 11. I've watched them grow and seen the struggles they've had with their bleeding disorder. They have never let it hold them back despite long periods of time in hospital with various bleeds. I will be walking in support of them."

You can donate to Wyatt's fundraising page following this link:

www.justgiving.com/fundraising/wyatt-ko



Youth Ambassadors' Instagram takeover

With no physical events taking place and everyone working from home, it was difficult to find content that would fit on our social media channel. Luckily, our wonderful Youth Ambassadors gave us a hand and ran the account for a week. We ran Youth Ambassadors' Instagram takeover for seven weeks, with eight ambassadors sharing their experiences of living with a bleeding disorder.

Here's what they thought:

"For me the social media takeover was an awesome experience and it created a great opportunity to interact with people in the bleeding disorder community. My main focus was to talk about switching to a novel treatment, talking with my sister about her experience as a woman with a bleeding disorder and to talk about things people can achieve despite having a bleeding disorder."

Scott McLean

"Being able to take over The Haemophilia Society's Instagram, was a great opportunity to speak with more people from the community and share my experiences growing up and being LGBT with a bleeding disorder."

Jay Gardner

"I did the takeover as I thought it would be a good way to meet people and for people to get to know me as a new ambassador. I focused on haemophilia B, living away from home and sport. The highlight was the questions and bumping into Michael Atherton, former England Test cricket captain, while cycling."

Ross Bennett



"I completed an Instagram takeover because it is important for the bleeding community to know that there is support for all and that you can lead a normal life with a bleeding disorder. My highlight was replying to people, not only could I give advice, but it also made me feel good being some sort of role model... plus it made me realise being an influencer isn't such a bad job to have... maybe something I should look into!"

Josh Taylor-Rose

"It was fantastic to do the Instagram takeover with my twin brother; we decided to do this as it was a bit different to the others, funny and entertaining. As well as this, we were able to get across the importance of topics such as self-injecting and taking your bleeding disorder seriously. The highlight was to be able to answer the questions that people had and knowing that my knowledge and experiences were actually helping people within our great community."

Alex Taylor-Rose

"I did the Instagram takeover because I wanted there to be a female voice too – not just the boys! I made sure to focus on raising awareness of women with bleeding disorders and how we can have very similar but also very different symptoms and experiences. Lots of people from the community said they found the same thing too and I enjoyed getting the chance to talk to more women with bleeding disorders and carriers."

Jessica Page

Bloody shave

Our Youth Ambassador's Scott, Matty, Ethan, Josh, Alex and Josh have decided to avoid the bleeding shave for November to help raise awareness for bleeding disorders and prostate cancer!

Having a bleeding disorder can make shaving problematic so they have decided to forego the shave for a month and see who can grow the most impressive facial fuzz and see which ambassador will have the best moustache.

We have posted pictures of their facial hair progress on our social media so head over to our Instagram and let us know who you think can pull off facial hair best.

You can also donate to the cause following the link below. Thank you for your support!
www.justgiving.com/team/thebleedingshave



The Virtual London Marathon and HaemTeam

The 40th anniversary of the event was a year like no other, with participants being asked to take on the equivalent distance of a marathon in their own way.

We had four amazing runners representing us at the first virtual London Marathon and they all finished the gruelling 26-mile trek in impressive time Christina Gutsell (06:16:38), Jack Bailey (04:36:01), Jessica Page (07:08:59) and Scott McLean (07:10:21).

Thank you for all your hard work and support. We are so proud of your achievement and we can't wait to cheer you on at next year's event!



Offering new families expert support

On 31 October 2020 we held our first Newly Diagnosed virtual event. We didn't want our new families to miss out on this educational and informative event due to the ongoing COVID-19 restrictions.

This event, designed to support parents who have recently found out their child has a bleeding disorder, brings together experts in bleeding disorders care so families get the help they need to ensure their child gets the best possible care. The presentations included:

Overview of bleeding disorders by Dr Kate Khair, Haemnet

Kate looked at how best to look after your child with a bleeding disorder and gave an overview of Glanzmann thrombasthenia and von Willebrand disease. There was then an in-depth talk about haemophilia which included the classification, inheritance, bleeding and bruising, signs and symptoms, target joints, treatment, PRICE and bleeding disorders care.

How can my haemophilia nurse support us? by Julia Spires, Great Ormond Street Hospital

Julia's presentation included the Comprehensive Care Centre, what it is; the role of the haemophilia nurse; when to contact the haemophilia nurse; what the haemophilia nurse can support you with and other places to seek support.

Physiotherapy and its benefits by Sarah Jones, Cardiff and Vale University Health Board/HCPA

Sarah gave an overview of what physiotherapy is, defined the role of a physiotherapist, why we need physio for haemophilia and physio within haemophilia care.



Stress management for parents of a child with a bleeding disorder by Martin Sugg, psychotherapist

While parenting is rewarding, it can also be one of the most difficult times in your life. Having a child who has recently been diagnosed with a bleeding disorder presents new challenges. This presentation aimed to identify some of the emotional aspects of caring for a child with a lifelong disorder e.g. how this can impact on the individual and relationships; coping techniques and mindfulness; how to help your child.

If you would like to watch our speaker presentations, please register on the link below. <https://col.eventsair.com/ndw/ndw2020/Site/Register>

We hope to be able to run our newly diagnosed weekends again in summer 2021

Our NDWs are free to our members and open to families who have a child aged 0–5 years and recently diagnosed with a bleeding disorder. These weekends are very popular and there is often a waiting list.

If you would like to attend you can also let us know that you're interested by emailing nicola@haemophilia.org.uk

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

2021

Fundraising events

- 20 March** Virtual Big Red London Bridge Walk
- 27 June** Parallel, Windsor
- Aug TBC** Prudential RideLondon, London

Member events

- July** Newly Diagnosed Weekend, Colchester
- 28 Jul-1 Aug** Youth Camp, Derby
- Oct** Newly Diagnosed Weekend, Manchester
- TBC** Family days across the UK
- TBC** Young People's Activity weekend (15-17 yrs)
- TBC** Talking Red, York

Awareness days

- 1-7 Feb** Children's Mental Health Week
- 28 Feb** Rare Diseases Day
- 8 March** International Women's Day
- 7 April** World Health Day
- 17 April** World Haemophilia Day
- 28 July** World Hepatitis Day
- 7 Sept** Youth Mental Health Day
- 10 Oct** World Mental Health Day
- 19 Nov** International Men's Day

Please note: due to uncertainty around COVID-19 all events can be subject to change following government guidelines.



Hold a virtual Buddies Who Brunch!

With COVID-19 and the limitations that come with it, we would like to invite you to host your brunch virtually – you can still connect with your friends and loved ones via one of several online platforms we are all very used to using now!

Not only will you break routine and enjoy a catch up and some delicious food, but you will also help The Haemophilia Society in this time of uncertainty with your fundraising.

The vital money you raise will allow us to continue to provide free access to our membership and services for all those affected by genetic bleeding disorders, whenever and wherever our community needs us.

So please consider hosting a virtual brunch today! Please visit haemophilia.org.uk/get-involved/fundraising/buddies-who-brunch/

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



THE HAEMOPHILIA SOCIETY

"We have been able to maintain friendships with people we met at the Newly Diagnosed Weekend. My time there taught me that a child with haemophilia can do anything and the world is their limit!"

Parent who attended one of our Newly Diagnosed Weekends.

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
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