



70 years of support



THE
HAEMOPHILIA
SOCIETY

The Haemophilia Society magazine
Summer 2020



Celebrating 70 years of support - putting our community first

Also inside: A mum's story: 'I want my son to have choices'
| Haemophilia centre review latest | Women's bleeding: survey results
| Global haemophilia care report | Public inquiry to restart hearings

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.

It's time to **liberate patients**.

It's time to deliver **long-lasting therapies** designed to produce a consistent supply of factor for years from a single treatment.

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, talk to your healthcare provider or visit sigilon.com.

From the chair

Despite the current challenges that Covid-19 presents, an enormous amount of work by the team at The Society continues to be done. As we approach our 70th birthday, we are reminded that despite decades of endeavour, there is much still to achieve on behalf of our community.

We have always relied on you, our members, to help us raise vital funds as we work to inform, support and inspire everyone affected by a bleeding disorder. Now, as we face new and unexpected financial challenges as a result of Covid-19, we need your support again. Please donate to our Birthday Appeal, which aims to raise £7,000 to help us continue our work.

I have been bowled over by your fundraising ideas during lockdown – some of them are featured in this edition – and I can't wait to see more of your inspiring projects. Keep sharing your fantastic fundraising on social media and among your family and friends. Together, I know we can hit our target. There's a letter about our Birthday Appeal inserted in this magazine.

While we may not be able to celebrate our birthday in person with you all, we are celebrating 70 years of change in this edition of HQ, which I hope you enjoy.

The care, treatment and recognition of bleeding disorders has come a long way during The Society's lifetime – but, with your help, there's so much more we want to do.

On behalf of us all, I do hope you are staying safe and well, and we all look forward to a time when we can once again meet face to face.



C. Smith

Clive Smith, Chair

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Youth Ambassadors

Developing and empowering our young members to become our future leaders and advocates. Some of our Youth Ambassadors tell all...

Name: Jess Page

Age: 24

Occupation: primary school teacher

Bleeding disorder: mild haemophilia A



I became a YA because: I wanted to help The Society raise awareness of bleeding disorders, particularly in women.

Best thing about being a YA: getting to meet so many different members of the community and really making a difference.

Proudest achievement [as a YA]: youth camp! I really enjoyed spending time with the kids and helping them to do stuff they might have not tried before. Also getting to apply for the Youth Leadership training with the EHC and Youth Ambassador programme with the WFH, even if they did get corona'd off!

Name: Alex Taylor-Rose

Age: 24

Occupation: Data Analyst & Researcher

Bleeding disorder: severe haemophilia A



I became a YA because:

To raise awareness about bleeding disorders, as well as encourage the younger members. I've been able to explain my stories and journey having haemophilia to many people - showing I'm living proof that you don't have to be scared or worried having haemophilia. It's pretty much living a normal life, if you keep on top of your medication.

Best thing about being a YA: To encourage and empower other members. Additionally, I am able to work alongside the other YAs to make a real change in the community.

Proudest achievement [as a YA]: I have more than just one proud achievement - every time I speak to a new family to give advice or just tell my journey with haemophilia - this is what gives me a great deal of pride. Knowing that I've been able to help a family for whatever reason just gives a great feeling.

Name: Josh Taylor-Rose

Age: 24

Occupation: Swim Coach/ Accountant/Student

Bleeding disorder: severe haemophilia A



I became a YA because:

To raise awareness on bleeding disorders especially to fellow sufferers. Additionally with the resources available at The Society, I get to encourage and empower young people and their families with bleeding disorders.

Best thing about being a YA: Connecting with fellow bleeding disorder sufferers, whilst inspiring the next generation, and having fun with your peers and new people.

Proudest achievement [as a YA]: Trekking Machu Picchu in August 2019. Although I wasn't quite a YA, the sense of fulfilment I got raising awareness of bleeding disorders was one of the reasons why I became a YA.

Name: Scott McLean

Age: 28

Occupation: Customer Service Manager

Bleeding disorder: severe haemophilia A



I became a YA because:

after seeing first-hand all of the work The Society does for the community and how

they engage with their members I immediately wanted to get involved in any way I could.

Best thing about being a YA: is meeting new people all the time and being able to share experiences and raise awareness. It really has given me a sense of belonging. It's like one big family.

Proudest achievement [as a YA]: my proudest achievement is attending the Newly Diagnosed Weekends and seeing the positive impact they have on the families we meet. Being able to show the good side of haemophilia and what can be achieved.

Name: Matthew Minshall

Age: 23

Occupation: Physiotherapy Assistant/Product Design Graduate

Bleeding disorder: severe haemophilia A

I became a YA because: To have an impact and support others within the community.

Best thing about being a YA: There is not one specific thing that outweighs others. But the community is awesome!

Proudest achievement [as a YA]: The Lads and Dads Weekend to engage more members of the community. Starting off the concept and proposal with Rob and Luke to it being successfully delivered two years running!



Older teens activity camp

We're looking for the next generation of Youth Ambassadors!

If you are aged 15-17 with a bleeding disorder you could take part in a new activity camp for older teens next year and discover what it takes to be a YA.

We are looking for young men and women who want to have fun, connect with others who have a bleeding disorder and learn some new skills. Activity camp is a chance to find out more about being a YA as well as an opportunity to tell us what matters to you and what you'd like from The Society.

The camp is a potential stepping stone to the YA programme, which gives people aged 18-30 the chance to develop new skills, travel and – most valued of all – use their life experience to inspire and reassure others with a bleeding disorder.

Launched in 2015 the YA programme aims to encourage, develop and empower young people in our community to become our future leaders and advocates. The role involves a three-year commitment to working with The Society.

One of the YAs' most important roles is to give children and parents an insight into what it is like to live with a bleeding disorder. Many parents who have attended our Newly Diagnosed Weekends tell us that listening to a YA talk about their everyday life gives them confidence and hope that their child will go on to live a normal and fulfilled life.

And YAs are really important mentors for our younger members, helping them to develop their independence at Youth Camp as well as answering those burning questions on tattoos, playing football and how to self-treat.

The future of The Society depends on our younger members getting involved, so if you want to challenge yourself and help make life better for others with a bleeding disorder, please register your interest in our training camp 2021 for 15-17 year olds by emailing info@haemophilia.org.uk

News

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

Get involved in a new study of women's bleeding

Haemnet is looking for women and girls to take part in its Cinderella project – a study of unmet medical need among females who bleed.

The study is being managed by Dr Kate Khair, vice chair of The Haemophilia Society's board of trustees and Director of Research at Haemnet, who is running an on-line survey on the theme of 'What's my normal?'. She will also host eight focus groups across the UK to hear the experiences of girls and women who bleed.

Any woman or girl with an inherited bleeding disorder – or who comes from a bleeding disorder family but does not yet have a diagnosis – is invited to get involved.

To participate in the survey please go to haemnet.typeform.com/to/uWufTI



Cinderella

Tribute to former chair of The Society

We know many of you will be very sorry to hear that Chris Hodgson, a former chair of trustees at The Society, has died aged 79 after years of living with Parkinson's Disease as well as having severe haemophilia A.

Chris became a trustee in 1992 and served as chair from 1996 to 2003. He was married to Jane and had two sons. A successful businessman, Chris also loved gliding, golf and fly fishing and will be remembered fondly by our members.

He also worked as a bereavement councillor until a few years ago. Keith Colthorpe, who served with Chris as a trustee for many years, said: "Chris had a lot of wisdom in guiding The Society. He never stopped doing things for The Society, long after he was a trustee. He was very dedicated and was always there when the charity needed him. He will be greatly missed."



Research on attitudes towards new haemophilia treatments

If you are an adult with moderate or severe haemophilia A or B, you are invited to take part in research to help understand attitudes towards new treatments.

The research, carried out by HCD Economics, will be used to inform health care decision making in the future. Questions will examine the preferences of people with haemophilia for hypothetical haemophilia treatment options to understand the relative importance and value of novel treatments.

The online survey will take about 20 minutes to complete and is open to people aged 18 or over. A £30 Amazon voucher is provided to anyone eligible who participates in the survey.

Please look out for future emails and social media posts from The Society to find out more about taking part in this research. Register your interest at research@haemophilia.org.uk

UNSPEAKABLE now available in the UK

The award winning eight-part series Unspeakable, based on the Canadian contaminated

blood scandal is now available in the UK on Amazon Prime.

In May 2019, The Haemophilia Society hosted the first public screening of Unspeakable's initial episodes in the UK to add our support to the studio's efforts to get the series aired. We hope Unspeakable, which has many parallels with UK, will help raise awareness of the contaminated blood scandal. www.unspeakabletv.com/



New artificially made VWD treatment reviewed

A second attempt to get the first artificially made treatment for people with severe types of von Willebrand disease (VWD) funded by NHS England will be made later this month. [July]

The Vonicog Alfa recombinant VWD product will be reviewed by NHS England's Clinical Priorities Advisory Group (CPAG) on July 29 which will make a recommendation about whether to fund the treatment. It will then be up to NHS England's specialised commissioning to decide whether to make it available to patients.

In February, CPAG turned down an application to fund

this product, meaning that people with VWD who need factor cover during surgery or for bleeding complications continue to rely on plasma-based treatment.

Sign up for the EHC's virtual conference

The European Haemophilia Consortium (EHC) is holding a virtual conference in October 2020 which is open to all.

Taking place between 5-9 October, the conference looks at a range of issues including managing pain, mild haemophilia, von Willebrand disease, education and shared decision making between a patient and their clinician.

You can register for this free event through the EHC's website www.ehc.eu/events/ehc-conference-2020/

Counselling service launched for people living with HIV

A new free counselling service is on offer to former beneficiaries of the Macfarlane Trust (MFT).

The Terrence Higgins Trust, which now manages the remaining funds from the MFT, is providing up to 24 free counselling sessions per person. To be eligible, you will be a former MFT beneficiary with or affected by HIV as a result of contaminated blood products.

To find out more call 0808 8021221 or email macfarlane@tht.org.uk

Join the conversation – live!

We've launched Bleeding Matters – Live! to keep our community in touch and talking about the issues that are affecting your lives.

Our new webinar series aims to bring together families and experts to share experiences and learn more about a whole range of subjects which matter to you. We're covering everything from first-hand experience of new treatments to an insider's guide to how your haemophilia centre is run.

Expect lively debate and lots of interesting expert opinion as well as personal experiences. Feel free to join in, or just listen – you are always welcome. If there's an issue you'd like to see featured on Bleeding Matters – Live! let us know.

To find out more about the latest Bleeding Matters – Live! webinar check our website for details.

Bleeding Matters Live!



World Haemophilia Day 2020

Marking this important day together.

This year's World Haemophilia Day on Friday 17 April was one with which we had mixed feelings. With everyone stuck at home in lockdown, we wondered how the community would experience this day, one of the most important in our calendar.

Here at The Society, this year was not about making money and getting donations, but one of support and engagement with the UK community.

As the only UK-wide charity for people with genetic bleeding disorders, we wanted to find a way to be as inclusive as possible.

The response from you all was #AMAZING – from people wearing red to the Buddies Who Brunch events that took place, we saw so many people getting involved!

We had people dying their hair red, making red food and children colouring in pictures of Buddy from our Buddy Kids Corner.

Companies such as Sobi, Roche and Takeda all held virtual events. Roche even held a Town Hall meeting that one of our team spoke at, along with a Buddies Who Brunch Cake Bake Off!

Sobi organised a teamwide brunch, and also supported us with a Radio Day that our vice chair of trustees, Kate Khair spoke at, reaching thousands of people across the UK, talking about bleeding disorders. Other trustees got involved too, the pinnacle was our chair of trustees, Clive Smith who did a sponsored 100 mile bike ride, from his indoor gym (garage). Clive, who has severe



haemophilia A, took up the challenge as part of his training for an Ironman competition this autumn, which will be his fifth.

Thank you for all of your support in making this year so special, even in these unprecedented times.



Service of Thanksgiving and Remembrance



THE
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Saturday 31 October at 2.30pm

St Botolph without Bishopsgate, London EC2M 3TL

To remember those who have died from contaminated blood products within the bleeding disorders community.

We are currently in the process of looking at options for hosting the service online as well as in person if safe to do so.

We will be updating our website with more details as we have them and full booking information will be available in the coming months.

If you would like a candle lit or a name entered in the Book of Remembrance, please contact us on 020 7939 0780 or at info@haemophilia.org.uk

Please note: due to uncertainty around COVID-19 this event can be subject to changes following government guidelines.



THE
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Help us to always be there through a gift in your will

By creating a lasting legacy in your will you can help us ensure that everyone affected by a genetic bleeding disorder lives the best life they can.

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

Infected Blood Inquiry hearings to re-start

The Infected Blood Inquiry is preparing for hearings to take place in London this autumn.

Chair of the inquiry, Sir Brian Langstaff, says he wants witnesses to give evidence in person 'wherever possible'. There will be limited space for people to attend the hearings, with priority given to those who have a direct connection to the witness.

The next hearings will focus on clinicians and others who could shed light on the policies and practices of haemophilia centres across the UK.

After that, the hearings will turn to the trusts and schemes that were set up in the wake of the contaminated blood scandal.

While the Covid lockdown has meant inquiry staff have had to work from home, their investigations have continued and the team says it is still on track to deliver its final report in 2022.

The closure of the National Archives has, however, slowed some elements of the inquiry's work and means that it has had to delay the evidence given by politicians, who will now not appear before Sir Brian until next year.

A series of 'virtual' local meetings across the UK have been held by the inquiry in recent weeks to update those infected and affected on its progress, as well as to test opinion about how the new public hearings could work.

As the numbers of those attending the hearings will be far lower than during previous sessions, the inquiry is looking at ways of helping people stay in touch online,

recognising that many participants rely on the support of others during difficult hearings. This may be possible by hosting private discussions during the breaks between sessions or by being more proactive with the comments section of the Youtube live video feed.

The inquiry is also considering setting up gatherings outside London for those who prefer not to watch evidence sessions relating to their haemophilia centre alone.

Psychological support will continue to be provided by the inquiry's British Red Cross team, who will be available throughout the hearings.

Personal witness statements continue to be accepted by the inquiry, which is beginning to publish some written statements on its website.

By the time you read this, more details may have been announced. To keep up to date with the latest information check the public inquiry section of our website, join our dedicated statutory Facebook page or follow our public inquiry Twitter account @HaemoSocUK_PI.

Meet our new trustees

The Society couldn't operate without the hard work, expertise and enthusiasm of our trustees. Find out about our newest members of the board, Jo and Conan.

Name: Conan McIlwrath

Age: 37

Occupation: M&E Asset Performance Manager, NI Water

Home is: County Antrim NI



Why did you want to be a trustee?

To give something back to the community. I have had involvement with local groups from a young age and have many happy memories of a childhood involved in The Haemophilia Society activities with my parents.

What do you want to achieve?

Greater connection across the UK, rebuild connections and memberships within the devolved nations and to try to be more inclusive when running events.

Tell us a secret....

Hmm, I failed my driver theory test 5 times... When I finally passed it I may or may not have been under the influence of alcohol to calm my nerves... I did, however, pass my practical first time (and sober!).

Name: Dr Joanne Traunter

Age: 52

Occupation: Senior lecturer and researcher in Education and Childhood Studies at the University of Hull.



Home is: Yorkshire, the outskirts of the Yorkshire Wolds, between Hull and York.

Why did you want to be a trustee?

As a woman and a mother of two children with a bleeding disorder (von Willebrand disease) I decided to become a trustee to advocate for and support those who are also impacted, whether directly as a woman or as a parent or carer of a child with a bleeding disorder. As an educator

I believe that raising awareness, providing knowledge and educating people about bleeding conditions and particularly women's bleeding conditions will have a direct impact on the outcomes for women and children and quality of life they lead. I think it is vital that we continue to raise awareness and support research which investigates potential treatment and support for affected women and children and I am a strong believer in being the change you would like to see.

What do you want to achieve?

I would like to help raise awareness and support for women and parents of children with bleeding disorders and ensure that they are empowered and supported to seek diagnosis and treatment.

Tell us a secret....

My lucky number is 11, it seems to appear consistently through my life, my daughter was born on the 11th of the November at 11 o'clock, we lived at number 11, if I stay in a hotel I can pretty much guarantee they will put me in room number 11!

Board of Trustees

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

The Society's board of trustees meets six times each year to give strategic direction to our work. Trustees are responsible for governing our organisation, and as a smaller charity, they make a real difference to what we do.

If you are interested in becoming a trustee, elections are held each year. You can find out more here haemophilia.org.uk/who-we-are/workforus/

Developing a grant and trust fundraising strategy

Building meaningful and long-lasting partnerships

Reflecting on the past and envisioning the future are essential in developing a strategy – for some, birthdays tend to provoke similar mental exercises. While developing our grant and trust fundraising strategy with The Society's 70th birthday approaching, it is moving to recognise that in this case the past is seven decades filled with the very vivid struggles and triumphs of thousands in our community, and the future is of countless more still to come. That lights a fire in all the right places.

Grant and trust funding is crucial to The Society, and our approach is simple: build partnerships.

Even in the case of grant-makers where the "ask" is usually made in writing with little contact before, from the start the focus is on how we can help them achieve their objectives through our work.

While the purpose of fundraising is obviously to raise funds, in order to build a reliable source of grant and trust funding The Society must develop this capability. The vision is of an operation searching for new partnerships and nurturing existing ones; focussed on anticipating and satisfying the needs of our funding partners and the community; continuously looking for ways to improve; sustainable and adaptable; and in doing all that, able to provide The Society with a reliable source of funds into the future.

Fundraising is vital to the continuation of our free member services



Arguably the most critical element to grant and trust fundraising is the ability to show we have delivered change effectively in the past, and have credible plans and governance in place to continue to do so into the future.

While we harness your experiences, expectations, and feedback to drive what we do, your personal stories of how The Society's events and services have changed your lives are invaluable in showing funding partners the impact they have had and will continue to have through our work.

You are also instrumental in building our fundraising network – you may know people who may be able to advance our grant and trust fundraising.

The community's shared past of struggles and triumphs is a moving and motivating force – the hope is that our grant and trust fundraising will make The Society stronger in supporting those countless futures still to come.

Please send your impact stories and fundraising network suggestions to andrew@haemophilia.org.uk

Happy Birthday to Us!

As it's our 70th birthday this month, come and look back with us at the history of The Haemophilia Society to see how far we have come...

When Bob White and Frank Smith met in a hospital waiting room in London back in the **1940s**, they probably didn't know that their conversation would eventually result in the creation of The Haemophilia Society. The pair saw a need for a support group to bring those with haemophilia together, so alongside others with a mutual interest formed The International Haemophilia Society (IHS), which registered as a charity in **1950**.

The IHS began holding its meetings at the Hospital for Sick Children at Great Ormond Street. By **1954**, local groups were set up all over the UK, and the IHS change its name to the name we know today - The Haemophilia Society.

The same year saw the start of ground-breaking steps in the care of people with haemophilia. The Society began working with the Ministry of Health to create haemophilia centres and looked at tackling numerous challenges that were being faced by those with haemophilia – such as going to school, work, and accessing transport.

A famous face – the actor Richard Burton – helped raise both funds and awareness when, in **1969**, he pledged the proceeds from the royal premiere of his film, *Where Eagles Dare*, to an appeal in his name, donating the equivalent of over **£60,000** today.

As most of our members know, contaminated blood has had a massive impact on our community. After **30 years** of campaigning for a public inquiry, the Infected Blood Inquiry opened in 2018 and since then almost **200**



people infected or affected by the scandal have given evidence publicly. At last, their voices are being heard.

Today there are more than **32,000** people in the UK diagnosed with a bleeding disorder and The Society has grown to have thousands of members. We are now able to support our members online, face to face and over the telephone.

Treatment and care have changed beyond recognition since that fateful waiting room conversation. But we hope our founders' legacy lives on in our inclusive, welcoming culture and 'can do' approach.

So, as we enter our **70th** year, we would like to thank you, our members. Your fundraising and support mean that we can continue to help and empower people living with a bleeding disorder.

Together we will continue to work for a brighter future for everyone affected by a bleeding disorder.

Celebrating 70 years of change

Bill Payne and Lynn Wild share a birthday with The Society. Here they reflect on 70 years of living with a bleeding disorder.

Bill Payne was born the same year The Haemophilia Society was created and remains a loyal member today.

His mother joined in 1951 when Bill was diagnosed with severe haemophilia B. They benefited from advice and support from The Society and Bill later became volunteer, serving as a trustee and coordinating the Bristol and South West Haemophilia Group.

Bill remembers a childhood disrupted by frequent hospital stays, when bedrest was the main treatment for haemophilia. It was not until he attended Treloars school in Hampshire aged 11 that Bill had the chance to be independent. Bill said: "I was able to be me, rather than somebody that was wrapped up in cotton wool."

The contaminated blood scandal infected both Bill and his brother Michael with hepatitis C and resulted in the death of many friends. Bill said: "We've got to keep this issue alive so that people understand what happened and make sure it could never happen again."

Born in Bristol, Bill has lived in the city for most of his life. He served on the city council for 12 years and was honoured to be made an alderman.

Bill said: ***"The Society has always been there when I needed it. It has provided support and advice."***

As gene therapy brings the prospect of "curing" haemophilia ever closer, Bill has



mixed feelings about this.

He said: "Being a haemophiliac is part of who I am and, as strange as it may sound, I would be losing something if that was taken away."

Lynn Wild shares her 70th birthday with The Haemophilia Society.

And if anyone understands life with a bleeding disorder, it is Lynn. Her dad had haemophilia and she was diagnosed with von Willebrand disease at the age of 30.

Growing up, she was used to her dad's nosebleeds and bruising, but also had to deal with being a 'bleeder' herself.

Now an ambassador for The Society's Talking Red campaign, Lynn raises awareness about women's bleeding disorders.

She said: ***"I feel very proud to be able to offer help, positivity and awareness to other women."***



Ellen, Josh and Austin's story

Newly Diagnosed Weekend helps to change family's outlook on the future.

For Ellen, attending The Society's Newly Diagnosed Weekend marked a turning point in how she deals with her son's haemophilia.

Austin was diagnosed with severe haemophilia A shortly after his birth 18 months ago, after his heel prick test resulted in excessive bleeding. The news was a complete surprise to Ellen and her partner Josh, and the couple have been learning about haemophilia ever since.

Ellen said: "I had never heard of haemophilia before Austin was diagnosed. It was a very hard time, but with hindsight I am so glad that the diagnosis was made so early. We've had exceptional support."

"We left feeling positive, as if a huge weight had been lifted off us. We feel really lucky to have had this experience."

Attending a Newly Diagnosed Weekend earlier this year gave Ellen and Josh the chance to meet other parents of children with a bleeding disorder as well as health professionals, our youth ambassadors and staff members.

Ellen said: "The whole weekend was brilliant but a highlight for me was meeting the youth ambassadors. Seeing young people living life very normally, doing what they want to do, not letting anything stop them, that was a huge positive for us.

"The first year of Austin being diagnosed was all about what he wouldn't be able to do, and as a mum all I want is for my son to grow up with choices and options like any other child. So, to meet young people with haemophilia



Ellen, Josh and Austin found support at a Newly Diagnosed Weekend

who showed us that it doesn't stop them from doing what they want to do – that was incredible."

As part of the weekend, mums and dads get together separately to discuss family life, which Josh found particularly useful. Ellen said: "Josh can bottle things up, but he was able to really open up about our experience with the other dads and felt loads better afterwards."

The couple feel that attending the Newly Diagnosed Weekend changed the way they think about Austin's future.

Ellen said: "The weekend gave us a completely different mindset. We left feeling positive, as if a huge weight had been lifted off us. We feel really lucky to have had this experience."

Raising awareness about women's bleeding disorders

Talking Red, The Society's campaign to raise awareness and improve standards of care for women and girls with a bleeding disorder, has never been more important.

Thanks to the hard work and determination of women within The Society and healthcare professionals over the last 25 years, women's bleeding disorders are finally being recognised – but there is still a long way to go.

Twenty years ago, trustees Liz Rizzuto and Eileen Ross were so inspired by a talk on women's bleeding disorders at the World Federation of Hemophilia (WFH) in Montreal, Canada, that they returned determined to form and develop The Society's women's project work. At our Annual General Meeting in 2004 the first break-out session on this issue took place.

Since then, many dedicated women have helped The Society to raise the profile of women's bleeding disorders – now our Talking Red campaign. International organisations such as WFH, European Hemophilia Consortium (EHC) and European Association for Haemophilia and Allied Disorders (EAHAD) all have women's committees.

Women carriers with low factor levels are now diagnosed with mild haemophilia and von Willebrand disease is gradually becoming better understood. However, much more progress needs to be made. Liz Rizzuto, chair of trustees from 2007-2011 said: "From those early days to the more recent launch of Talking Red, there is no doubt that we have empowered an educated women and healthcare

professionals. There is a much better understanding of the effects of inherited bleeding disorders in females and it is now recognised that women do indeed bleed too."

New committee gives powerful voice to women and girls

A new committee has been formed which will ensure that women's bleeding disorders are kept at the heart of The Society's work.

The women's sub-committee, led by Kate Khair, vice chair of the board of trustees, has a strategic role in making sure that the interests of women and girls with bleeding disorders are represented at the highest level.

Kate said: "Girls and women with bleeding disorders are still fighting to get the same access to care that boys and men take for granted. This committee means female voices will be louder and more powerful both within The Society and beyond."

Inspired by the experiences of the many women who responded to our bleeding disorders survey, the committee is looking for volunteers to join a working group to help establish key priorities. Contact info@haemophilia.org.uk for more details.

Women's bleeding survey

A survey carried out by The Haemophilia Society has highlighted the impact of women's bleeding disorders on work, finances and socialising.

Of the 181 women and girls who took part, 63 per cent said their period lasted for seven days or more – many for between 14-21 days. Almost a third had to miss one or more days a month of work or study because of heavy bleeding and many others described rearranging shifts or working from home to avoid having to leave the house on heavy bleeding days.

Women said they often felt tired and in pain during their heaviest bleeding with many revealing that they would not socialise during this time for fear of flooding. Forty five per cent of women said their bleeding disorder affected their social life.

I'm constantly worrying about leaking. I lose a lot of blood, I'm restricted in what I can wear and the activities I do.

Many women reported having to regularly spend extra money on replacing stained bedding and underwear, as well as extra sanitary protection, with 10 per cent spending more than £25 a month. Thirteen per cent said they struggled to pay for their sanitary products. A total of 43 per cent thought it was "extremely important" that people with bleeding disorders got free sanitary products, with 58 per cent believing this should be funded by the NHS.

I bleed so heavily I don't feel comfortable going out or socialising as often I will leak through my tampon and pad.

The survey found that as well as using multiple sanitary products, some women wore nappies or incontinence pads to reduce the risk of overflow. Many of the women who responded said their bleeding disorder meant that they missed out on exercise, such as swimming.

Of the respondents, the majority had haemophilia A or von Willebrand disease, but there were a range of conditions represented, including very rare disorders. The point of diagnosis ranged from birth to 60 with the majority being diagnosed in either their teens or within their childbearing years.

The main symptoms the women experienced as a result of their bleeding disorder were menorrhagia (very heavy periods), easy bruising, bleeding longer than expected after cuts and nosebleeds.

The Society is now looking at ways of analysing the data so that we can share it more formally with the wider community in order to improve and highlight the needs of women with bleeding disorders.

Camp memories

The Society's adventure holidays, activity weekends and youth camps have given generations of young people with bleeding disorders the chance to be independent, try new challenges and - most importantly - have fun with their friends.

Ros Cooper remembers attending The Haemophilia Society's adventure holidays in North Wales as a teenager in the 1980s.

Although Ros had an active life, these adventure holidays in Anglesey were her first chance to spend time away with other young people who also had a bleeding disorder.

Ros, who has von Willebrand disease (type 3), said: "These holidays felt really different for us. At school, if there was anything remotely 'outward bound' on offer, I wasn't allowed to go because of my bleeding disorder.

"Here, we got to mess around and there were always pillow fights going on. It was a license to behave like a normal kid, which we weren't used to."

"We shared an understanding - we could talk to each other about our bleeds and bruises in a way that we couldn't with other people."

Ros was generally the only girl at the adventure holidays with a bleeding disorder – and it was assumed she was the sister of someone with haemophilia when she first attended. However, she quickly established friendships with the boys and even picked up some tips.



It was thanks to these holidays that Ros decided to learn how to self-treat after watching boys younger than her injecting themselves. Choosing to treat herself gave Ros more independence and, she believes, gave her more freedom to travel, which she has done extensively since.

Ros said: "The North Wales adventure holidays felt empowering as well as reassuring. We shared an understanding - we could talk to each other about our bleeds and bruises in a way that we couldn't with other people."

A highlight for many was piling into Pete's Eats in Llanberis for hot chocolate and chip butties. "It was the best moment of the holiday!" said Ros. She's even been back since for a nostalgic chip sandwich.

But for Ros and her friends, the experience was not entirely carefree. In 1987, the first year Ros attended aged 14, the impact of the contaminated blood scandal was being discussed and it formed a growing shadow in subsequent adventure holidays in that period.

Ros said: "Those were really good times, but I also look back with a sadness because I don't know which of those guys are still with us and which ones we lost."

Lockdown Fundraising

We are so grateful to you for supporting us during this crucial time and for raising vital funds to help us to continue to provide our services and support to anyone who needs it.

If you would like to get involved in any of our fundraising challenges and help celebrate our 70th birthday, please email events@haemophilia.org.uk or head to our website.



Celebrate The Haemophilia Society's 70th Birthday with the 7.0 challenge

Supporters, Nicholas Phylaktis and Nicole Turner decided to embark on a 70km bike ride around Richmond to celebrate The Society's 70th birthday. They were up and ready at the crack of dawn and cycled to Richmond Park, which was only open from 6am to 10am due to the Coronavirus restrictions. After three hours they reached the 50km milestone and managed to finish the last 20km before lunchtime! They celebrated their achievement and an impressive £898 raised with a smoothie, Nandos and a nap.



Buddies are still brunching!

New member Sarah Hepples recently hosted a virtual Buddies who Brunch with loved ones. She said: "The whole family could get involved from baking to colouring in bunting or making a prize for the quiz winners. In total we raised £280, not a bad days fundraising from our sofa whilst making memories during these unusual times! Looking forward to our next virtual fundraiser with more cake and laughter."

Fundraising fun for the whole family



Claire, Tris and their amazing friends Hannah and Richard will be undertaking an ultra challenge, walking 30 miles in 1 day and they have already raised an incredible £310 on their JustGiving page (www.justgiving.com/fundraising/claire-brown134) They have also involved Claire's dad, who is a member of Salisbury City Masonic Lodge and they have donated an astonishing £1,000 to The Haemophilia Society, which we are very grateful for.

Their lovely friend Pauline made 15 gorgeous tote bags to be sold with all funds donated to The Society, which made an amazing £160. A big thank you to Browns and their incredible team for finding so many great ways to raise vital funds for The Society.

Campaigning for a better future

As well as supporting members, providing services and liaising with health care organisations, The Society has a proud history of campaigning for change.

Our campaigns have resulted in improved treatment and greater awareness of the challenges living with a bleeding disorder brings.

The Society launched its #bruisednotabused campaign in 2018 which highlights difficulties that some parents face during the time their child is initially diagnosed with a bleeding disorder. Using specially commissioned research, we produced a series of recommendations for safeguarding experts, healthcare professionals and policy makers that we hope will be adopted to improve the experience of families during initial diagnosis in the future.

In 2003, The Society achieved a major breakthrough when the government committed £88m to our five-year Recombinant For All campaign which ensured access to non-plasma based treatment for most people with haemophilia A and B.

For our community, the move towards safer treatment was an enormous relief. Roddy Morrison, a trustee from 1997-2008 who also served as chair of trustees, said: ***"The impact of the campaign on the community was huge. It gave us a degree of belief that our kids and grandkids wouldn't face anything harder than just being a haemophiliac. Recombinant for All provided optimism – we were able to look forward for the younger generation."***



The Society has also campaigned to get the needs of people with inhibitors more widely understood and is also working to ensure that the care of older people with a bleeding disorder is of a high standard.

We first started campaigning for a public inquiry into the contaminated blood scandal in 1988 and, now that the Infected Blood Inquiry is underway, we continue to campaign for long-term specialist psychological care and fair financial support for those infected and affected.

Today the need for campaigning is as high as ever. Despite the success of our Recombinant for All campaign almost 20 years ago, some bleeding disorders still have no choice but to use plasma treatments.

Earlier this year the first recombinant treatment for serious forms of von Willebrand disease was licensed, but it was turned down for use by NHS England. The Society continues to campaign to make it available on the NHS.

Now, more than ever, The Society is working to ensure your voice is heard.

Remembering those who died as a result of contaminated blood

While there is so much to celebrate from the last 70 years, we cannot look back without reflecting on our community's devastating loss as a result of the contaminated blood scandal.

In the 1970s and 1980s around 5,000 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 1,200 people infected with HIV less than 250 are still alive.

The Society held its first Service of Thanksgiving and Remembrance in 1991 to act as a private focal point for families' grief for loved ones who had died as a result of the scandal.

Organised by Reverend Alan Tanner, who was The Society's chair of trustees at that time, and his daughter Mary Ann, the service took place at his church, St Botolph's Without Bishopsgate in the City of London. It was attended by 140 people from around the UK, many of whom had not had the chance to grieve with other families, or even acknowledge how their loved one had died due to the stigma surrounding HIV at the time.

It became an annual event and in 1998 permission was given to establish a permanent memorial at the church. An icon of St Luke the Physician was mounted at the memorial, where a candle burns in memory of those who died.

The Society is honoured to be entrusted with the Book of Remembrance which contains the names of those who died. At each service, the first names are read out and a candle is lit by every member of the congregation. Sadly,



the list of names in the book continues to grow every year.

Today, as much as ever, the service offers the chance to grieve and reflect in privacy with others who have been through similar experiences.

Now that the Infected Blood Inquiry is investigating how the scandal happened, we are pleased that the voices of those infected and affected are finally being heard. We hope this inquiry will at last deliver closure and justice as well as recognition of the suffering it has caused.

The Service of Thanksgiving and Remembrance will take place this year on Saturday, 31 October. Details of how to reserve your free place will be available on our website soon.

Helping to improve haemophilia care around the world

Thousands of people with bleeding disorders in the developing world are not getting the treatment they need. One volunteer gives us an insight into the work of the World Federation of Hemophilia in Botswana.

Barry Flynn, a trustee of The Haemophilia Society, has witnessed the shocking differences in global haemophilia care first-hand as part of his volunteer work with the World Federation of Hemophilia (WFH).

Now retired, Barry's expertise as a chartered accountant and partner in a global financial firm, means he plays a valuable part in the WFH's work since being appointed to its non-executive board in 2017. A year later he was elected to the role of Vice-President Finance and now also chairs the organisation's Accreditation Committee.

The WFH has a global network of 140 national member organisations, including The Haemophilia Society, which is working to help developing countries to support people with bleeding disorders.

Last year Barry visited Botswana, which has only one hospital and no testing facilities for haemophilia. Any tests are sent to South Africa for diagnosis, which can often result in delays, making the blood samples invalid for diagnostic testing.

With only about 50 people diagnosed with haemophilia in a population of 2.5m, many people in Botswana are living in pain with their undiagnosed condition. Some will die of their haemophilia without knowing it existed.



One of the people Barry met was a man who'd been diagnosed with haemophilia aged 29 and now, in his 40s, uses a wheelchair after his leg was amputated as a result of complications following repeated severe bleeds into his thigh.

Barry said: "I hate to think of the pain he had suffered. I grew up in the late 50s and 60s when there was no factor VIII treatment, so I remember how life-limiting and painful it was. I spent most of my childhood either on crutches, wearing metal callipers or in a wheelchair.

"I remember that like it was yesterday and that is what motivates me to be involved with the WFH. I don't want anyone to have to go through that, yet that is the lot of the majority of haemophiliacs around the world."

The result of Barry's trip to Botswana was that a new group of engaged healthcare professionals and parents has been established who are determined, with the support of WFH and others, to introduce diagnosis and increase factor VIII supplies to cover the increasing demand that more rapid and widespread testing will bring.

A small, but important, step forward in the work of the WFH.

Report looks at quality of care in all UK haemophilia centres

The Quality Review Service has published the first national overview of the quality of care for patients with bleeding disorders in the United Kingdom.

The QRS's peer review teams – made up of consultants, nurses, scientists, managers, social workers, physiotherapists, psychologists, patients and carers – assessed all the UK's 28 comprehensive care centres (CCC) and nine haemophilia centres (HC) between November 2018 and January 2020.

Its report found that although professionals were providing the best quality of care that they could for their patients, they were often working in difficult circumstances due to under provision – and sometimes complete lack - of key members of the multidisciplinary team. Staffing issues were behind the majority of the concerns raised by the review teams.

The review teams highlighted over 350 areas of good practice from which others can benefit, but also identified 89 areas of concern and 384 areas where services should consider making changes. The reviews found seven immediate risks to safety and outcomes where Trusts were required to take immediate action, which have now been resolved.

Of significant concern was the lack of specialist physiotherapists, social workers and psychologists at the centres. In two thirds of the CCCs and over half of the HCs there was no named psychologist working in the team.

In almost half of the CCCs and more than half of the HCs specialist physiotherapy was either lacking or was too limited to offer the acute and long-term joint care needed. Twenty of the 27 CCCs, and all the HCs, lacked a named social worker.

Although centres had previously been audited this was the first time that they had undergone a peer review of their services.

The purpose of the visits was to review compliance with Quality Standards, which are designed to ensure that patients with a bleeding disorder anywhere in the UK can be confident of receiving care which follows national guidance and uses accepted best practice.

Of significant concern was the lack of specialist physiotherapists, social workers and psychologists at the centres.

The review highlighted that across the centres there was a consistent theme of professionalism and enthusiasm shown by the highly dedicated staff who are committed to providing the best quality of care for all their patients. The many positive findings offers opportunities for centres and their staff to learn from each other to further improve services.

We would like to thank all the patients who took part in the review teams.

The Clinical Reference Group (CRG) for specialised bleeding disorders will now work with local commissioning teams and provider organisations to encourage them to act on the issues raised in the report.

You can read an overview of the report here: <https://qualityreviewservicewm.nhs.uk>

'Things will change if we appreciate what others can bring into our world'

Mark Ward has been an active member of The Haemophilia Society more than 25 years.

He has campaigned around the world to get justice for those infected by the contaminated blood scandal as well as raising awareness about living with HIV, equality and diversity.

In November 2019, Mark officially became the world's first LGBT Ambassador for the UK Haemophilia Society. Here he tells us more about what motivated him to take up his role and what he hopes it will achieve.

I believe the role of LGBT Ambassador is much more than a name badge. Having a person to identify with immediately takes away the sense of being alone.

Growing up in 1970s was a scary place for people with disabilities, which at that time included those of us with a bleeding disorder. I didn't have any role models or people I felt I could relate to.

We were continuously reminded of the things we could not do or the people we could not be. People seemed to forget that we had feelings and dreams, just like everyone else. That's where the battle to justify my place in the world began and has never stopped.

During the 1980s my whole world was falling apart, I had no idea of what was going to happen, who or what I was. I was frightened and alone.

When I finally found the courage to ask my haemophilia centre if there were many gay



LGBT Ambassador
Mark Ward

haemophiliacs, I was told, 'No, there aren't any', and the subject was placed off limits. Nobody wanted to talk to me about sexuality in the middle of the AIDS crisis which was being blamed on the gay community.

So, I did what thousands have done for generations and tried to suppress my feelings. But if I felt that way, how many others around the world were also suffering alone in silence?

Things will change if we appreciate what others can bring into our world. I believe we need to understand the importance of good mental health and that different does not mean wrong.

Diversity is being embraced like never before throughout the business world because they have witnessed greater achievements from inclusion rather than exclusion.

Recognising everyone within our amazing community has to be at the heart of our future and improving society. I am here for anyone who wishes to reach out.

If you want to contact Mark in complete confidence you can email him at:
mark@haemophilia.org.uk

New treatments discussed at global conference

New treatments and their possible impact on clinical study trials and data collection were discussed at an international conference earlier this year.

The Global Haemophilia Advocacy and Leadership Conference in Lisbon, held in January, focused on new treatments, risk and data.

Attended by The Society's chair, Clive Smith and our then CEO Liz Carroll, more than 40 countries were represented. The conference raised some interesting questions about the future of research and the use of personal health data.

Key note speaker, Dr Hans Georg Eichler, Senior Medical Officer of the European Medicines Agency (EMA) spoke about the current situation in terms of the history of medicinal innovation.

He discussed the importance of alternative therapy medicinal products (ATMPs) and the impact they will have in the evolution of evidence and clinical study trials.

There are currently four ATMPs in use:

- Gene-therapy medicines
- Somatic-cell therapy medicines
- Tissue-engineered medicines
- Combined advanced-therapy medicines

As of August 2019, there are 14 ATMPs authorised for use on the EU market, out of 22 submitted and reviewed. There are currently 1,000 ATMP clinical trials underway globally, 100 of these are in the final stage before coming to market. In the mid to long-term future, 25 per cent of all new approved drugs will be ATMPs.

Although the randomised control trial (RCT) has always been considered the "gold standard" of clinical evidence generation, Dr Eichler believes there will be a need to enlarge the tool-box of clinical evidence gathering.

The conference raised some interesting questions about the future of research and the use of personal health data.

He accepted that many would be uncomfortable about his belief that the majority of research questions on these new treatments could not be answered at the time of market authorisation and that there was a need for a "lifespan approach" to getting the necessary data.

He argued that we will need to find additional data sources and analytical methodologies but emphasised that ethical concerns would be a key driver of change.

The conference was told that this new era presents an opportunity for one-off interventions with long-term outcomes.

Whilst not a haematologist, Dr Eichler was signalling the start of a new era which will be particularly important for the bleeding disorders community.

Not only will treatment change, but so will the way we authorise, monitor and pay for these products. With change always comes a degree of uncertainty, but approached in the right way, this presents an incredibly exciting new era in medicine.

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

Big Red Glasgow Bridge Walk

Just before the lockdown we held our first Big Red Glasgow Bridge Walk. Despite battling challenging weather conditions, our Scottish supporters showed us that a little rain and wind can't stop them and made the walk a huge success.

We had a fantastic day with everyone who registered turning up and also bringing along their friends and families.

Our walkers not only raised almost £3,000 for The Society but they also showed us fine Scottish hospitality and friendliness.

We would like to say a huge thank you to each and every one of you who took part. We could not do what we do without you.



Big Red London Bridge Walk

With our traditional Big Red London Bridge Walk cancelled this year, we decided to find a way to still go ahead with the walk while following social distancing rules and ensuring everyone's safety.

To make that happen, we are launching our first virtual Big Red Bridge Walk,

which you can do in your own time and your chosen route.

Keep your eyes peeled on our website and social media in the next weeks to be the first to get our exclusive virtual fundraising pack!

Oct

4 - London Marathon (pending)

26 - Family day at Paradise Park, Hertfordshire

26 - Family day at Bristol Aquarium, Bristol

30 Oct - 1 Nov - Newly Diagnosed Weekend, Colchester

31 - Service of thanksgiving and remembrance, London

Nov

14 - Member conference, virtual/ London

28 - Family day Glasgow Science Centre, Glasgow (pending)

Dec

1 - World AIDS Day

2 - Christmas carol service, London

2021

Feb

6-7 - Newly diagnosed weekend, Manchester

June

27 - Parallel, London

July

28 July - 1 Aug - Youth Camp, Mount Cook, Derbyshire

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

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

Annual member conference

Saturday 14 November 2020
Virtual/London



THE
HAEMOPHILIA
SOCIETY

#Empower #Educate #Advocate

As you are aware, we have had to cancel or postpone all of our face-to-face events since March due to Covid-19. This was absolutely the necessary choice but we know it is still important that we come together as a community where possible.

We are currently in the process of looking at options for hosting our annual member conference online as well as in person if safe to do so.

We will be updating our website with more details as we have them and full booking information will be available in the coming months.

Please note: due to uncertainty around COVID-19 this event can be subject to changes following government guidelines.



THE
HAEMOPHILIA
SOCIETY

Christmas Carol Service

**Join us for an evening of traditional carols,
choral singing and guest readers**

Wednesday 2 December at 7pm

**St Botolph without Bishopsgate
Bishopsgate, London EC2M 3TL**

Please note: due to uncertainty around COVID-19 this event can be subject to changes following government guidelines.



THE HAEMOPHILIA SOCIETY

"Information from specialists was pitched at the right level for me having a newly diagnosed child. It was great to meet other parents and the youth ambassadors and I feel more confident and informed. I felt the information I have learned regarding "inclusion" will directly impact my son and stop me trying to wrap him in cotton wool." 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**. You can also request more copies of HQ for your centre, friends or family.

Your Society: getting in touch:

The Haemophilia Society
52b Borough High Street
London SE1 1LXN
Phone: 020 7939 0780
Email: info@haemophilia.org.uk
Web: haemophilia.org.uk



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