For everyone affected by a genetic bleeding disorder

HQ

The Haemophilia Society magazine

THE HAEMOPHILIA SOCIETY

Summer 2018 edition

WFH Congress
a fantastic success

Read all about it in this issue

Contaminated blood inquiry update

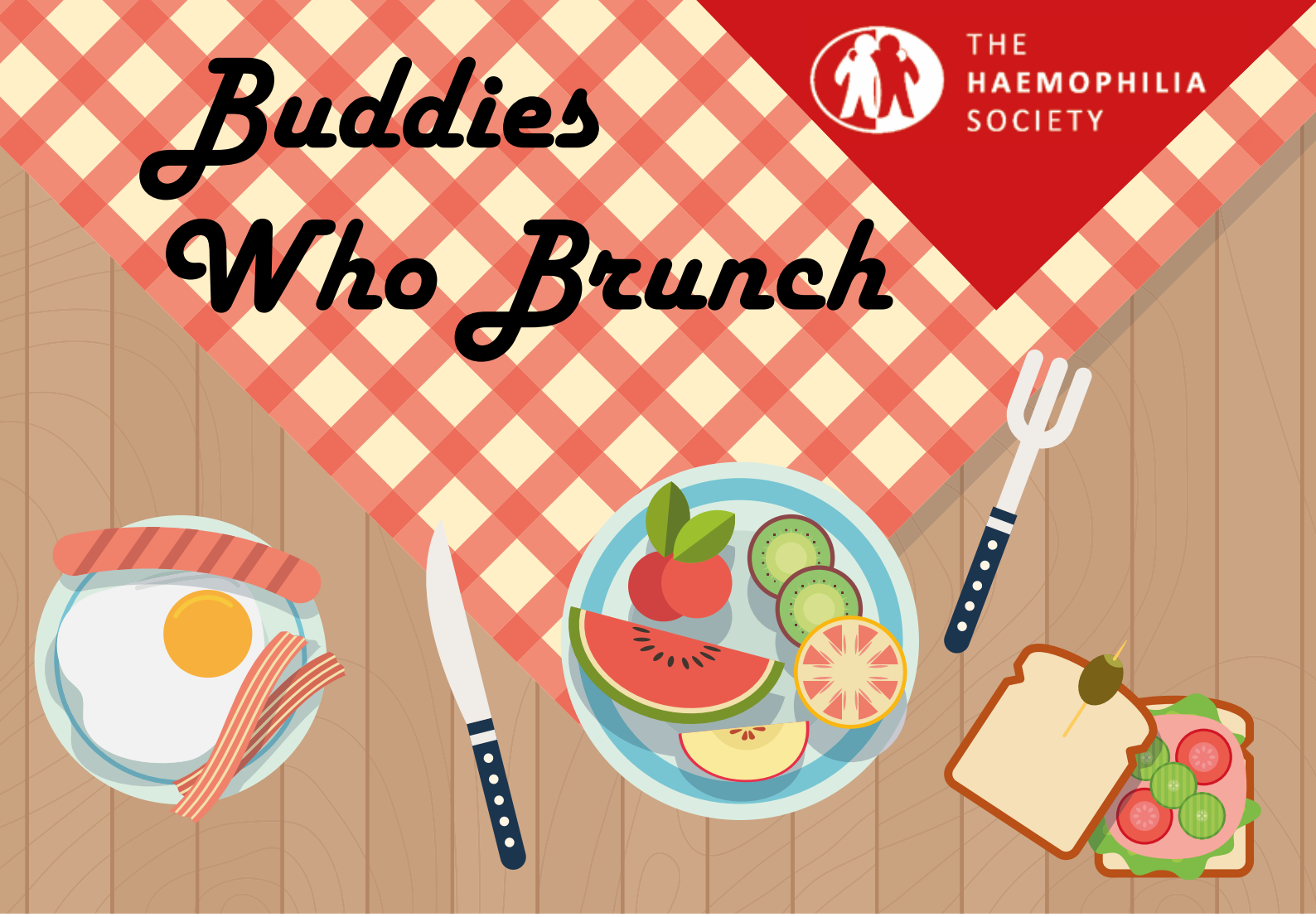
Come and join us – events and activities for all

How Talking Red got one woman talking

Inhibitors survey results in

Buddies Who Brunch

THE HAEMOPHILIA SOCIETY



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For everyone affected by a genetic bleeding disorder

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Summer's here…
and so is a bumper edition of HQ!

2018 has been a whirlwind of activity so far, with May's WFH Congress being the absolute highlight. Among lots of positive feedback, the most consistent was that this was the most welcoming Congress many had been to, and for those who have been to every Congress for many years, it was possibly the best ever. We are incredibly proud. Thank you to everyone who supported us with the event, but also to those who understood when we didn't manage to respond to their email, or run all our usual services. We are almost back on track!

Our other major focus has been preparing for the public inquiry into contaminated blood. There's a full account of our activity and the Inquiry's progress on pages 21-24. To stay in touch with what's happening and to sign up with our experienced legal team, who have had successful outcomes with other contaminated blood inquiries, see the flyer in this issue.

Though scaled back, we have continued to offer information and support. We undertook a survey for anyone affected by an inhibitor – read the update on page 20. We held our first Newly Diagnosed Family Weekend for families who have a child with a mild or moderate bleeding disorder and a successful Talking Red awareness week and conference. In August, 40 children aged 8-16 joined our four-day Lake District summer camp to climb high ropes, abseil, canoe, try archery and tell stories around the campfire, as well as try treating themselves if they didn't already. We have weekends soon for lads and dads, and mums and daughters, following our Youth Ambassadors' survey of members aged 18-30. As the year progresses we will be hosting ageing and inhibitor conferences, and sharing what our local groups are doing across the UK.

Last but not least, our annual conference and AGM takes place in November and we really hope to see you there – more details on page 17.

Liz Carroll, Chief Executive

Barry Flynn, Chair

In this issue

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WFH Congress 2018 round-up

A Congress to remember!

Chief Executive Liz Carroll reflects on an exhausting but uplifting experience

As the host nation for WFH Congress 2018 we were involved in planning and preparing almost every part of the event. For many years Board Trustees (past and present) have been working away in the background, and in May we were incredibly proud to finally welcome 5,110 delegates from 132 nations, every one affected by a bleeding disorder, whether their own or a family member's diagnosis, or professionally. Doctors, nurses, physios, dentists, surgeons, psychologists, data managers, health economists and more came together to share and learn from each other.

Our role was to ensure:

- delivery of a humanitarian aid treatment room – huge thanks to Haemnet for managing the logistics, and the nurses and physios who volunteered their time over two weeks of events
- an opening ceremony that was both welcoming and went with a bang
- that the 70+ volunteers all knew what to do and had a fabulous uniform
- that people from across the world had their visas processed and that every aspect of Congress complied with UK law and pharmaceutical regulation, and
- an interesting, inclusive and varied programme!

The week was inspirational, with volunteers from across our community coming together to create an incredible atmosphere – you will forever be known as the 'pink presence'! We were very proud to have many of our staff and Trustees invited to speak, and our community choir and Special Ambassador Jack Bridge ensured the opening ceremony sent people away with memories that will last a lifetime. We also introduced our mascot Superbuddy: he was surprisingly popular with our guests and will be making appearances at future events, so look out for him soon!

Congress closed with a gala dinner, when Aberdeen local group chair Keith addressed the haggis. From start to finish it was a complex but fascinating experience for the staff team – uplifting and exhausting! We came away with sore feet, many new friends and brimming with ambition – what more could we ask for?

Throwing down the gauntlet

Chair of Trustees Barry Flynn attended the WFH President's keynote speech

In his keynote speech at the Glasgow Global Congress Alain Weil, President of the World Federation of Hemophilia (WFH), challenged the pharmaceutical industry to demonstrate through action their commitment to making 'treatment for all', the Federation's core mission, a reality.

Treatment for all?

He began by highlighting the huge gap between the 'haves' and the 'have-nots' around the world when it comes to access to FVIII and the extent of haemophilia diagnosis in developed and developing countries.

Alain demonstrated this by comparing Finland and France, where 100% of haemophiliacs are diagnosed and FVIII usage is 8 IU (international units) per capita (4 IU is considered to be the minimum level needed to allow low-dose prophylaxis to be the standard of care for the haemophiliac population), with Pakistan and Zambia, where only 8% and 5% respectively of haemophiliacs are diagnosed and FVIII usage is a minuscule 0.02 and 0.01 IU per capita.

He highlighted the point further by summarising how in 55 countries FVIII usage is less than 1 IU per capita, less than a quarter of the minimum level considered acceptable in the developed world, and in 23 countries less than 10% of haemophiliacs are diagnosed.

Ending inequality

Alarmingly, Alain outlined how, across the world, on average 42 haemophiliacs are being born each day, only 16 of who will ever be diagnosed at the present rate. The remaining 26 will die prematurely without ever being treated for – or even knowing that they had – haemophilia. He then called on the pharmaceutical industry to urgently bring to the market a cheap, reliable, easy-to-use and universally available diagnostic device to end this inequity.

Alain then showed that to provide all the world's haemophiliacs, assuming that one day soon they could all be diagnosed, with sufficient FVIII to treat themselves prophylactically and achieve 1% trough levels, would require the annual production of FVIII concentrates to increase from the current level of 12 billion IU to 33 billion IU, an increase of 21 billion IU, or 270%.

Meeting the challenge

He went on to challenge the clotting factor concentrate producers to create new manufacturing facilities, increase production levels, decrease prices and increase their production donations. His view was that, with new drugs being invented and new market entrants coming over the horizon, cutting operating margins, improving production efficiencies and reducing prices in the face of increasing competition is inevitable. So to extend their global market reach and increase the working life of their plants, existing manufacturers should be willing to adopt these strategies – but are they?

Alain ended by emphasising how, tragically, until these two challenges have been addressed, despite all efforts to close the gap between the haemophilia world's 'haves' and 'have-nots', it will continue to widen.

WFH Congress 2018 round-up

Women with bleeding disorders

Ria Peake, Youth Ambassador, reports on an insightful and emotional presentation

This presentation by Dr Claire McLintock unpicked the common misconceptions and attitudes surrounding bleeding disorders, global shaming of periods, and period poverty.

Psychological and physical

Dr McLintock began by discussing some of the psychological issues surrounding bleeding disorders – both in the past and unfortunately still in existence today – namely that women simply 'pass on' bleeding disorders, while men are true sufferers. This ideology causes conscious and subconscious guilt in mothers of children with haemophilia, while ignoring the fact that women who carry the gene commonly inherit it from their father. More dangerously, this idea also ignores the fact that women carrying the haemophilia gene may have symptoms themselves.

Dr McLintock went on to expand on the common symptoms women affected by a bleeding disorder might present with. These include menorrhagia – heavy menstrual bleeding, reported in nine out of ten women with bleeding disorders. She clarified helpful questions doctors might ask women experiencing menorrhagia, emphasising that in the clinical diagnosis of menorrhagia, the impact of the bleeding on a woman's quality of life should be considered, rather than simply the amount and duration of the bleeding.

Period poverty

In an emotional turn, McLintock went on to describe the discrimination and neglect imposed on menstruating women in certain cultures, as they are deemed 'unclean'. For example, some women may not be allowed to be in the same household as their family and are turned out to live in huts during this time. She also discussed the 'period poverty' experienced not only in the developing world but also by women and girls in developed countries. The financial burden of sanitary items can be a costly one, particularly in a family of many women of reproductive age. This burden is hugely increased in women and girls with bleeding disorders due to the increased duration and amount of bleeding, leaving families of women with bleeding disorders at a financial disadvantage. Factoring in the associated pain and anaemia, these women and girls are also losing time from work and education, making their circumstances much worse.

Dr McLintock summarised her insightful, moving presentation by praising the WFH and explaining that education and increasing awareness of bleeding disorders is the first step towards a positive change for women and girls with these conditions.

Find out more about Talking Red – our campaign to help raise awareness of bleeding disorders in women. haemophilia.org.uk/support/talkingred/

WFH Congress 2018 round-up

Relationships and haemophilia

Talking Red Ambassador Laina Cores found this an interesting subject

This session explored the different kinds of relationships people with haemophilia have throughout their lives. The speakers presented research findings as well as statements from people with haemophilia and those they have relationships with, covering friendships, intimate relationships, and interestingly, mothers of sons with haemophilia.

Mothers must be heard

Here, Erin Stang presented research on the perceptions of vulnerability, protective behaviours and stress in mothers of sons with haemophilia. It was found that mothers of an only child were more protective than those who had more than one, and that having one child generated more stress for mothers. To me, this makes sense: having more than one child means that they can play together and learn from each other, taking some stress off the mother. This may give her more time to herself and less need to worry, as the children can look after each other too. This is something I've experienced from a sibling perspective: we were always expected to look out for each other and given more freedom when we did things together. Stang shared her gratitude to the mothers who contributed to the research and said that mothers were very eager to be heard and tell their stories. Recognising this is important, as parents will go above and beyond to learn about their children's bleeding disorders. They often know their children best and Stang acknowledged how much healthcare professionals need to listen to mothers.

Friendship and intimacy

Linda Dockrill spoke on the value of friendships through the lifespan and presented research suggesting that the connections between young and old in a bleeding disorder community were stronger than those outside the community. This shows that bleeding disorders bring people together in a way that might not happen otherwise and just adds to the idea that there is a need to understand the full lives of those with bleeding disorders. Simply understanding their clinical needs is not enough, as there's so much more to life and relationships than clinic.

Susan Cutter also looked at intimacy in relationships, though this was explored more widely elsewhere. The final topic, Managing towards healthy relationships, from Ana Inmaculada Torres Ortuño, gave some ideas about ways to solve some of the issues previously presented. It was a shame that there was less focus on this, as those who have a bleeding disorder or are close to those with a bleeding disorder already know what the issues are – we live them. What we need now is non-clinical support and guidance, and shared experience, like the wonderful youth tennis camps that Torres Ortuño showed us photos of.

Join us at our AGM this November, and connect with people of all ages and experiences. haemophilia.org.uk/who-we-are/agm/

WFH Congress 2018 round-up

A child is not a small adult

Youth Ambassador Matt Minshall found food for thought in this intriguingly titled session

Though I thought I'd be out of my depth with topics directed at health professionals the presentations were intriguing. What surprised me most were the differing professional opinions on treating children, depending where in the world the speaker hailed from.

Clinical assessment and management

Melanie Bladen, a paediatric clinical specialist physiotherapist from Great Ormond Street Hospital in London, came first. Looking at improving clinical assessment she reviewed current assessment and outcome measuring tools for people with haemophilia (PWH), quoting relevant research. For me, the two main points she highlighted for treating children differently were (i) the constant psychological and physiological change and development children go through; and (ii) them being politically powerless, relying on adults to make decisions.

Ultrasound came next, presented by Vancouver-based physiotherapist Sandra Squire. It was enlightening, although technical in places, as portable ultrasound was suggested as a suitable option for assessment and management of bleeds/joints in PWH. It allows healthcare professionals to better analyse changes in joints and muscles, enabling early detection of synovitis and aiding prevention/management of joint damage. This could provide better outcomes, as it is real-time assessment, which could in turn see children adhering better to suggested treatment because they can actually see what's happening in their joints.

The sport issue

The third topic was 'Sport or not' given by Carla Daffunchio from Buenos Aires, Argentina. She presented ideas from her experiences in haemophilia paediatric care as to what sports should be considered for children with haemophilia (CWH). She fitted sports into three categories (from 1 being appropriate to 3 not being appropriate), judged on the amount of contact and risk of injury/bleed. She concluded that sport was necessary, but if a child insists on playing something potentially too dangerous the game/rules should be adapted for inclusivity. Some challenged this view, feeling that categorising sports was not always appropriate and adapting rules for just one individual was unrealistic. There was general agreement that a child shouldn't be told they couldn't play a particular sport, but it should be a decision between healthcare professionals, the child, their family and their sports coaches, so a plan can be formulated on how best to approach the child's inclusion.

Surgery – the last resort?

Finally, we heard from Gianluigi Pasta, an orthopaedic surgeon from Italy, who presented pros and cons on whether surgery is appropriate and what other treatments can be used before it. He examined why surgery should be considered the last option for PWH, then went on to explain the considerations for surgery for both synovitis and arthropathy. He referred to time as the point when surgery becomes the last necessary resort because it would improve the patient's quality of life long term, as other treatments do not allow continued tolerance of these conditions. His final point made it clear that actions around treatment and care should always be joint decisions between patients and healthcare professionals, and that clear communication is essential.

Ask the experts – bleeding from the mouth

Trustee Lisa Bagley reports on a session looking at dental issues for people with rare bleeding disorders

Louise Bowles, a haematologist from the Royal London Hospital, began her presentation with an overview of rare bleeding disorders (RBDs), which affect 3-5% of all bleeding disorder patients. She discussed what the different RBDs have in common and what distinguishes them from each other in terms of clinical features and how they are managed and treated. I learned that for most people with RBDs, treatment is generally on demand rather than prophylactic. The most common treatments are plasma and/or tranexamic acid.

In general, RBDs don't follow the same rules as the more common bleeding disorders. Treatment choices are more complex, with some of the most complex management issues found in dental care. In Louise's experience, RBD patients rarely come to hospital, so when they need care it's often a dental issue that brings them, such as having a tooth out.

Dental issues and RBDs

Restorative Dentistry Consultant Lochana Nanayakkara began her presentation by emphasising that healthy gums do not bleed – and the key is preventing periodontal (gum) disease, which 83% of the British population have! It is challenging treating periodontal disease in patients with RBDs – so it's much better to prevent it. Gingivitis is 100% reversible, although some treatment such as debridement (removal of plaque and tartar from the teeth) can cause bleeding.

Several themes emerged from case studies of three patients with RBDs in relation to dental health:

- fear of brushing teeth in case bleeding occurred
- assumption that it was their bleeding disorder causing the bleeding
- impact on socialising as don't want to be seen with bleeding gums
- reluctance to go to the dentist because of taking time off work to attend dental appointments resulting in being treated unfairly by employer.

Innovative treatment

Laser treatment should be considered as an effective treatment to reduce inflammation. The Royal London Hospital dental team had successfully treated several patients with a low-level laser device (LLLD). Treatment took place twice a week for two to three weeks, with no overnight stay required. Gums become less inflamed and capillaries are closed off. In the case studies no further treatment was needed, and no other interventions required such as factor, DDVAP or tranexamic acid. At approximately £5,000 for the laser, this is good value as compared with the cost of factor. It could be a good investment for countries without access to factor.

WFH Congress 2018 round-up

Ageing well

Our Head of Policy and Programmes Jeff Courtney reflects on Ahmad Farooq's Congress presentation

As treatments continue to improve the challenges of ageing are increasingly an issue for people with haemophilia as they live longer. That makes it more important than ever for the haemophilia community to think about healthy ageing.

Now at the South London Health Innovation Network, Ahmad's interest in this issue started from his clinical background as a GP and healthy ageing clinical lead. The aim of his presentation was to ensure our members age as well as possible and remain fit.

Making ourselves aware

We should start by seeking better awareness of the risks associated with ageing such as cancer and heart disease. What's more, people with haemophilia will have higher risks than the general population for joint health, osteoporosis and liver and kidney disease. There are also particular challenges in ensuring the proper treatment in case of mental health issues and dementia for people with haemophilia.

What struck me was that long-term conditions, as well as ageing, can lead to stigma, depression and anxiety. So, with mental health issues already under-diagnosed in people over 65, access to psychological therapies needs to be made available through easier referrals into counselling.

Addressing frailty

The talk also addressed frailty, which is a common impact of ageing. Frailty is caused by reduced resilience and increased risk. This can be a result of the physical and mental health issues already mentioned, but can be countered by actions and interventions to improve people's resilience and reduce frailty.

In many ways the solution is very simple and so the key advice from Dr Farooq was:

- having a good diet and plenty of exercise
- reducing isolation and loneliness
- ensuring preventative medications and activities.

Joined-up care is important to address the vulnerability and risks associated with ageing. Those with multiple conditions are at increased risk, which needs to be identified and responded to.

The graphic below shows how the balance for people who are ageing can be thrown out of order if something changes, such as new health condition, a fall, or decreased social activity and loneliness.

Good quality of life is achieved by balancing resilience and interventions against that increased vulnerability.

For more information on the frailty fulcrum and ageing well you can watch the video here: youtube.com/watch?v=Wzq_MzWQhwo&feature=youtu.be

Our Ageing Conference will be held in December. The date will be confirmed later in the year.

A bleed or not a bleed... that is the question

Trustee Andy Martin reports on a session relevant to his own situation

As a 'mature' man with mild haemophilia A, this session really caught my eye. Are the aches and pains I get just age creeping up on me or am I becoming susceptible to bleeds as blood vessels weaken with age? The content was geared to mild haemophiliacs who (like me) get a pain but reject the idea of a bleed, thinking it will go away by either applying an ice pack or resting. If the pain hasn't gone after a couple of days then it's off to the treatment centre, generally to be reprimanded (in the nicest possible way) for not making contact sooner.

Early treatment is best

The impact of this type of response in both developing and developed countries was looked at. The outcome is similar: long-term issues with joint damage and potential psychological damage, with fear of continual pain being the most common. All evidence suggests that early treatment, possibly within two hours of identifying a bleed, leads to the best possible outcome, with the aim of getting back to normal life as soon as possible.

Chronic pain was considered too: how this might or might not be due to a bleed and how we respond. Are we conditioned into thinking pain is always a result of a bleed and as such do we shy away from activities that might cause one, or should we spend more time considering other causes before jumping to conclusions and treating for a bleed? Perhaps the psychological effect of treatment is just as good as the actual treatment.

New diagnostic tools

The most interesting topic was the development of tools to determine if there is actually a bleed. Current tools involve MRI and ultrasound, which are expensive and confined to specialist units. Work is being carried out to develop Point of Contact – Ultra Scans (POC_US) for clinics or surgeries that will enable fast diagnosis of a bleed. Caution is needed as the interpretation of results in such situations may not be as accurate as in the specialist units. But these scans, plus consideration of how an injury occurred and the patient history, may be the best way of determining whether a bleed has actually occurred. Or perhaps the best way is to aspirate the site of an apparent bleed and see if blood comes out!

What had I learnt?

After a week of Congress my legs were really sore. Of course I didn't go to my treatment centre. But the blue-black thigh told me I did have a bleed and three days later I did go for treatment – and the ritual reprimand!

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WFH humanitarian aid – catalyst towards global change

Trustee Eileen Ross links a personal experience to what she heard

Glen Pierce, one of the WFH Board, spoke about how in 2012 the WFH began to scope the problem of untreated patients with haemophilia A and B, von Willebrand disease and other bleeding disorders. They found huge unmet needs and undiagnosed bleeds in the world of bleeding disorders.

Many patients in the world are undiagnosed, while many who are diagnosed are under-treated. Low-income countries use a very low level of factor, nothing like the 4 IU per capita recommended in Europe, which rises to 8 IU with prophylaxis. In fact 15% of the world uses 65% of the factor products, while 85% of the world uses 34% of the factor products – the disparity is huge.

Predictable supply

John Cox, CEO at Bioverativ, presented an idea: a 1 billion unit donation of factor over 10 years would give developing countries a predictable supply. The donating companies would make an extra few per cent of factor each month for the Humanitarian Aid Program.

Patients in developing countries would no longer have to rely on small irregular donations from a few pharmaceutical companies.

The Humanitarian Aid Program was launched in Senegal in October 2015 with 12 nations from Eastern Africa attending. An education programme for doctors, nurses, therapists and patients was provided. Better-resourced haemophilia treatment centres were established. Standards of care were set and governments were encouraged to commit to haemophilia centres and factor product supply. Many people with haemophilia received factor supply for the treatment of acute bleeding disorders; a few had prophylaxis and some surgery could be planned.

Donated clotting factor had been used in 40 countries, with a great increase in the number of children treated, some of who were receiving prophylaxis. But this was just the beginning of the journey – 'closing the gap' will take much more momentum.

Real-life impact

It was a very moving session that received great applause. Later, a personal experience exemplified what I'd heard. On the Sunday morning I passed a man from Nepal, probably in his mid-thirties, who was walking with tremendous difficulty. He was going to the treatment room at the Congress. Later that evening in the exhibition hall reception my family met him near our UK Haemophilia Society stand. He had had treatment and had temporary loan of a wheelchair for a few hours. However, he had lost his friends from Nepal and could not make it to the hotel courtesy bus. Chatting cordially, we took him some distance to his bus. This encounter showed my family how fortunate they have been to have exceptional haemophilia care and treatment in the UK. Elsewhere in a developing country, their lives would have been so very different.

WFH Congress 2018 round-up

Can't or won't pay: health economics and bleeding disorders

Trustee Clive Smith summarises the arguments

In this session, informed and passionate speakers looked at one of the biggest questions we face in both the western and developing world – who is going to pay for this?

Mark Skinner, former WFH President, began by discussing concepts such as Health Technology Assessment (HTA), which is the process from market authorisation to a treatment being available in the market place for patients. One limitation he highlighted is that patient perspective is often not incorporated into this process.

Cost of course is one thing. Value is another. The question with treatments is how this value is incorporated: there are different viewpoints and it is important to define value and to incorporate patient-relevant outcomes. In all of this, real-world evidence is transforming healthcare. We are fortunate that haemophilia care is ahead of the curve and we are fortunate to have contributed to all of this.

Demand versus resources

Jamie O'Hara (Health Economics lecturer and Haemophilia Society Trustee) spoke next on 'What is health?' Healthcare is a derived demand solely to improve health. We have ways of quantifying things like gold or oil, but health is somewhat intangible. It needs to be defined to assist with the distribution of scarce resources. Demand is infinite while resources are scarce: this leads to having to make choices and prioritise. Various methods are employed, such as a simple cost-benefit analysis. Or a cost-minimisation analysis – there are homogenous products on the market; whose is the cheapest?

Differences across Europe

Next up was Brian O'Mahoney, EHC President, who highlighted an EHC survey from 2015. This showed a significant disparity in access to treatment across Europe, with countries falling into distinct groups. Barriers include cost and reference pricing. Some countries lack a national tender programme along with involvement from medical professionals and national societies.

The proposed solution is an increase in access at a sustainable cost. Countries would promise to buy more and companies would agree to supply at a lower cost. To date, 12 countries have been spoken to and significant progress is being made in several. Brian made the point that we should be seeing lower prices for products that have been around for some time and we should not see a situation where new products come to market and access to older products does not go up.

The Canadian picture

Lastly, David Page from the Canadian Hemophilia Society spoke about their situation, as the first to be approved to use extended half-life (EHL) treatments. It was agreed that they could be used if it was cost neutral, and the cost has gone down year on year. But per capita, use is going up, due to new children and larger people, meaning more units are required. Payers are interested in improved outcomes – they are not heartless, thinking only of cost. At the moment data is missing on subjects such as efficacy, safety and patient recorded outcomes (PROS). The more data we have, the more we will be able to argue for better outcomes.

Healthy ageing

In this session, Youth Ambassador Hannah Yarnall picked up some tips for the future

It's something we hear every day: eat a healthy diet, exercise more and take care of yourself. As we know, the more you take care of yourself now, the more beneficial it will be in the long run – which is especially true in the bleeding disorder community. Easier said than done, but this session led by Nicholas Goddard offered some help. This is what I learned…

Good dental health

Alison Dougall, chair of the WFH Dental Committee, emphasised that preventing dental issues/diseases does not differ between the bleeding disorder community and the rest of the population. Interestingly, many people with haemophilia don't seek treatment for bleeding gums, something we should all do as bleeding gums are an easy way in for bacteria, potentially leading to gingivitis. Dental health can have a big impact on your quality of life but maintaining good oral care with mobility issues such as elbow joint restrictions can be difficult. Helpfully, there are many different toothbrushes available to help people with limited mobility.

Exercise goals

Physical therapist Angela Forsyth's message was exercise, exercise, exercise! It might not feel like it, but apparently it is good for you. As people age they can develop osteoarthritis, osteoporosis and increased fall risks. Bleeding disorder patients with a history of joint and muscle bleeding can develop haemophilic arthropathy. Angela advocates exercise innovation: setting yourself goals through an individually tailored exercise plan created by your physio. Frequent exercise increases joint circulation, strengthens the muscles and maintains a healthy weight. All these will help reduce pain and stiffness and improve your balance, reducing the occurrence of falls.

Change now for the future

Cathy Harrison, advanced nurse practitioner, identified the rest of the pillars for health – healthy eating, sleep, mental health and social connections – and how ageing is a journey not a single destination. Lifestyle changes we make now, such as healthier snacks, high water intake (for easier vein access) and exercise, can stay with us as we get older. One key point that stuck in my head is that we reach peak bone density at 26, so it is important to exercise now to have strong bones for the future.

Finally, social worker Rudd Bos gave a little insight from the Netherlands: to keep patients physically and mentally fit the physio organises swimming sessions and the social worker provides a mental/social support group several times a year.

DWP working group update

In October 2017, the Department for Work and Pensions (DWP) set up a working group with individuals affected by contaminated blood and blood products to hear about their experiences of the application and assessment procedures for disability benefits.

The APPG on Haemophilia and Contaminated Blood, a group of around 100 MPs and peers led jointly by Diana Johnson and Sir Peter Bottomley, had been lobbying the DWP to consider passporting people in certain circumstances through aspects of the benefits system.

The hope was that this working group would be able to make the case for how some of the people living in very difficult circumstances and relying on support from the state due to the contaminated blood scandal were being deprived of even that support they had long relied on. Forced to jump through hoops, many had seen restrictions in their access to Personal Independence Payments (PIP) with rising uncertainty about long-term support from the contaminated blood support schemes.

While the Government has not gone as far as many wanted the group has been able to make some progress in two useful areas.

Better guidance

Following the presentation of a number of cases where people were being investigated for benefit fraud or having their benefits reduced, the DWP is working with EIBSS (the provider of contaminated blood support in England) to provide better guidance to local authorities, job centres and local DWP offices. The aim is to reduce the number of people in receipt of contaminated blood support payments who are investigated by the benefit fraud system. We hope to see this guidance introduced in the near future.

Haemarthropathy claims review

The working group also highlighted issues with how claimants with haemarthropathy (a severe type of arthritis caused by bleeding into joints) were being assessed for PIP. A need to review all such PIP cases was identified and those reviews began in June. While all applications will be reviewed, no one will have their awards reduced as a result of this review.

The review will happen automatically and there is no need to do anything at this point. But anyone with haemarthropathy who thinks their case should be reviewed but did not receive a letter by 23 July 2018 should phone the dedicated DWP phone line (0800 121 4296) as soon as possible after that date.

Thank you

We are grateful to our members and others affected by contaminated blood and blood products who gave up their time to work with the DWP. We hope that the engagement continues.

The Last Tsar:
Blood and Revolution

Image credit:
Universal History Archive/UIG/Science & Society Picture Library

This September the Science Museum opens a new exhibition exploring the extraordinary century-old investigation into the disappearance of Russia's former Tsar Nicholas II and his family. The Last Tsar: Blood and Revolution will reveal the medical science behind the key events of the Romanovs' lives – and deaths.

The exhibition will retrace the lives of Nicholas II and Tsarina Alexandra as they navigated their roles as autocratic rulers of Russia, while caring for their young son and heir, who was born with haemophilia B. The royal household faced a turbulent backdrop of social upheaval and war between 1900 and 1918, but medicine also had a significant influence on their lives.

The family kept Alexei's haemophilia a secret and withdrew from public life, relying on help from doctors and controversial healers such as Rasputin. They were determined that no one would know about Alexei's illness – but their actions ultimately contributed to the fall of the 300-year-old dynasty.

The exhibition will feature possessions of the imperial family, including personal diaries, family photo albums and an imperial Fabergé egg the Tsar gave to his wife.

We are honoured to have been a part of developing this exhibition and hope to have special sessions for members.

The Last Tsar: Blood and Revolution opens 21 September 2018-24 March 2019, tickets are free and can be booked now.

Save The Date

Saturday & Sunday 17/18 November 2018
Central Birmingham

THE HAEMOPHILIA SOCIETY

All members are invited to join us for our two-day mini congress including AGM and gala dinner

Enjoy sessions on a wide range of relevant topics, meet others with bleeding disorders and find out the results of trustee elections for 2018.

Crèche and activities for children provided throughout the weekend

Further details will follow

For everyone affected by a genetic bleeding disorder

haemophilia.org.uk/who-we-are/agm/
info@haemophilia.org.uk 020 7939 0780

HaemophiliaSocietyUK
HaemoSocUK
thehaemophiliasociety

Charity no. 288260 (England & Wales) SC039732 (Scotland) UK company 1763614

Talking Red
Ignorance isn't bliss

The Society's Talking Red Conference was just the start for Laina

Growing up with von Willebrand disease in a small town, Laina, 20, knew almost no one outside her own family who had a bleeding disorder. It was only when she and her mother attended The Haemophilia Society's Talking Red Conference last year, designed to get women talking about bleeding disorders, that they realised how much support was available.

A world of choice

Laina said: 'The Talking Red Conference has given me choice that I didn't know I had. Choice of people to talk to, choice of medication to seek and choice to change my treatment plans, as well as a communications network with women who really get it that I've never had before.'

'I arrived at the conference believing that the care I was receiving was brilliant, but I left realising that if we'd ventured a bit further beyond our county border there was far better, tailored treatment for people with bleeding disorders which we just didn't know about. For me, the conference emphasised how important it is for people with bleeding disorders to communicate, so that this sort of information is widely known.'

A refreshing change in approach

As a result of the conference, Laina asked her GP to transfer her to Birmingham, only an hour away, where she experienced a very different approach to her local hospital. She said: 'I wanted to make an appointment at my usual hospital. I couldn't talk to anyone and ended up leaving seven telephone messages for the haematology nurses and I never heard anything back. We have a really poorly funded NHS in Shropshire, so I don't want to criticise them, but when I was transferred to Birmingham I was amazed by how different it was. Someone phoned me quickly and I was seen before I went to uni. They gave me a Bleeding Disorder Information Card, which I'd never had before, and offered a level of support that I'd never previously experienced.'

When she arrived in Manchester to study modern languages, a sporting injury meant

it wasn't long before Laina required medical help in her new home city. A rapidly swelling finger put her writing hand out of action just days before an exam. In desperation, she called Manchester's haemophilia centre and, to her amazement, was seen within half an hour.

She commented: 'The care I received was fantastic. I was seen three times that week and they wrote a letter so that I could use a laptop for my exam. They also realised that the medication I'd been taking wasn't that effective. I had taken it all my life and it had never been changed. I was seen by multiple nurses and doctors, all of whom knew what von Willebrand disease was without me having to explain it. They were incredible.'

It's good to talk

Laina, who hopes to teach personal, health and social education (PHSE) when she finishes her degree, also found that the Talking Red conference opened up topics that she'd never discussed with anyone, such as how bleeding disorders impact on new relationships.

She said: 'When you start getting into relationships or if you get together with someone at a party, you don't want to sit down for half an hour to discuss your bleeding disorder before you head to the bedroom. But, that said, it is easy to cause bruising during sex, which could be alarming if you weren't prepared, and there could be extra bleeding. I realised at the conference that this was something I'd never been able to talk about before, as I didn't have any contact with other women with bleeding disorders. It was great to be able to talk about this and the other women just got it. I didn't feel like I was the only one.'

Advocating for others

Laina is now part of The Haemophilia Society's Talking Red Focus Group and is an Advocate for the Manchester Haemophilia Centre. 'Before the conference, ignorance was bliss,' she reflected. 'I thought what I was getting was good. It wasn't bad, but it wasn't fulfilling my need. It's really important that everyone has access to the best healthcare services. I feel very grateful to The Haemophilia Society for the opportunity to take part in the conference and to find out so much.'

Update on inhibitors support

An inhibitor is a type of antibody that prevents factor replacement treatment from working. When an inhibitor develops, it binds to factor concentrates such as factor VIII or factor IX, stopping them from working and making bleeding more difficult to treat.

Gathering members' experiences

We know that living with an inhibitor or caring for someone who has an inhibitor is exceptionally hard, and for many it has a significantly greater impact on life than most of us can imagine. In 2015/16 we filmed several of our members to better understand their experience, and in spring this year we followed this up with a survey of all members affected by an inhibitor to gather more information about what gaps in care members experience and how we can help.

Turning results into action

The survey has now been analysed and we have some very useful information on the types of information and support you would like from us, and areas where we can influence treatment and care from haemophilia centres.

We have been working with our Inhibitor Ambassador Carreen McCay and others to look at how we turn the results into action, so please check what is going on at: haemophilia.org.uk/bleeding-disorders/inhibitors

There is already a new email address (inhibitors@haemophilia.org.uk) that will be managed by volunteers who have an inhibitor or care for a child who has one, so you can contact them for support. If you are looking for medical information, please do contact your centre, but we know that being able to speak to someone else who fully understands what you are living with day-to-day is incredibly valuable.

We will also be developing an information pack for everyone affected by an inhibitor and a passport with all your essential information, so if you have an emergency and can't get to your centre, hospital staff will understand more about the care you need.

2019 inhibitors event

We are just starting to develop the programme for our inhibitors day in March next year, so do let us know if there is something specific you would like to see at that event.

One parent wrote:

'Life has stopped. No education, no family time, tears, depression, no compassion from employer, psychologically and physically damaging, breakdown of relationship, loss of finances, unmaintained home, devastating.'

Public inquiry officially gets underway

The long-awaited statutory public inquiry into the contaminated blood scandal officially got underway on 2 July, following the announcement of the detailed Terms of Reference in the House of Commons.

Our community has campaigned long and hard for this moment. The Terms of Reference cover all the essential elements and areas of investigation members wanted to see, so now the way is finally clear for the Inquiry to begin and justice to be served.

The inquiry team is now beginning to gather information and evidence, and there will be three days of preliminary hearings from 24-26 September, which will include covering procedural matters. The main public hearings are not expected to get fully underway until the New Year.

Inquiry Chair Sir Brian Langstaff has recognised the sheer scale of what happened in the 1970s and 1980s, and also that the impact persists today, with thousands of people continuing to live with the mental, physical, social, work-related and financial effects. He understands that his team are investigating a cover-up, and is determined to put the people who have been infected and affected at the heart of the Inquiry. He wants the Inquiry to be as open and accessible as the law permits and where necessary will use its power to compel witnesses to explain their actions to get to the truth.

The Inquiry has agreed to work with the community to help develop a public opening to the Inquiry that will give proper recognition to all those people who have already lost their lives and those still living with the consequences of contaminated blood products.

We urge anyone with knowledge or personal experience of the scandal and who believes they can help the Inquiry to come forward. If you would like to join with us and be represented by our legal advisers Malcomson Law at the Inquiry, contact us at publicinquiry@haemophilia.org.uk.

If you have any questions about the Inquiry or want to be kept up to date with its progress, visit haemophilia.org.uk, join our Facebook pages or email publicinquiry@haemophilia.org.uk. Or see the Inquiry's own website at infectedbloodinquiry.org.uk.

Inquiry Update

Introducing Sir Brian Langstaff, chair of the Inquiry

In February this year, High Court judge Sir Brian Langstaff was appointed as the chair of the contaminated blood products inquiry. Announcing the appointment, David Lidington, Minister for the Cabinet Office, said: 'The Inquiry will be established under the 2005 Inquiries Act, with full powers, including the power to compel the production of documents, and to summon witnesses to give evidence on oath.' He added that the Lord Chief Justice had recommended Sir Brian who he described as 'a highly respected and hugely experienced High Court judge.' With previous experience of health-related public inquiries, Sir Brian has now retired as a judge in order to chair the Inquiry full time.

Getting ourselves into gear

As the Inquiry gets underway, we've now put our full team together

We have appointed specialist health law firm Malcomson Law as our legal advisers. Leading their team will be managing partner Raymond Bradley, who has over 20 years' experience in representing victims of health scandals at public inquiries and appeared at the Lindsay Tribunal (the Irish contaminated blood products inquiry) on behalf of the Irish Haemophilia Society.

As we announced in the last issue, Debra Morgan leads the Society's inquiry team. Experienced in patient advocacy in rare diseases, including haemophilia, Debra is co-ordinating the work across our legal advisers, policy and research, and communications.

A new addition as Communications Manager is Martin Cresswell, a former journalist who has spent 18 years in the NHS managing public consultations on service developments, establishing patient representative groups, producing information, and managing media relations. Also supporting us in communications is Jo Tanner, a co-founder and director of iNHouse Communications, an independent communications consultancy based in Westminster. Jeff Courtney, our policy and programmes lead, will be backing up the inquiry team while continuing his work on access to treatments, awareness and diagnosis, and disability and work.

Finally, we have set up a special subgroup of the Society's Trustees to work on the Inquiry and report back regularly to the full Board.

Open letter from Chair of Trustees

As Chair of the Haemophilia Society, and a member of many years standing, I welcome the official start of the long-awaited statutory public inquiry into the contaminated blood scandal. As part of this community I am acutely aware of the impact this has had on individuals, their families and loved ones. We have waited decades for this and want the truth to be revealed and for people to find justice and, hopefully, closure.

The Inquiry has deep personal significance for me: I both lost a brother and sister-in-law, infected through contaminated blood, and I contracted hepatitis C as a result of the factor VIII treatments I received.

Through my role as Chair and the conversations I have had with those who live with or have lost relatives through this tragedy, I know there are many who do not feel they can be heard as they are not natural 'campaigners'. Our role at the Haemophilia Society is to help the 'quiet voices' of those affected by bleeding disorders in the UK and, through our international networks, ensure best practice is shared across the world.

We recognise there will be difficult questions for our own organisation to answer, and are happy to be scrutinised. All individuals or organisations must be asked to account for their actions in the quest for the truth.

I am very pleased that, at last, the Inquiry is getting underway and that whatever the truth is, it comes out and we all get the answers we have deserved for so long. I want to be able to tell my mother, who is 83, why her son and his wife died, what the cause of that was. After all these years this will, hopefully, give her peace.

I urge you to follow this historic inquiry and to keep in touch with the Society. The Society welcomes questions from members and is keen to provide information and support to anyone affected by the Inquiry and its areas of exploration. To get in touch, you can join our dedicated Facebook Community for the public inquiry, email publicinquiry@hamophilia.org.uk or call 020 7939 0780.

Please show this letter to any family members who have ceased to be, or have never been, Society members but who are stakeholders in the Inquiry. Like all of us, they too are seekers of the truth.

The Society is committed to seeking the truth and will not rest until justice is achieved for all. This has been a long time coming for so many people, some, like those in my family, who have not lived to see it. Together, we can ensure justice is served.

Best wishes

Barry Flynn

Chair of Trustees, The Haemophilia Society

Fundraising round-up!

As always, our fantastic fundraisers have done an amazing job so that we can keep providing services for anyone who needs them – thank you all!

A great drive!

Every year Archie Clark's dad Alex holds a charity golf day – the 'Archie Cup' – in support of our charity. This year's event raised a staggering £4,545! Thanks to Alex and everyone who joined in.

Marathon effort

Mike King, Tara Spicer, Clare Banks, Kate Dance-Jones, Chris Powell and Julieann Holmes were all part of our Virgin Money London Marathon team. Collectively, the team has raised an incredible £14,000! A massive thank you to everyone who helped them to reach this amazing total!

Paddling prowess!

Sixteen-year-old Peta Dixon took part in the Devizes to Westminster International Kayak Race between 30 March and 2 April. She kayaked an incredible 125 miles along the Kennet and Avon Canal and then the Thames, raising an astounding £1,115.04!

Tasty treats

Anne-Marie Salmen and her family threw a cake sale in honour of World Haemophilia Day this year. Pictured is her son Theo who has haemophilia. They raised £500 – brilliant work!

'We found out our son had severe haemophilia A when he was just under two. Not long after we found out we were put in touch with The Haemophilia Society by our nurse from St George's Hospital. We were invited on a 'newly diagnosed' weekend to CenterParcs where we had the chance to learn lots of things about our son's condition and meet other families learning how to cope like us. Ever since that weekend I wanted to give something back to The Haemophilia Society, so each year I've held a coffee and cake afternoon and invited family and friends to my home. We've raised an amazing amount from enjoying cake and chatting! This year my brave little bruiser even let his teacher and TA and a few others watch him have his treatment. I love holding the event and am so proud of my family and friends who help us to raise funds for a charity that is so close to our hearts. Look forward to planning next year's!'

Anne-Marie Salmen – Community Fundraiser

One step ahead

Raising an incredible £347.50, Stephen Wilson (pictured front centre) and his team hiked the 18-mile-long Genk Hike. Well done everyone!

For a full list of events and ways you can get involved, please see haemophilia.org.uk/get-involved/fundraising/

Olympic Park Abseil

Sunday 16 September, 11am Stratford, London

THE HAEMOPHILIA SOCIETY

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haemophilia.org.uk/events-page/olympic-park-abseil

events@haemophilia.org.uk 020 7939 0780

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Fit Kit - From Concept to Reality

Severe Haemophiliac, Jeremy Carson, has developed a range of toiletry products designed with benefits for exercisers.

From an early age Jeremy exercised most days as he felt it improved his mobility and reduced bleeding. His basic program consisted of a variety of low impact activity including Swimming, Iyenger Yoga, Weight Lifting and Cycling.

Like non-haemophiliacs Jeremy would have some discomfort after exercise and he used to manage this through cooling sprays, nose-strips or rubs. However he found these products time-consuming to use and would often forget to put them in his sports bag.

This led him to the idea of combining the benefits you'd find in post-workout products with everyday toiletries he'd use anyway. For example to soothe muscle discomfort he put the cooling ingredient Peppermint Oil into a shower gel to work in the same way as a cooling spray but in a much more convenient format. He's replicated this principle with a range of three shower gels and two moisturisers.

Jeremy's background was in developing new products for companies like Nestle and Danone so he had a good background in developing new products.

He started developing his exercise toiletries by creating a cheap version of the idea with the help of some friends and tested the product's popularity in gyms and natural retailers.

As people found the products of benefit the company gained the attention of industry experts who have supported Jeremy in developing the company further. This resulted in Jeremy creating the Fit Kit brand to increase in-store attention to the products and better communicate with his customers.

Fit Kit was launched in November 2016 and has grown dramatically now being sold in over 1000 UK stores including Waitrose, Holland & Barrett, Ocado and Wholefoods.

Jeremy also found it much easier to manage his haemophilia working for himself. "When I used to work in big firms involving so many people it was critical that activities were completed at specific times and places. Having my own business enables me to work at times when I feel at my best and also to arrange meetings around my health."

If you're interested in speaking to Jeremy further about how he manages his fitness or his business please get in contact on info@fitkitbodycare.com

Upcoming activities and events – something for everyone!

August

Five-year strategy member consultation, venues TBC

18-19 – Rough Runner, Scotland (Edinburgh)

September

Five-year strategy member consultation, venues TBC

14-16 – Newly Diagnosed Weekend, Longleat CenterParcs

15 – Zombie Evacuation, East Anglia

15-16 – Spartan Beast/Super/Sprint, Scotland

15-16 – Rough Runner London

October

6- 7 – Spartan Beast/Super/Sprint, Windsor

7 – Bournemouth Marathon

13-14 – Rough Runner, South West

14 – Manchester Half Marathon

21 – Amsterdam Marathon

27 – Service of thanksgiving and remembrance for those who have died from contaminated blood, London

TBC – Rough Runner, Manchester

November

17-18 – Annual Conference and AGM, Birmingham

December

Ageing conference, venue TBC

January 2019

25- 27 – Newly Diagnosed Weekend, venue TBC

February

23 – Youth Ambassadors Day, venue TBC

Lads and Dads Weekend – TBC

March

Mums and Daughters Weekend – TBC

Inhibitors event – TBC

All year round

Spartan Trifecta, UK Bungee, UK Parachuting, Big Fun Run, Dog Jog

To find out more about any of the events we have planned, please contact info@haemophilia.org.uk

We look forward to seeing you soon!

THE HAEMOPHILIA SOCIETY

'Thank you for making us all very welcome at the Talking Red event – we really enjoyed it. My mum became a bit emotional; she has dealt with her bleeding disorder and mine for years with little support, making sure that medical professionals knew I had a bleeding disorder and required specialist treatment. She's my inspiration to be the voice for my daughters and ensure I continue to make professionals aware and help them understand this condition.' Nicola

Find the information you need on our website at www.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

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President: Baroness Meacher

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