

# HQ

The Haemophilia Society magazine



THE  
HAEMOPHILIA  
SOCIETY

Winter 2018

## Member Conference and AGM



Also inside: Contaminated blood inquiry launched | Local Groups  
| Genetic screening survey report | DOLHPIN Study | Talking Red  
| New Chair of Board of Trustees |

For everyone affected by a genetic bleeding disorder

## Change to Board of Trustees

At the recent AGM I completed my term as Chair of The Society, although I'm delighted to be continuing as a trustee and a member of the Inquiry subcommittee. I will also take what the last three years has taught me into my new role as the WFH VP Finance.

It has been a successful three years for The Society, delivering the Mission and action plans set out in our Strategy for 2015-18, as well as hosting a great WFH Congress in Glasgow and making preparations for the long-awaited contaminated blood inquiry which got underway in September.

I am confident that The Society is in resilient shape to meet the challenges ahead. Our financial reserves are the highest they have ever been – soon to be further increased by our share of the surplus from the Congress; our plans for delivering services to the community have never been more ambitious; our staff team is at last at full strength; we have an experienced and committed Board of Trustees; we are all set to represent the community in seeking the truth as the Inquiry takes its course; and we are well placed to advocate for treatments to be made available to all as safely and as quickly as possible.

I am delighted to be handing the baton of Chair onto such a young and active successor, Clive Smith. I have worked with Clive for three years now and know how committed he is to the community and to the role. I am confident that with Clive in the chair The Society will go from strength to strength. Thanks for your support, it's been a privilege, and now over to you Clive.



Barry Flynn, Trustee

As the youngest of three brothers all with severe haemophilia A and an uncle to nieces of whom one is a symptomatic carrier, I am heavily invested in the bleeding disorders community. Many of you may have seen my exploits undertaking triathlons in recent years and I am very passionate about getting people more active with the help of their haemophilia teams. I have been privileged to speak at the WFH Congress and EHC Conference about this and hope to work with the community to further this work.

I appreciate this is not for all and I myself spent many years on crutches and in a wheelchair before the advent of prophylaxis. As such we face a new challenge with our ageing community, assisting them along a path not many have had to take. Of course we also remember those no longer with us and those still suffering. I, like the rest of the team, am fully committed to the public inquiry and its essential work. Since the inception of the Inquiry I have chaired the subcommittee set up to deal with The Society's work, bringing my legal expertise as a barrister to the mix. Rest assured that like my fellow trustees I am committed to ensuring justice is done.

Over the last three years I have had the pleasure of serving alongside Barry, watching and learning from his experience. The Society is incredibly fortunate to have had his wisdom and experience during such a formative period of its existence. I'm comforted knowing he will continue alongside me and the other trustees and he will be a great source of strength and support going forward. Since becoming a trustee one of my frustrations has been how much The Society does and how little we tell you about it. It's only by virtue of being a trustee I have seen how much is done behind the scenes. To that end we have tried and will continue to increase communication with you, our members, through social media, newsletters and by meeting you face to face through more events.

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As a board we always feel we can be doing more. We know that The Society itself, through its staff, board and members do an incredible amount already. More than so many of us realise. Along with the Inquiry we know we face many challenges in the next few years. The treatment landscape is changing rapidly and making sure everyone knows about these changes is imperative. We must continue to work alongside our haemophilia treatment centres, continue to grow our local groups and build bridges with our new Society in Northern Ireland, whilst strengthening links with our sister Societies in Scotland and Wales. To that end I have already travelled to both Belfast and Glasgow and we will continue to work alongside Haemophilia Wales providing help and assistance to all with an inherited bleeding disorder in our devolved nations.

Furthermore, we must continue the work we have already begun. We are acutely aware of our reliance on pharmaceutical companies for funding. We must continue to diversify our funding to ensure the vital services we provide to our community continue. Despite this, we will not fear challenging companies when necessary. The safety of our community is paramount and that includes our work on the Inquiry.

Finally, despite being a London-based charity, many of our trustees are located around the country, including north Wales, Manchester, Lincoln and myself in West Yorkshire. We look forward to meeting and engaging with you at events – please come and say hello and ask us any questions.

Here's to a successful 2019 and beyond.



C. Smith

Clive Smith, Chair

## Happy campers!

A good time was had by all at our Lake District summer Youth Camp

It is difficult for children and teenagers with bleeding disorders to meet with others 'just like them' in school or public environments. Most of the time they are the only one with a bleeding disorder at school, in the park or at a birthday party.

So our summer camps for children with bleeding disorders and their siblings are vital. The camp gives them a 'place of belonging' and they feel more connected with their friends with the same condition.

We include siblings because bleeding disorders affect the entire family, not just the child with a bleeding disorder.

Our camps are specially designed to offer children a happy and stress-free environment

**46** YOUNG PEOPLE

AGED BETWEEN  
**6-17**

FOR  
**7**  
DAYS



where they can be challenged to try new activities, have fun and above all be children again.

Camp provides a safe environment for children to gain self-confidence and it's a place where they can develop a variety of social skills. Children attending also acquire a sense of independence and learn new skills.

## Summer Camp

Back in the summer – from 27-30 July – we took 36 children to camp in the Lake District. Of these, 28 were children with a bleeding disorder. There they took part in activities including archery, rock climbing, abseiling, canoeing, high ropes, low ropes and obstacles.

We had a total of 12 volunteers at camp, including two paediatric nurses and two physiotherapists. The healthcare professionals ran the treatment room and encouraged

campers to self-treat. It was fantastic how the older campers, together with our Youth Ambassadors, were able to show the younger ones how they regularly self-treat.

*"This is the first trip away where we, as parents, have not had to worry about a possible bleed and for staff not to be equipped with the skills to manage one. Although Hayden is on demand treatment it can be a worry for us if we cannot oversee any symptoms from a bump. Hayden has difficulties socially in bigger groups and this is the first time he has been away where he has come back to tell us he felt 'accepted' and no one said negative things to him. With a child with additional needs, this meant the world to us too."*

Sam, Hayden's mum

Our welcome campfire filled with songs and games



Pioneering



## Looking forward to summer 2019

We are beginning work on our summer activities for 2019. If you're interested in finding out more, please get in touch by emailing [services@haemophilia.org.uk](mailto:services@haemophilia.org.uk)

## New event – Lads and Dads Weekend 15-17 February 2019!

We are excited to launch our new event – a two-night/two-day action weekend held in the Brecon Beacons National Park.

The event will accommodate 10 lads (aged between 18-25 living with a bleeding disorder) and their dads. It will be led by a team of highly experienced and qualified experts in outdoor action activities.

Proposed by our Youth Ambassadors, this event will re-engage our members and provide a fun-filled weekend bringing sons and dads together. For more details, contact [nicola@haemophilia.org.uk](mailto:nicola@haemophilia.org.uk) or call 020 7939 0780.



Our little campers canoeing



Brave campers!

## Improving policy and practice around bleeding disorders

Find out more about The Society's work on initial diagnosis in children and emergency department care

### Initial diagnosis report launched

Early this year The Haemophilia Society began a project to understand the experiences of families when their child is initially diagnosed with a bleeding disorder. Drawing on some of the stories shared through our *#bruisednotabused* campaign we reached out to our community to ask them to share their experiences.

We are extremely grateful to the families who took the time to be interviewed or contributed their stories to this report. Without them we wouldn't have been able to complete this project.

The Society conducted this research to highlight some of the challenges that families face during the time that a child is initially diagnosed with a bleeding disorder. In doing so, our primary aim is for families to feel reassured that they are not alone during this time and that there is a community of support available once a child is diagnosed.

Based on the report, we have produced a series of recommendations aimed at safeguarding professionals, healthcare professionals and policymakers. We will work to get these adopted to improve the experience of families during initial diagnosis in the future. You can read the full report at: [haemophilia.org.uk/wp-content/uploads/2018/10/ID\\_report\\_v9.pdf](http://haemophilia.org.uk/wp-content/uploads/2018/10/ID_report_v9.pdf)

### Managing bleeding disorders in emergency care settings

People with bleeding disorders will inevitably require access to emergency care services at

least once or twice in their lifetime, in some cases more. When someone with a bleeding disorder needs urgent care, particularly in the evening, night or weekend, many will have to attend their local emergency department.



This can pose a number of challenges for both patients and emergency department staff, who are often unfamiliar with the complexities of inherited bleeding disorders and their management. As a result, patients can have difficult experiences in these settings, and may be faced with delays and complications in getting appropriate treatment.

*"Our primary aim is for families to feel reassured that they are not alone during this time."*

With this in mind, we are working on publishing a report with two main aims. Firstly, we hope to provide our members with advice on what they can do to ensure that they receive the best possible care in emergency care settings.

Secondly, we want to highlight the challenges and burden posed to the NHS by existing emergency care practices and make recommendations that aim to improve the safety and efficacy of emergency service provision for people with bleeding disorders.



**Celebrity Ambassador Jack Bridge  
with his family**

## Member conference – a resounding success!

**An inspiring and informative weekend was had by all; so much was shared and experienced that we can't possibly show you everything, but here are some of the highlights...**

Our Member conference and AGM took place this year over the weekend of 17-18 November in Birmingham. The weekend, which also included a fabulous gala dinner, gave our community the chance to come together, share experiences and be part of a programme packed with sessions and workshops delivered by leading health professionals, our staff team and members themselves.

### The conference programme

This year, we wanted to offer members a chance to enjoy a flavour of the World Federation of Hemophilia Congress that was held in May in Glasgow. We had a choice of three tracks that focused on Haemophilia, Von Willebrand Disease and Rare Bleeding



**Professor Mike Makris**

disorders on day one and Women, Inhibitors, and Sports and Exercise on day two. A range of topics was covered in each track, for example; current and future treatments, dental care and surgery. Members were able to listen to presentations about areas relevant to them, ask questions and share their experiences and thoughts.

Youth Ambassador Luke Pembroke and Chair Clive Smith raced each other to factor up



Members vote in the AGM



Chief Executive Liz Carroll said of the conference:

*"It was incredible to see almost 200 people come together over the weekend to learn more about their conditions, treatment options and living well. So many members told us they had learnt something new despite living with their bleeding disorder for many years. With a good mixture of long-standing and new members coming together, friendships were formed or rekindled and we were also able to discuss ideas on what you would like The Society to be in the next five years that will inform our new strategic plan. We hope to see you again next year!"*

Exploring the Thinktank garden



We also made sure that the children attending the weekend were kept entertained. Over the weekend, we took children aged between 6 and 16 to Cadbury World where they got to learn how chocolate is made and sample a variety of treats and to Thinktank, Birmingham Science Museum where they experienced themes of engineering, mechanics and transportation through hundreds of hands-on exhibits.

Members from our Leeds local group



Members take part in discussions





Church House

## Infected blood inquiry opens

The public inquiry into the infected blood scandal began on 24 September at Church House in Westminster, London with three days of preliminary hearings.

Before the formal proceedings there was a moving Commemoration of the infected and affected with pictures, words, video statements and music. (You can watch the Commemoration on the Inquiry's website: [infectedbloodinquiry.org.uk](http://infectedbloodinquiry.org.uk))

In his opening remarks, Chair of the Inquiry Sir Brian Langstaff set out the principles under which he expects the Inquiry to operate. He said that people would be at its heart, and those infected and affected will be heard first. Sir Brian also said the Inquiry will be completed 'as quickly as reasonable thoroughness permits,' recognising that those infected and affected are still suffering today.

The formal hearings will resume on 30 April 2019 when the Inquiry will hear evidence from a range of infected and affected people. These

hearings will be held in London, Edinburgh, Belfast, Cardiff, and probably Leeds. It is anticipated that this will happen over three months from May to July next year.

These are provisional plans and may change. You can keep up to date with the Inquiry's planning at [infectedbloodinquiry.org.uk](http://infectedbloodinquiry.org.uk)

*"The first duty of any government is to protect its citizens. If it fails, its secondary duty must be to redress its wrong. Yet, in this case Government has consistently refused to acknowledge the true scale of this humanitarian disaster."*

Raymond Bradley, Solicitor for  
The Haemophilia Society

## Opening statements

Following the opening remarks from Sir Brian and Counsel for the Inquiry Jenni Richards QC, 'core participants', including The Haemophilia Society, made their opening statements.

For The Haemophilia Society, Raymond Bradley, Managing Partner at Malcomson Law, who leads our legal team, told the Inquiry that the Government abdicated its responsibility to do the 'right thing' by the haemophilia community and hid behind the concept of litigation to avoid its moral responsibility. He showed the Inquiry letters from both Margaret Thatcher and John Major when they were Prime Ministers. One from Mrs Thatcher said: 'The question of compensation has been made a matter for the courts to decide,' while a later letter from John Major suggested people suffering 'might be able to benefit from Lottery grants, but this would be a matter for the Board to decide in response to any applications received.'

Concluding his statement, Mr Bradley said it was now necessary for the Inquiry to make interim recommendations to alleviate financial hardship and address the compensation issue without further delay. 'It says to this government and to previous governments you ought to hang your head in shame for failing your vulnerable citizens and our members in their greatest hour of need,' he added.

## Coping with stress

For many people, the public inquiry has brought back difficult memories. Although it is perfectly normal for you to find this stressful, it can be helpful to express these feelings with people you trust and help you manage better in the longer term.

However, if you are not comfortable sharing your feelings with friends and family and you



The Times coverage

are still experiencing anxiety, confusion, emptiness, anger or exhaustion you may need help.

*"Things happened that should not have happened and so, on behalf of my clients, I say, unreservedly, that we are sorry."*

Eleanor Grey QC for the Department of Health and Social Care

If you have been affected by the coverage of the Infected Blood inquiry and feel you want to talk to someone there is confidential psychological support from the Red Cross available on 0800 458 9473. Alternatively you can get help through your GP, the social services department of your local authority, CRUSE Bereavement (0870 167 167, [crusebereavementcare.org.uk](http://crusebereavementcare.org.uk)), the Salvation Army (0845 634 0101, [salvationarmy.org.uk](http://salvationarmy.org.uk)), or the Samaritans (116 123, [samaritans.org.uk](http://samaritans.org.uk)).

Keep up to date via our dedicated inquiry channels at:

Web: [inquiry.haemophilia.org.uk](http://inquiry.haemophilia.org.uk)

Twitter: [HaemosocUK\\_PI](https://twitter.com/HaemosocUK_PI)

Facebook: [www.facebook.com/groups/HSInquiry/](https://www.facebook.com/groups/HSInquiry/)

(Please request to be added as this is a closed group.)

Email: [publicinquiry@haemophilia.org.uk](mailto:publicinquiry@haemophilia.org.uk)

## Factor tenders

Chief Executive Liz Carroll explains The Society's involvement in this important area

A key element of our work is to bring the patient voice to decisions about which treatments are available to be prescribed across the UK (factor tenders). For factor tenders, a Tender Board makes decisions about which treatments will be available to be prescribed by haemophilia centres.

Our aim is to ensure treatment is safe, always available and best value for money. We also influence objectives related to ease of use, for example by running workshops with patients and carers to test products for how many steps they take to unpack and mix, with results contributing to the final decision scoring.

We look at vial sizes too: two bottles to mix score lower than one; more choice of vial size, meaning less wastage, may score more. Packaging is also considered.

### Multi-stage process

Recently, we've been involved in the tender for factor IX for haemophilia B. In a multi-stage process, every company wanting a product considered must provide detailed evidence on fundamental issues such as safety and supply. If these criteria are met, the product will be accepted and be able to be prescribed.

However, at this point the price the NHS will pay is set for each product, as each company submits the price they require. This process is confidential and competitive. It can also be a challenge as not every product is the same: one unit of standard product can't be directly compared with one unit of an extended half-life product, so other ways of measuring price need to be considered. Commissioning support for FIX products will likely be

### Testing products for ease of use



determined by how much it costs on average to treat a patient in a year.

One reason why entering your treatment on Haemtrack is important is that this data helps towards making such decisions. Accurate data is vital for measuring cost, but long-term monitoring also gives information on safety, treatment effectiveness and issues like inhibitor development, which can impact future decisions about treatments.

Finally, each nation (England, Scotland, Wales and Northern Ireland) decides which approved products it will fund. Decisions may mainly be made on cost-effectiveness, but number

of infusions a week or any evidence about frequency of bleeds may be taken into account (again influenced by Haemtrack data). If one product is much more expensive than another, it can mean it isn't supported by commissioners, or it's restricted to people for whom other products don't work.

*"Our aim is to ensure treatment is safe, always available and best value for money."*

### Market shares

For von Willebrand disease, there are currently no directly comparable treatments, so the tender is slightly different. For other factor deficiencies, often only one treatment is available, so a competitive tender isn't required. For factor VIII, with so many products on the UK market the tender not only looks at safety and usability, but also defines how much of which product should be prescribed in England: the product which proves to be the most economically advantageous is guaranteed the biggest market share, with others given minimum usage guarantees.

The other nations decide independently how they would like to allocate how much product is used. Capacity is always left for niche or new products, but if the product you use gets changed from a higher to lower usage band in a future tender, you may be asked to switch.

You will always be able to ask why: it may be that a new-to-market treatment has shown improved outcomes, or provides best value for money. You will never be asked to switch to a product that is cheaper but not as safe or effective.



THE  
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## Become a Youth Ambassador today!

Are you interested in volunteering?

Do you have a desire to make a difference in our community?



### Are you?

- 18-22 years and living with a bleeding disorder
- Passionate about promoting The Haemophilia Society
- Interested in building skills

### Then we want to hear from you!

For more information about this role, email [services@haemophilia.org.uk](mailto:services@haemophilia.org.uk) or call 020 7939 0780.



## Women's world

Women can have bleeding disorders too. Services Co-ordinator Rose Ozdemir explains.

Ten per cent of women go to the doctor with heavy menstrual bleeding. Of these women, 29% may have a bleeding disorder, but only 2% get tested for bleeding disorders.

As we already know, someone with a bleeding disorder can experience many symptoms, from nosebleeds to joint bleeds, bruises, dental complications and more. Unfortunately, these experiences can have a bigger impact on a woman with a bleeding disorder because of menstruation and childbirth. Absenteeism and social isolation linked to these physical complications can really affect their quality of life.

We believe efforts to alleviate the physical and psychosocial impact of bleeding disorders on women should involve increasing awareness. This will inevitably stimulate research, hopefully leading to improved diagnostic and treatment facilities. But while providing effective treatment for bleeding disorders is critical, it isn't enough. Many women are unaware that their symptoms are abnormal, so they do not seek medical attention.

### How Talking Red helps

Our Talking Red programme aims to tackle these issues by ensuring a strong collective voice for women. Each year we have more and more Talking Red Ambassadors advocating locally, attending conferences, visiting universities, sharing experiences and networking.

We hold an annual conference for all women affected by bleeding disorders, physically and/or emotionally. This year we led up to

it with a whole week of sharing stories and case studies on our website and social media! Many people joined in by either painting their pinky, baking red, sharing their story or fundraising. I used my birthday as an opportunity to raise money and much-needed awareness on Facebook and had an amazing response. Our conference in Birmingham was a great way to end the week.

**10% of women go to the doctor with heavy menstrual bleeding. Of these, 29% may have a bleeding disorder, but only 2% get tested.**

A few months before the conference we used a social media poll to ask what attendees would like to know more about and what topics would most interest them. The results really helped us tailor the topics to their needs. We had sessions from Sarah Bowman (social worker), Debra Pollard (lead specialist nurse), Rebekah Tennyson (clinical psychologist), and Linda Wild (Talking Red Ambassador). We also had updates from Ambassadors Antonia Lambis, Ria Peake, Hannah Yarnall, and Jeff Courtney, Head of Policy and Programmes.

We also got attendees' feedback about our Talking Red pack: we're pleased to say that updated pdf versions are now online!

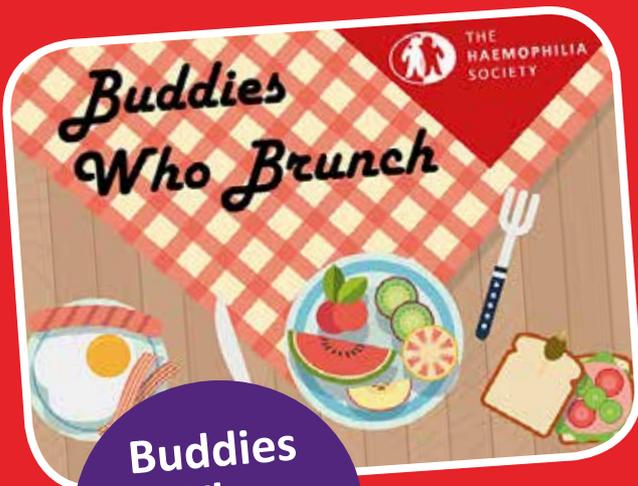
We are already preparing our 2019 Talking Red conference! Email [services@haemophilia.org.uk](mailto:services@haemophilia.org.uk) for more details. We're also looking for keen Talking Red Ambassadors – if you would like to find out more, please email for the role description.

# Fundraise for us in 2019!



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We have an exciting year planned, and we want you to be a huge part of it!



Buddies  
Who  
Brunch



Prudential  
Ride London-  
Surrey 100



Great  
North  
Run



World  
Haemophilia  
Day

Get in touch to join us!

For everyone affected by a genetic bleeding disorder

To find out more, visit [haemophilia.org.uk](http://haemophilia.org.uk) or contact us on  
020 7939 0780 or at [events@haemophilia.org.uk](mailto:events@haemophilia.org.uk)

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

 HaemophiliaSocietyUK

 HaemoSocUK

 thehaemophiliasociety

## Local groups round-up

Here, some of our local groups report on recent activity. To find out more about any of our local groups, please email [services@haemophilia.org.uk](mailto:services@haemophilia.org.uk)

### Yorkshire

Over the past year the Yorkshire local group has been really busy supporting children and adults and their families, all living with a bleeding disorder, in our region.

Volunteer led by committed individuals, we have given our community opportunities to socialise and fundraise, coming together to co-ordinate a more 'local' approach from The Haemophilia Society for our Yorkshire Folk.

The activities provided by the local group are aimed at our wide community interests and needs. They have included canal and riverboat experiences, family days out to local attractions, children's Christmas parties, bowling and laser tag, to name a few.

Everyone is welcome to attend local group meetings that are held every term. These are when planning takes place, but it's not all about meetings and time commitment! In February, many of our regional families took



part in our 5p February campaign, a chance to raise awareness and funds in Yorkshire schools and workplaces. In July, a team of us had great fun in the local dragon boat race: hard work but a fabulous outcome when we were placed in the top 10 of over 40 teams!

We welcome all members of The Society: if you'd like to know more about what we offer, please email [services@haemophilia.org.uk](mailto:services@haemophilia.org.uk)

### Northern Ireland

In September, the newly reformed Northern Ireland group held its first event at Belfast Zoo. Joined by The Society's local groups representative James Hunt, six families from Belfast, Banbridge and Strabane embarked on a fun day of activity and advocacy for the haemophilia community in Northern Ireland.

It was an important opportunity for us to meet up and reach out to each other as a family; gaining insight into what our community needs

and making future plans easier.

Plans are afoot for fundraising events and more focused coffee mornings and events targeted at the wider haemophilia family here in Northern Ireland.

[www.facebook.com/groups/thehaemophiliasocietyNI/](https://www.facebook.com/groups/thehaemophiliasocietyNI/)



## London and South

The London and South group was relaunched in November 2017 following a few years of inactivity. Our first job was to kick-start our Facebook group. Adding 75 members over the last year, we now have almost 160 members.

Our group covers London and the Home Counties. Our mission is to provide support to those living with bleeding disorders via the Facebook group but more importantly, through face-to-face events. So far we have held a wine and cheese launch night, a Sunday afternoon bowling session, a summer picnic, a mums dinner and a trip to Hobbledown Farm in Surrey.



We hope to raise funds to support more events for families to come together and share the experience of living with a bleeding disorder, as well as having some fun and making new friends along the way.

We have lots more planned, so please join the group: we are always happy to welcome new members. Find us at: [www.facebook.com/groups/haemophilials/](https://www.facebook.com/groups/haemophilials/)

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## Lincolnshire

On Saturday 18 August Lincolnshire Haemophilia Group members met for a four-mile walk around the lake at Clumber Park, Nottinghamshire.

We invited members from the East Midlands to join us and everyone who came enjoyed the beautiful surroundings. It was lovely for everyone to walk and chat, and share family and The Society news. We followed the walk with a great picnic of homemade food brought by members.

Some of our group members have had a difficult year but we continue to support one another with friendship.

A highlight of our year was when 12 members attended the WFH Congress in Glasgow back in May, most as volunteers. We also held our Lincolnshire Group AGM on 14 October and supported members to attend The Haemophilia Society AGM in Birmingham in November.



Our Christmas lunch this year is at The Thatch, Bottesford – those with bleeding disorders are sponsored for this event, while other members self-fund. A Sunday 10-pin bowling session followed by lunch at a member's home is planned for early February 2019. And later in the spring we'll be holding a sponsored cycle ride at Rutland Water, followed by a lakeside BBQ and games.

New family members are most welcome to join us – please contact us via The Haemophilia Society.

## Fundraising – there's something for everyone!

James Hunt, The Society's Head of Fundraising and Engagement, takes to two wheels for his own fundraising challenge

Can he do it? Yes he can!



When your wife asks 'are you stupid?' as her opening line after you tell her you're thinking of doing an Ironman, you realise that you may not have chosen the best fundraising idea to support your charity. Actually, she laughed first and then said it, one of those typical laughs that results in a few tears as what you've said is just too, too funny – but we all need a challenge, right?

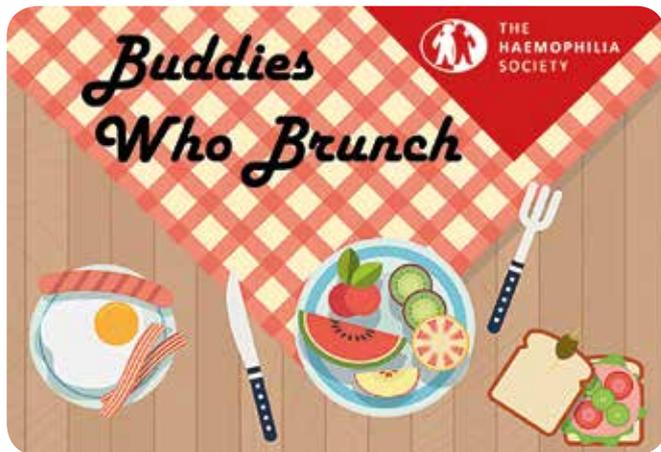
I've been looking to do some kind of ambitious fundraiser in 2019. You see it's a milestone birthday for me next year. Sadly not 19 or even 21, and it's kind of you to maybe think 30. I'm afraid it's the next one – 35 (plus 5) – and I decided long ago I needed something epic to make it one to never forget!

### More choice for all

Over the last year we've been finding ways here at The Society to make it easier for people to get involved in fundraising, in particular away from traditional running events. When I started the job back in 2016, I was keen to find out from as many members of the community as possible what drives them to support us from a fundraising perspective and what they would like most.

So we changed it up a bit: we added some abseils, found some fun runs and a lottery, and started asking people for pocket change. And now we've launched Buddies Who Brunch – coffee and full English instead of sweat and tears.

Following suggestions from members, we signed up to Facebook Giving, and since we started using it we have seen over £4,000 raised, through simple things like people asking for birthday donations. It's very easy to do, and all you have to do when you've set it up is tell people. And every pound you raise helps us to provide our services for free.



## If not an Ironman, then what?

I've been working in fundraising for 13 years now, and one thing I've learned is never to expect supporters to do something you won't do yourself. For me, the exception is abseiling – I'm sorry, but that's one thing I absolutely can't do! Preferring to stay firmly on the ground, or at least near it, now I'm looking at doing something on a bike.

*"I've been working in fundraising for 13 years now, and one thing I've learned is never to expect supporters to do something you won't do yourself."*

I haven't ridden a bike since I was about 10, so this could either be inspiring or it could go horribly wrong! So why am I doing it, I hear you ask. Well, I was inspired by a couple of people, including our trustee and new Chair Clive Smith. As you may know,

Clive is one of three people in the world with severe haemophilia A to have completed the Ironman challenge – you can read about his latest exploits on page 23. And then of course, there's my wife...

I will never run far, and I haven't swum in a pool bigger than on holiday in years, so a bike seemed more attractive. It was really some colleagues from the Dutch Haemophilia Society, who are crazy about riding bikes and convinced me to do it when we were at the WFH Congress in May.

So I bought a bike and now I am psyching myself up for the New Year. One option is Ride London – we have places for 2019 if you fancy it – email [fundraising@haemophilia.org.uk](mailto:fundraising@haemophilia.org.uk) ASAP) or some kind of inter-country ride, maybe with other colleagues from the European Haemophilia Consortium.

Whatever I decide to do, I will make sure I raise plenty of money for The Society! So keep an eye on our Twitter, Instagram and Facebook pages for updates.

## Will you join me?

If I've inspired you to think about your own fundraising challenge, why not sign up for something today – see page 27 for upcoming events. Or if you'd prefer something more relaxed, how about organising a Brunch, or just setting up a birthday fundraiser on Facebook. To steal a line from a well-known supermarket, 'every little helps' – and we need as much support as you can give us.

Thank you!

## Fundraising feats

Over the summer and autumn our fabulous fundraisers have been busy raising money to support our vital services – a huge thank you to you all!

### Birthday giving through Facebook

Did you know that you can raise funds for The Haemophilia Society through social media for your birthday? This is just one of the many ways you can help to support us!

Josh Goddard says about his father Kevin's recent request for donations:



*"I'm really proud of my dad – for his 50th this year he asked friends and family for donations to the wonderful Haemophilia Society. He smashed his target; he's my absolute hero and inspires me every day. It was great to be able to celebrate this amazing day with all our family and friends."*

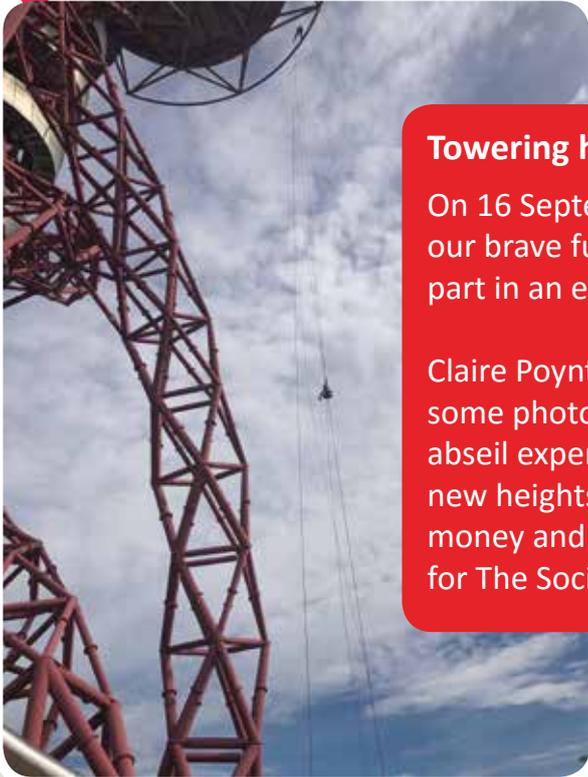
### Runnin' runnin' runnin' runnin'

The Great North Run was a great success this year, taking place on 9 September 2018. Our fabulous runners managed to raise over £4,000: participants fundraising for us included Dr John Hanley, Helen Farrer, Charlie Anderson, Emma Davis, Andrew Robinson, Izzy Mahoney and Sam Bowers.

Izzy said: "I chose The Haemophilia Society because my three younger brothers have severe haemophilia and I have found out I am also a carrier of the gene." On the Great North Run she said "It was a great experience and I'm so glad I have raised the money to help a cause that is close to my heart."

A huge thank you to all our fantastic runners!





## Towering heights

On 16 September, some of our brave fundraisers took part in an exciting abseil!

Claire Poynton sent us some photographs of her abseil experience, scaling new heights to raise money and awareness for The Society.



## Nanda Segani participated in the Cardiff Half Marathon on 7 October 2018

"I ran in the Cardiff Half Marathon to support my partner and others with haemophilia. My partner is profoundly proud that I completed the race and raised over £700 through my JustGiving page, cash donations and CAF cheques. It's been an amazing experience and fundraising gave me a chance to raise awareness of what haemophilia is and what The Society does. I would like to thank my partner, friends and family for coming to support me."

## Treasure trove

### Kimbo's Norfolk Social Metal Detecting Fun Weekender

Thursday 20 - Sunday 23 September 2018

We have had some amazing support from Kim Clarke and 300 metal detectorists in a field in Norfolk. As part of a rally weekend where they spent time searching for hidden treasures, they raised a whopping £5,000 through event entry and activities. THANK YOU!



## Bleeding Tough

**Carl Sanderson recounts his personal challenge to the 'can't do' attitude**

I was born in 1973 with haemophilia A: I currently treat myself on demand. Growing up with this condition was challenging but thanks to support from my parents and the Newcastle RVI staff, I was able to lead a near to normal childhood.

In my late teens I took up martial arts, achieving a 1st dan black belt. During my early 20s I found a new interest in exercise, mainly weight training, which continued into my 30s. Then at the start of 2012, aged 39, I decided I wanted to become fit again. A friend mentioned Tough Mudder, a 12-mile long obstacle course designed by the British Special Forces that tested strength, stamina, mental grit and camaraderie. This seemed to be a perfect goal for me to aim for and to celebrate my 40th birthday in 2013.

### Getting fit fast

So the diet and training began, giving me 18 months to get fit enough to take part. I went from doing no exercise to running, circuit training and more. Five months on training had gone so well I didn't want to wait another year to do a Tough Mudder event. At this point I felt I should discuss my plans with the haemophilia centre. Initially shocked, the staff told me I was crazy but said they would support me. This was a huge weight off my mind and we discussed a treatment plan to ensure that I could compete and succeed. It meant me taking my treatment before and after an event, making sure that I had the correct level of clotting factor in my blood to help prevent any bleeding.

I completed my first Tough Mudder on 17 November 2012. I felt a real sense of



achievement as people thought I wouldn't be able to do it because of my haemophilia. As a result I decided to continue with my original plan to complete the Tough Mudder event in 2013, but now to raise awareness and challenge the 'can't do' attitude. Deciding to complete two events in one weekend, I also got help to make a mini documentary about what I was trying to do, called Times Have Changed – The Stigma of Haemophilia (<https://youtu.be/ajyrS2zfSHU>).

### No stopping now

I started 'Bleeding Tough' in 2014, using Tough Mudder events to raise awareness for haemophilia and other bleeding disorders and help change how others see us. That year saw me do three more events, including my first double lap. In 2015 my challenge was to complete all 16 UK Tough Mudder events. In 2016 I completed another seven, bringing my total to 30. I finished my 2017 season on 41 events including completing the first Europe's Toughest Mudder, an eight-hour night event.

### My biggest challenge yet

Now it's 2018 and I've done 53 events, including Europe's Toughest Mudder again. By the time you read this, on 10 November I'll have competed in World's Toughest Mudder in Atlanta, USA. It calls itself the most extreme, insane, imposing, pulse-pounding, heart-stopping 24-hour obstacle course challenge on the planet! I can't wait!

## Challenge Roth 2018

### Severe haemophilia A won't stop friends and rival triathletes Clive Smith and Markus Bachhuber

Regular readers of HQ will be familiar with my exploits completing Ironman triathlons over recent years. 2018 was no different, though this year's race involved a few twists. First, the race I entered was one of the biggest outside the Ironman World Championships in Hawaii: the race is so popular that it sells out online in about a minute.

The second twist was that I wouldn't be the only person with severe haemophilia A on the start line. A couple of years ago I'd come across a German haemophiliac, Markus Bachhuber, who had completed this race the year after I completed Ironman Zurich in 2014. Markus wrote to the race organisers and they kindly gave us a priority entry slot for 2018.

By happy coincidence, Markus and I were both in London the week before the race. We managed to meet for the first time at The Society offices, where Markus also got to meet the team.

#### Friendly rivalry

As well as competing together, Markus and I would also go off in the same wave at the start, along with all the pros. We'd compared our previous race times and expected to be somewhere between 30 minutes to an hour apart by the end. I came out of the swim ahead and set off on the bike. About two hours in, I took a corner too sharply and ended up in a ditch. As a result, I completed the bike slower than anticipated.

I went through the first half of the marathon in 1:45 so was on pace for my planned run



Triathlon success for Clive and Markus

time. It was only then that I had something of a surprise. At one of the turn-around points I suddenly saw Markus. And he was ahead! He had overtaken me on the bike when I crashed – now the battle was on.

#### The race is on

We ran together for some time and around five km from the end there was a turn-around point. Markus went through first and got an energy gel I had had my eye on. I picked one up on the way back through and when I next looked up, Markus had about a 100m lead on me. I knew I couldn't let the lead get any bigger and so I pushed on for the next kilometre. When I reached Markus, I decided to push past and see if I could drop him. My plan worked and I kicked for home. I crossed the line in just under 11 hours, with Markus following a few minutes later.

An incredible day out and an incredible experience with Markus. I look forward to being on the start line again with him one day.

## The best exercise

Physiotherapist David Stephensen reports on developing a haemophilia physiotherapy intervention for optimum musculoskeletal health – the DOLPHIN study



Melanie Bladen, Haemophilia Physio at GOSH ran the session

It is often said that exercise is good for boys with haemophilia and that strong muscles lead to healthy joints. While it seems logical that exercise would be effective for people with haemophilia, there is a lack of information about whether this is true or indeed what exercises are beneficial.

A group of researchers from haemophilia centres at Canterbury, The Royal London Hospital and Great Ormond Street Hospital are working together with researchers from the University of Kent and King's College London as well as The Haemophilia Society to answer this question.

### First steps

Working with physiotherapists experienced in haemophilia care and those who have worked with elite gymnasts and ballet dancers, the team have developed a programme of muscle strengthening exercises they think might be beneficial for optimal musculoskeletal health in boys with haemophilia. After modifying the exercises with a group of children and their families from The Haemophilia Society they are now beginning to test the effects of the exercise programme in a group of boys aged between 6 and 11. David, who is leading the research, said that working closely with The Haemophilia Society on the design and implementation of this research has been hugely beneficial in terms of finding out patients' views on how to do this study better.

### Testing the theory

The researchers are first looking at whether the exercises are safe, the best way of doing the exercises and how to measure the effect. The team expect to finish this part of the study next year.

If the exercise programme is safe and the boys can do it, the researchers plan to expand the study to find out if certain muscle strengthening exercises are indeed beneficial for boys with haemophilia.

Healthcare and safeguarding professionals were also consulted during the production of this report.

## What does the haemophilia community think about genetic screening?

### Warwick Medical School researchers report their project findings

As genomic medicine advances, screening the whole population for genetic conditions is now possible. However, little is known about what people living with bleeding disorders think about screening, nor the social and ethical issues it raises.

In 2017, researchers Drs Felicity Boardman, Rachel Hale and Philip Young began to explore this topic, using interviews and a survey. With The Haemophilia Society's support, 22 people were interviewed and 415 people completed a screening attitudes survey, all of whom had a bleeding disorder or were relatives of someone who did.

#### Mixed views

The results showed a mix of perspectives towards both screening and bleeding disorders. A minority of participants described bleeding disorders as debilitating and burdensome; however most considered them manageable, particularly when well controlled. The most obvious differences in attitude were between older adults with haemophilia (many of whom had been exposed to blood-borne viruses) and younger participants, many of whom are benefiting from treatment improvements, particularly prophylaxis.

#### Concerns around screening

Both survey and interview participants were quite critical of the idea of population screening for bleeding disorders, the major concern being that it might lead to pregnancy terminations. Instead, they emphasised the need for early diagnosis and treatment, with 77% of survey participants believing that

newborn screening was the most acceptable screening programme. The prospect of pregnancy or pre-pregnancy screening generated less support, at 59% and 57% respectively.

Given the negative attitudes towards termination, it was initially surprising that pregnancy screening was viewed slightly more favourably than pre-pregnancy. However, further analysis revealed that this was because participants believed the information could assist preparation for the birth of a child with haemophilia, rather than inform a termination decision. Indeed, 90% of survey participants regarded termination for haemophilia as ethically unacceptable.

Overall, bleeding disorders were largely viewed as liveable conditions. Screening was supported when used for information, although fears emerged about the accuracy and quality of that information, particularly when the general public were viewed as largely ignorant of bleeding disorders. High quality information, early diagnosis, education and access to treatment (especially prophylaxis) were considered the most important goals of any screening programme, rather than prevention per se.

#### What will happen to the results?

These results will be prepared for a report to the UK National Screening Committee and also distributed to academics, researchers and clinicians, giving them an overview of the main concerns that families affected by bleeding disorders have about screening.

## Youth Ambassador Update

Find out more about what The Society's Youth Ambassadors get up to... and perhaps join them?

Our Youth Ambassadors are fundamental to our work. They attend many of our events and services, sharing their experiences, demonstrating treatment and offering a role model to younger members as well as reassurance to parents that a bleeding disorder won't hold you back in life. A Youth Ambassador also attends board meetings to update the board on the work they've been doing.

### News from two of our Youth Ambassadors

**Matt Minshall writes:** Since Congress in May the Youth Ambassadors have been involved in Newly Diagnosed Weekends and Youth Camp. We're proud to be part of these events, hopefully inspiring other young people and their families. In the background we've been working on an activity weekend to engage the millennial generation – see page 6. While Luke and I have been involved in filming for a small (top secret) project that will be released later in the year, Ria got selected to be on the European Haemophilia Consortium Youth Committee, which we are immensely proud of!

**And from Ria Peake:** On 23 June I attended and presented at the Talking Red conference in Birmingham. The event highlighted the barriers women face in terms of access to treatment, stereotyping and cultural issues, namely reduced awareness around female bleeding disorders and the stigmatism of 'heavy



*"I feel so much better having met your Youth Ambassadors – my daughter had never met anyone with von Willebrand disease before. Seeing her face when she realised she wasn't the only one was incredible." Debra, Lucy's mum*

bleeding' and discussing female bleeding symptoms publicly. The conference inspired a united front among attendees and developed a methodology in terms of overcoming these barriers. Personally, it gave me a feeling of inclusion and of safety. Safety in knowing that I have a network of people I can turn to who understand. This was illustrated only too well when I became unwell at Congress. Thankfully I received the correct care and treatment, which might not have been the case elsewhere – another good reason to raise awareness of female bleeding disorders.

**Are you aged 18-22? Living with a bleeding disorder? Could you be a Youth Ambassador? We are looking for enthusiastic Youth Ambassadors.**

**If you want to make change in our community, this volunteer role is for you. To find out more about this opportunity, please email Rose or Nicola at [services@haemophilia.org.uk](mailto:services@haemophilia.org.uk) or call 020 7939 0780.**

**There are events and activities for everyone in 2019 – we'd love you to take part!**

**December**

- 1 – World AIDS Day**
- 5 – Christmas Carol Service**

**February**

- 1 – Newly Diagnosed Weekend, Sherwood Forest**
- 15-17 – Lads and Dads Weekend**
- 23 – Youth Ambassador Day**

**March**

- 17 – Reading Half Marathon**
- Mums and Daughters Weekend – TBC**
- 17 – Bath Half Marathon**
- Ageing Day – TBC**
- 23 – Big Red London Bridge Walk**
- 24 – London Landmarks Half Marathon**
- Inhibitor Summit – TBC**

**All year round**

You can join our *Buddies Who Brunch* campaign and host a brunch or coffee morning, fundraise on Facebook for your birthday, and take part in any event (not just those we've helped to organise) to fundraise for us!

To find out more about any of these upcoming events, please contact [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk).

We look forward to you joining us!

**April**

- 7 – World Health Day**
- Various – a choice of Marathons across the UK**
- 17 – World Haemophilia Day**
- Family Day – TBC**

**May**

- 5 – Belfast City Marathon**
- 25-26 – Edinburgh Marathon Festival**

**June**

- 16 – London to Brighton Bike Ride**
- 22-30 – Talking Red Week**
- 22 – Nightrider Glasgow**
- Newly Diagnosed Weekend – TBC**

**July**

- Youth Camp – TBC**



# THE HAEMOPHILIA SOCIETY

*"The weekends are not only beneficial to all who attend, but I see them as absolutely crucial to the whole family. We learned so much, we laughed, cried and supported each other. What an amazing group of adults and children. I feel it's an absolute privilege to say I'm part of this. From the bottom of my heart and behalf of my whole family, thank you all so very much."* Parent who attended one of our Newly Diagnosed Families Weekends

Find the information you need on our website at [haemophilia.org.uk](http://haemophilia.org.uk), email us at [info@haemophilia.org.uk](mailto: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.

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