

For everyone affected by a bleeding disorder

HQ

The Haemophilia Society magazine

Winter 2016 edition

Together we're amazing!

2016 AGM and conference report

**Innovative treatment
developments – an update**

Buddy Awards winners

**Fundraising –
how you can help**

**Living Well, Going
Forward – HIV day**





Liz Carroll, Chief Executive

A warm winter welcome!

Welcome to the winter edition of HQ. It's been another busy six months, with several new staff on board and our two biggest events of the year.

Head of Fundraising James Hunt joined us in September, together with Angela Spencer to boost capacity in our finance team. Very recently Elisha Richardson started as our administrator and social media coordinator and Anila Babla took up the new post of communications officer. We hope these appointments will help us work more efficiently and communicate better what we're doing, so you, our members, feel more connected.

This year we were pleased to be able to return the service of thanksgiving and remembrance for those with a bleeding disorder who have died from contaminated blood to St Botolph-without-Bishopsgate. Around 80 people came to remember their loved ones. Then on 5th November over 120 adults and children joined us in Bristol for our AGM, conference and Buddy Awards.

You can read more about these events and more as you work your way through HQ, but do please get in touch and come along to our member events and fundraising activities. This charity is here for you and without you it wouldn't exist.



Barry Flynn, Chair

From the Chair...

Members at the AGM were asked for feedback on proposals to change our name and logo. Originally formed to support men with haemophilia, The Society's role has expanded and membership grown to include those with other bleeding disorders and carriers. A proposal to change the name and logo was discussed along with suggestions for new branding presented by Tony Jones of 52 Oaks Communications, who have worked on this for free.

Tony explained the rationale and thinking behind a new name and logo. The discussions provided useful feedback and members offered interesting and valuable perspectives. It was encouraging that members voted overwhelmingly in favour of a more inclusive name, but more work is needed on both a name and logo. Thanks to everyone who attended and contributed – we will continue to work on this issue!

Buddy Awards – the winners!

An important element of our November AGM and conference was celebrating the Buddy Awards winners. Here they are, together with some of their nominations – congratulations to them all!



Best Adult Buddy
Northern Ireland

Mary Dornan

'My wife Mary has showed unbelievable dedication to our whole family. I want her to know how much I appreciate her!'



Best Child Buddy
Northern Ireland

Freya Nelson



Best Adult Buddy
Scotland

Ashleigh England



Best Child Buddy
Scotland

Evie Moulds



Best Adult Buddy
England

Michael Wild

'Evie plays with me when I get treatment and talks a lot to stop me thinking and worrying when it hurts!'



Best Child Buddy
England

Ollie Thomas-Wilcox



Best Adult Buddy
Wales

Sophie Ockenden



Best Child Buddy
Wales

Alicia Lloyd



Best Buddy
Nurse

Aileen Gibson

'Sophie wipes away my tears when there is pain, makes me giggle when I am fed up with it all, and cuddles me for forever when I just feel sad.'



Best Buddy
Physio

Hannah Harbridge



Best Buddy
Doctor

Dr Jay Alamelu



Best Buddy
Haemophilia Centre

Belfast

'Physio Hannah is amazing: she is outstandingly kind and friendly and ensures that every visit to the hospital is great fun.'

The Buddy Awards are kindly sponsored by Novo Nordisk.



From sceptic to convert

Another successful weekend for newly diagnosed families sees dad Ashley Hodges feeling positive

Married to Kelly, a haemophilia A carrier, I knew there was a 50% chance the condition could be passed on to our children: Declan (6), Elijah (4) and Astrid (2). Elijah was diagnosed shortly after birth: he has a factor level of 12% but has severe phenotype, meaning he has symptoms and spontaneous bleeds similar to someone with severe haemophilia.

I've always had the 'brush it off, you'll live' attitude to falls, grazes and bumps – I'm their dad, they are from 'good stock', right? With Elijah it was the same; perhaps in the back of my mind it was hard to accept. It wasn't until his first bleed that my attitude altered to 'come here, let's take a look' before the 'brush it off' comments.

Some months ago, Kelly told me she'd signed us up to a weekend with The Haemophilia Society. What had she got us into? I was sceptical; what could we possibly gain from it? How wrong I was!

The event was held at Longleat Center Parcs. On arrival Christina greeted us warmly; throughout the weekend she and her team were fantastic. Once all the families had arrived, the children went into a pre-arranged crèche so as not to be bored during the 'talks' between the parents and the wonderful people from The Society. Not only was the weekend extremely informative and beneficial, but we also met some lovely people in similar situations and got to spend quality family time away from everyday stresses.

What did I learn? That I can continue to allow Elijah to do what he wants to do; I can guide him and provide advice, but over time he will learn himself. As one attendee said, 'Is 90 minutes on the football pitch worth a day or two in the hospital?' – this is Elijah's decision to make.

From sceptic to convert – I'm certain The Haemophilia Society will be seeing more of my family in future!



Making connections

Two of this summer's member events illustrate some of the many benefits of joining in

Creating a stir!

In September we held our second Create weekend for all ages to come together and be creative. We danced, sang, learnt about creative writing and used huge quantities of paint and glitter in the art sessions.

At Create, it doesn't matter if you aren't arty; it's all about having a go and being part of something amazing. And perhaps the biggest benefit is meeting others who totally understand what life with a bleeding disorder is all about; the fears, anxiety, the day-to-day issues you deal with, the sense of achievement when you do something you always thought wasn't possible.

One great moment was when one of the younger participants met someone for the very first time who also has von Willebrand disease. Her joy in meeting someone like her and the relief on her parents' faces to find a young adult who truly understood was incredible.

Whatever your age, Create is here for you; so do join us next summer when you too may learn that your husband can do the splits!

Scottish Youth Weekend – a satisfied customer reports

I'm Shaun England, aged 16, and I went on an activity weekend with The Society to a place just outside Glasgow. The living quarters were just what you'd expect from an activity centre, clean and comfortable. And the food was amazing – I couldn't help but go up for seconds and it definitely helped for the cold days of activities!

The weekend flew by because the days were full of fun activities that everyone could get involved with. So those of us who were older, including me, weren't stuck doing little kids' activities for the whole thing. Activities included air rifles, rock climbing, archery, team building, quad biking and raft building – great for all ages.

It was a beautiful location and the staff were all super friendly – a great weekend!



Facing up to getting older

Our film and conference highlight concerns about ageing with a bleeding disorder

Made as part of the ageing project, our new 30-minute film gives a snapshot of the issues, needs and concerns for the future that many in our ageing community experience. To ensure accuracy and develop deeper understanding *The Ageing Project – An exploration of our community* was screened at three summer workshops: one for The Haemophilia Society staff, one for healthcare professionals and one for those who'd been filmed.

Its next outing was at September's Ageing Conference. It was well received and group discussions followed, eliciting additional input from attendees. At the conference there were also sessions on: Care Homes – and what this might mean for me, Ageing Positively, and Living Well and Feeling Well.

If you are 35 years and over you will shortly receive a questionnaire on issues identified as important to you, such as access to treatment. Please take the time to complete and return it – your input is crucial in helping us support you, and your family, as you grow older.

Noel Bennett was at the conference...

... I don't want to think about getting old, no one does, but as someone with severe haemophilia who's about to turn 40 perhaps it's even more important that I acknowledge this and get some ideas about what my future needs may be while I have time. This is why I attended The Society's Ageing Conference. It was a great opportunity for attendees to share with The Society concerns and feelings about getting old with haemophilia and the obstacles we face.

Who will do my injections if I can't? Will a care home understand my needs? Can I afford the care home I want? These were among many questions that came up, to which there were no simple answers, especially when NHS and social care budgets are in a constant state of austerity.

I can't lie: getting old with haemophilia scares me senseless, but I feel better having attended the conference and knowing support is there for the future.



Talking Red to students

As Talking Red focuses on young women at university, Emma Baker recounts her experience of von Willebrand disease and the campaign's importance

This year the Talking Red campaign shifted its focus from creating awareness among the general public to providing support for young women who are carriers or have a bleeding disorder. In November a focus group made up of female university students from across the country, including youth ambassadors Ria and Hannah, who both have von Willebrand disease (VWD), met to launch this project. The group is developing tailored information for inclusion in the existing Talking Red packs and intends to form four Talking Red university groups.

This initiative fits seamlessly with work being done over the next three years by the European Haemophilia Consortium's Women's Steering Group, of which Christina Burgess is a member. So, if you are a young woman carrier or have a bleeding disorder, are at university or college and would like to get involved, Christina would love to hear from you! Please contact: christina@haemophilia.org.uk

Emma's experience

I'm Emma, and my experience as a woman with VWD is that many people are completely unaware that women can have bleeding disorders, and most have never heard of VWD. Talking Red is extremely important as it focuses on women and inherited bleeding disorders, helping raise awareness of their impact, such as on periods, family planning and relationships.

I'm lucky in having family support: with many relatives with VWD I've been able to ask advice and learn from them. However, I'm aware that not all women living with a bleeding disorder are this fortunate. Many don't find out they even have a bleeding disorder till later life and many don't know anyone else in the same situation. A campaign specifically targeted at young women of university age has great potential for awareness raising and education – not only with students but also the wider population. It could also help with diagnosing the estimated hundreds of thousands of women unaware they have a bleeding disorder and enable women with bleeding disorders to be introduced to others to share their experience and get support.



Inhibitors won't inhibit us!

Anne Wareing tells us what it's like to work with patients with inhibitors, while Louis Marlow gives his perspective on October's Inhibitors Conference

Anne – CNS, St George's Hospital

As nurses, we strive to give patients the best care we can but there are no easy answers with inhibitors. With patients with inhibitors, I have two opposing reactions – it's frustrating but rewarding! We don't have many products to offer and we know it's going to be quite a journey for all involved. And it's patients and families who do much of the hard work: dealing with treatments that take a long time to mix and administer, more frequent hospital visits, treating bleeds and maintaining venous access.

But we are able to spend more time with this patient group to try to resolve issues together. We're here to provide other levels of support – such as liaising with schools or the work place or putting families in touch with each other. And as new treatments emerge we aim to keep patients informed about what these may offer.

Having volunteered at The Society's activity weekends, I've been so impressed with how positive and courageous these patients are! Despite the challenges, they show us what is really achievable when living with an inhibitor.

Louis

As the inhibitor community in the UK is so small, the chances to meet others with an inhibitor and their families are few and far between, so thanks to everyone who made this conference possible.

It was especially good to meet other young adults – Jude, Zoe and Josh. We had a long chat about the transition period we've all gone through – particularly hard during teenage years. Having only recently navigated this period myself I know all too well that balancing changes in school or university life and trying to develop your independence as well as managing your inhibitor can be really challenging. I certainly wish my parents still organised my treatment deliveries anyway!

It was also interesting to hear the range of inhibitor experiences as haemophilia care has changed over the years, and comforting to remember others are going through the same experiences as me.



Living Well – Going Forward

Head of Membership Christina Burgess reflects on an event for people affected by HIV from contaminated blood

On November 26th we held an HIV AIDS information day. Titled *Living Well – Going Forward* it took place in Birmingham and was attended by a good number of people.

Having met with members during the ageing project throughout this year, it became apparent that there wasn't enough support available for those in our community affected by HIV AIDS.

We know members have had to live for many years not only with the physical aspects of HIV but also the psychological anguish experienced by many, including extreme isolation, particularly those who have lost friends, partners or family members to HIV AIDS. Its format – including the choice of sessions and expert speakers – was informed by what members had told us they would like to see.

The day didn't quite work out as planned and not all the sessions on cognitive behavioural therapy, improving nutrition, and living well with HIV as you age were what those attending needed on the day.

Changes were made and time given to enable those attending to express their thoughts and feelings and share their ideas on how we can support them better and shape future services.

Those attending included people infected with HIV AIDS by their haemophilia treatment, women infected by their partner and also partners of those living with HIV today. The nutrition session was particularly welcomed and provided useful information. The insight we gained into the issues many of you face will enable us to support you better going forward.

This event was the first step in developing the support you want and will always be in addition to our campaigning work that continues to seek justice and a fair settlement.

If you would like to be involved in future HIV AIDS services events or you know of others who might be interested, please get in touch with christina@haemophilia.org.uk

Treatment – looking into the future

Treatment for bleeding disorders has come a long way in the past 50 years. The latest is extended half-life factor (EHL), which may mean that some people can have factor infusions less often. Now there are more new approaches to treatment on the horizon. Research in this area is becoming ever more complicated and it helps to understand a bit about the normal process of blood clotting in the body.

About clotting

When you are injured, three main things happen in the body to stop bleeding from damaged blood vessels:

- each injured blood vessel narrows to reduce the flow of blood through it
- small blood cells called platelets stick to damaged vessel walls to begin plugging the bleeding
- proteins in the blood are activated to make stable blood clots and stop bleeding.

These proteins are the 'clotting factors' – the proteins that can be missing in bleeding disorders. Each clotting factor acts on others in a sequence of chemical reactions that end with a blood clot forming and plugging the damaged blood vessel. Because these reactions have to happen in turn, this process is known as the 'clotting cascade'. The system has to be very complex, so that blood doesn't clot uncontrollably, which could be life threatening.

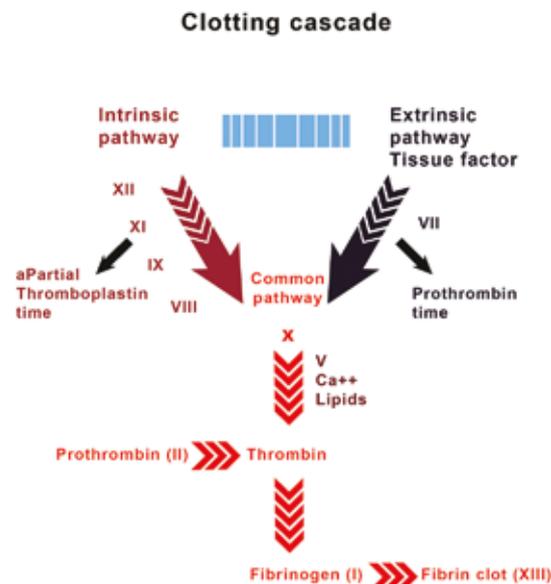
The clotting factors are numbered from I to XIII (1-13). Also important is von Willebrand factor, which helps platelets stick to damaged blood vessel walls.

As most of you will already know, factors VIII (8) and IX (9) are the factors missing in haemophilia A and B respectively. They are both very important in activating factor X (10), which leads directly to activation of the two most important clotting proteins, thrombin (factor II or 2) and fibrin (factor I).

The new treatments in development aim to get round the missing factors in different ways:

- by blocking manufacture of a protein that inactivates thrombin (RNA interference)
- by replacing the gene for the missing clotting factor (gene therapy)
- by replacing the role of missing clotting factors (monoclonal antibody therapy).

Here's a summary on how each area of research is progressing.



RNA interference

Collaboration between medical and pharma researchers has led to a new direction in drug development for haemophilia A and B. Doctors spotted different bleeding rates in people with apparently the same severity of haemophilia. Those with low bleed rates also had low levels of a protein called anti-thrombin. Others with higher bleed rates had high levels of anti-thrombin. Anti-thrombin is a normal part of the body's control of blood clotting. It works against another clotting factor, thrombin, to stop blood clotting.

Now a drug has been developed that can stop anti-thrombin production in the body. This exciting development is based on a Nobel prize-winning discovery. Scientists have found a way of blocking the action of a gene without affecting the gene itself. They use small snippets of a naturally occurring molecule called RNA to stop anti-thrombin being made. It isn't a gene therapy as it doesn't act directly on genes and there's no risk of infection as it's made entirely in the lab.

Early stage clinical trials are underway. You have the drug by injection under the skin (subcutaneously) once a month. Early results are very promising with very few side effects and good control of bleeding. The researchers hope it could become a leading treatment for haemophilia A and B in people with and without inhibitors.

Gene therapy

Gene therapy is an exciting area of research in haemophilia because it could potentially deliver a cure. In theory, one successful treatment to deliver a missing gene could mean that people no longer need any treatment with factor replacement (although the therapy wouldn't stop them passing on the haemophilia gene to their children).

Pharmaceutical companies are conducting research with people who have haemophilia A and B. The aim of the treatment is to put the correct instructions for making factor VIII and IX (the factor VIII and IX gene) into body

cells. The gene and its carrier are made in a laboratory. There is no risk of infection as no human tissue is used.

Early research trials with patients have already started, aiming to see how safe this treatment is and to find the best dose. The research is also looking at the bleeding rates of the participants after treatment and measuring how much factor replacement they need.

This is a single treatment you have into a vein (intravenously). Early trial results look promising and the researchers are already planning further studies.

Monoclonal antibodies

Another new area of research is using drugs called monoclonal antibodies. Antibodies are the targeting cells of the immune system. Monoclonal means all one type. Scientists can now make multiple copies of single antibodies in the lab and use them to treat diseases.

A monoclonal antibody to treat haemophilia A called emicizumab is now being tested. It works by doing the job that factor VIII would normally do. Because it replaces factor VIII, it may also be able to treat people with factor VIII inhibitors.

Emicizumab is another treatment that you have by injection under the skin once a month. The researchers say that early trial results show it's safe and has continued to work well for patients, some of whom have been having the treatment for two and a half years.

What's next?

While these are exciting developments, they are still in the relatively early stages of research. We will have to wait to see if larger clinical trials are successful and it will be some years before any of these treatments are likely to be available more widely to patients.

We have more information about all these treatment developments, and about the new extended half-life treatments at www.haemophilia.org.uk

Together we're amazing! 2016 AGM...

Welcomed by the city's Lord Mayor, on 5th November over 120 members gathered in Bristol for our AGM and conference



Treasurer Simon Mower began by picking out key points from the audited accounts and trustees report for 2014-2015:

- We have almost reached break-even point on in-year income and expenditure – a year ahead of plan while delivering more services and advocacy activity.
- We have robust reserves from legacy income, putting us in a strong financial position.
- With no government funding we are very reliant on pharmaceutical income, so we need to diversify our income further.
- We have a healthy community fundraising income, but need to increase regular and individual giving to provide a stable, secure income.

Services overview

CEO Liz Carroll gave an overview of our services and the 'seven key life stages' model – particular times when the lives of people in our communities change, leading them to seek information and support from The Society. She identified other groups needing particular focus, highlighting working with people with inhibitors and with women through our Talking Red projects.

A great debate

The final topic was a presentation and debate about our name and logo. We've been fortunate to receive free support following last year's request from members to consider changing our name to better reflect our diverse community. We outlined reasons for this, while recognising our name's importance to many and the need to respect our predecessors' incredible work.

After presenting a potential name and logo (see picture) we opened the floor to a lively debate. One clear message emerged: this name and logo need work to ensure the feeling of community, support and family is evident. Before closing, members were asked to vote on whether we should change our name, and on whether it should be to Bleeding Matters. The vote, including postal votes, was overwhelmingly in favour of a name change. The vote on whether this was the right name and logo was split almost 50/50, so more work is needed before a decision is made.



... and conference



Following the AGM we moved on to our conference, which began with leading haemophilia physio David Stephenson on preventing falls as we get older. This was followed by several breakout sessions with workshops to suit everyone. Three films about personal stories of living with haemophilia from across Europe were a stark reminder that not everybody has the access to treatment that they need.

Totally inspiring

We were also lucky enough to hear two incredible and inspirational speakers. Chris Moon lost an arm and a leg while clearing landmines for a humanitarian aid charity and is now an ultra marathon runner. Chris gave a frank and honest talk about how tough life can be, but showed us all that if you believe in yourself you can achieve something incredible. He suggested we all celebrate and be thankful for what we have and not be held back by the tragedy and injustice that may have affected our lives.

Celebrity supporter and champion cyclist Alex Dowsett, who has severe haemophilia A, followed Chris. Alex encouraged us to try every sport we can: being as fit and active as possible helps us stay strong and prevent bleeds. He believes bleeding disorders should never hold you back and that within reason most things are possible, particularly for the younger generation. Alex recognised that he's incredibly lucky not to have been affected by the terrible tragedy that impacted on so many of the older members of our community and makes the most of every opportunity given to him.

Time to party

After a closing question and answer session with Alex we left the room for a photo frenzy. On our return we found it transformed into a party venue to host the Buddy and Bangers Buddy Award party – a great end to a great day!

Aged 16-30?

Come and join us!



On behalf of our youth ambassadors, Laurence Woollard announces an exciting initiative

In 2014 I attended a patient network event at my haematology centre with the hope of meeting other young people with my condition. I guess I'd reached an age where I was open to sharing experiences and intrigued to discover more about bleeding disorders. This was when I was approached by The Haemophilia Society, which was recruiting youth ambassadors (YAs) – a unique role to represent the views and interests of my peers and encourage more young people to get involved in The Society. I said yes with some trepidation, without realising how life changing this decision would be.

Over the next two years it opened up new perspectives and opportunities, from advocating on behalf of young people with bleeding disorders at the European Parliament in Brussels to representing the UK at the WFH Congress in Orlando. Most importantly, I've made lifelong friendships with 'bleeders' from all corners of our community. This view is echoed by my fellow YAs – Luke, Ria, Rob, Hannah and Matt – who, up to now, have been the core group of young volunteers.

Now we have reached a critical stage of development. With support from the board of trustees, we want to build the youth movement by establishing a nationwide programme that gives highly engaged, motivated and socially active 16-30 year olds with bleeding disorders a voice on decisions and matters that affect them. We want to prepare and inspire young people to make a difference and become catalysts for change in their local regions, while developing The Society's next generation of youth leaders through a comprehensive training, mentoring and support strategy.

As a first step, in early 2017 we will be publishing a survey to get to the heart of what matters most to young people in our community and to gauge interest in becoming a youth member.

If you have any questions or want to get involved in the youth programme, please contact The Haemophilia Society on 020 7939 0780 or email info@haemophilia.org.uk

Policy and campaigns update

Our campaigning and public affairs work has continued to focus on contaminated blood support and welfare reform. We've improved our engagement with government and parliament through our lobbying and through campaigning groups such as the Disability Benefits Consortium.



PIP assessment

We are still working on many members' concerns, including responding to the call for evidence on PIP assessment. The Work Capability Assessment doesn't take into account the fluctuating impact of a bleeding disorder and the preventative adaptations members make to reduce the likelihood of bleeds. We've also pushed for greater co-ordination between the Department of Health (DH), DWP, local authorities and where appropriate the Alliance House organisations.

Contaminated blood support

In the summer the government announced the changes to contaminated blood support. While there are increases in the non-discretionary annual payments for all primary beneficiaries these are expected to be offset by reductions in other support payments for many.

Groups such as bereaved partners and parents, dependents, people infected with other viruses or those who didn't reach the chronic stage of hepatitis C infection have been overlooked entirely or will see their support reduced.

The Society has engaged with DH officials through the infected blood reference group. This has enabled us to provide evidence on the health impact of hepatitis C to improve the

special appeals mechanism. We've also been able to respond to the draft new discretionary support principles.

It's been confirmed that the new annual payments for people with stage 1 hepatitis C will be made by 22nd December. Other beneficiaries should expect new payments to be made early next year, though this is still to be confirmed.

We continue to work with the DH to improve the communication with beneficiaries on the changing support scheme and want them to work more closely with haemophilia centres to promote the support available.

What's coming up?

Over the next six months our priorities are to continue to represent the needs of the affected community on the infected blood reference group and push for more parliamentary scrutiny of the reforms through an upcoming debate. We will respond to the government's recent green paper on work, health and disability and press for improvements to PIP assessment.

We welcome feedback on issues we should be raising as well as case studies or evidence to support our work. Email jeff@haemophilia.org.uk if you can help or have further questions.



The iron man

Clive Smith recounts how one challenge leads to another... and another... and another

Growing up with severe haemophilia A in the 1980s meant that prophylaxis wasn't an option until I was about nine or ten. Like so many, I had target joints: first my left elbow then my left ankle. My ankle rendered me unable to walk – usually three weeks out of four. I was either on crutches or in a wheelchair.

I now have severe arthritis in my left ankle and I can't straighten my left arm fully. Prophylaxis however changed my life. I finally felt 'normal' and able to walk again on a regular basis.

The memory having faded, a few years ago I decided to try running. But after a few months my ankle was so painful I couldn't walk for three weeks. Undeterred, I started strength work in the gym. Over a period of time I built up enough strength that I could run 10km. From there I progressed to a half marathon. My

physiotherapist warned me not to get any ideas about a marathon. Even 'normal' people aren't built to run those he said!

Curiosity got the better of me and in 2014 I completed the Brighton Marathon for Great Ormond Street Hospital in 3 hours 17 minutes. That was only the start though. My main goal for 2014 was to complete Ironman Zurich – a 3.8km swim, 180km bike ride and 26.2 mile run (a marathon) at the end. I finished in under 12 hours. Last year I completed Ironman Copenhagen an hour quicker. Next year I plan on finishing Ironman Frankfurt.

Cycling and swimming are obvious choices for people with bleeding disorders, but don't overlook running. Done sensibly it is just as possible. After all, we never know what we are capable of unless we try.



Driving through the decades

John Buckley from Somerset sent in his memoir of a campaign of 50 years ago that was a factor in the eventual development of the Motability scheme

It was the early 1960s when I, and many other young men with haemophilia, moved to Oxford to benefit from the developments in treatment led by the Oxford Haemophilia Centre.

Travelling on public transport was not at all easy or safe. My first cars were a series of bangers, and, unable to afford servicing and repairs, I did much of the work, injuring myself on a number of occasions. In 1964, when my money ran out, I acquired an invalid tricycle. However, its heavy tiller bar steering required upper body strength and didn't suit my vulnerable elbows.

When I first moved to Oxford I stayed with Peter MacBryan, who also had haemophilia, and his wife Celia. Having lost both legs, Peter began a campaign to persuade the government's Ministry of Health to issue small cars instead of invalid tricycles to people with haemophilia. Together, we co-authored *The Haemophiliac and the Invalid Tricycle*, a report published by

The Haemophilia Society in 1966. It received widespread support from The Society's medical advisory panel, the press and members of parliament, and was revised and reissued the following year.

The Ministry of Health had already conceded the provision of 'Ministry Minis' to disabled couples and disabled mothers with children. Our case to government was finally accepted in 1968, and so later that year I exchanged my trike for the first of a series of automatic Morris Mini Minors. It was a tight squeeze going on family holidays as our children reached their teens!

In 1990 I leased my first car from Motability, and after a series of Vauxhall estates, took out my ninth lease last year. I am now 76 and can't say enough in praise of the scheme which has provided so many of us with safe, reliable, carefree motoring, and has contributed so much to my personal health and wellbeing.

WFH Congress 2016



Youth Ambassadors Ria Peake and Rob Barnard report on July's WFH Congress

This summer saw 7,000 delegates of the bleeding disorder community venture to Orlando, Florida as it played host to the biennial World Federation of Hemophilia conference.

The conference, held over five days at the extraordinary Orange County Convention Centre, welcomed the community to share successes, spread new ideas and unveil innovations. As youth ambassadors we had the privilege of representing the UK on an international scale; an opportunity we'd been looking forward to since beginning our roles.

Despite the many people at this event who had experienced terrible misfortune with regard to joint and internal bleeds, the atmosphere was extremely positive and joyful. When discussing how fortunate we are with access to treatment in the UK, the response was genuine positivity and enthusiasm for us; this supportive spirit gave the event a lovely familial vibe and is what truly makes us a community.

Sessions ranged from hearing the personal stories of some incredible people (including our own Zoe McGough) to information about the development of innovative treatments. We were lucky enough to visit Epcot (Disneyworld) for the traditional cultural event, which saw many of us dancing the evening away (rather questionably!).

We concluded our time at the closing ceremony, a time to say goodbye to friends made over the days. However, a feeling of great excitement ensued as the sound of bagpipes filled the room and we saw Chair Barry and CEO Liz receive a handover from their American counterparts. The night ended with reflections on an extraordinary conference and again, some rather questionable dancing!

With Glasgow 2018 on the horizon, it will soon be our turn to welcome our wonderful global family. We will be showcasing the best of British, and we hope you will all come and share it with us on May 20th-24th 2018 at the Scottish Exhibition and Conference Centre, Glasgow.



WFH Congress 2018 in Glasgow

With Congress 2018 fast approaching, Liz Carroll says it's a fantastic opportunity for members

In 2018 we will be the host nation for the World Federation of Hemophilia Congress, which will be held in Glasgow from 20th-24th May. This is the biggest meeting for the global bleeding disorders community and we anticipate welcoming between 5,000 and 7,000 people from across the world.

This is an incredible opportunity for our members, healthcare professionals, scientists, economists and anyone else you can imagine who is involved in the bleeding disorder community to come together, share their experience, learn from each other and make lifelong friendships.

How you can be involved

As the host we're in the privileged position of being able to help shape and deliver the congress, as well as take part. To ensure the congress runs smoothly and that our friends and colleagues from around the world are given a warm welcome and leave with fantastic memories we will need lots of volunteers to

welcome them, help them find their way around and understand our unique culture, and leave saying it's been the best congress ever.

We also hope over 1,000 delegates from the UK will attend, as this is a unique opportunity to meet others from around the world living with a bleeding disorder. It's also a chance to understand what research is showing us about the future of treatments, living well and how nursing and physio care is advancing to enable you to live your life to the full. You will also have the opportunity to meet friends from around the world and understand how their bleeding disorder impacts their life.

So this is where we need you! As we get closer to the date we will be seeking volunteers for a variety of roles and offering free places to attend the congress and be part of something incredible. Please put the date in your diary now, and encourage your healthcare team to attend too. Together we can make this a truly memorable congress!

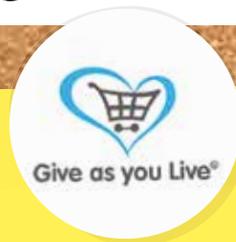
Fundraising – how can you get involved?



Does your employer support charity?

One way you can support us might be to get employers (yours, your friends' or connections') involved in our work. Most companies support charities, either locally or nationally: some choose a charity to support for the whole year while some will do events.

Our work as a charity covers all aspects of local and national support. This support can be adapted to each organisation, from small to large companies, and no matter what the event, we're always happy to help!



Want to donate from your armchair?

Did you know you can raise money for The Haemophilia Society when buying gifts, food and decorations this Christmas without it costing you a penny extra? Well you can, just by shopping online via Give as you Live. Please go to www.giveasyoulive.com/join/haemophiliasociety – and start shopping!



Individual Giving – it doesn't have to be an arm or a leg...

Some people are never going to run a marathon, parachute out of a plane or stand outside a railway station shaking a bucket. If this is you, there are still plenty of ways you can help.

How about donating the cost of your large hazelnut latte each month directly to us via our bank account? Or foregoing a takeaway and donating the amount you would have spent to support our work? Giving £5, £10 or maybe more each month via standing order or direct debit from your bank account would make a world of difference. For a standing order form please email fundraising@haemophilia.org.uk or call us today. Every little helps!

School fundraising

Starting school when you have a bleeding disorder can be a daunting challenge for children and their families. We work with parents to provide information and support to schools to make the transition as easy as possible: if schools have the right information they can be an immense support.

Getting information out to the staff and other families at the school can be done in the most creative ways – and raise some vital funds for our charity at the same time! Some schools have held 'wear red' days or 'superhero days' for their children with bleeding disorders – what better way to start a conversation with other parents? For a schools information pack or to speak to someone about fundraising at your school email events@haemophilia.org.uk or call us on 020 7939 0780.



Alex Clark holds an annual golf day: this year's has raised an amazing £4,430 so far. Alex's son Archie is pictured with his sister Elle at the event's face painting station.



Our London to Brighton cyclists did brilliantly back in September. Pictured here are Gabe Heskin, Paul Murchan and Dom Donoghue (who as a team raised £1,353.25) and Amanda Baker (who raised £1,211.25).

You've done it again!

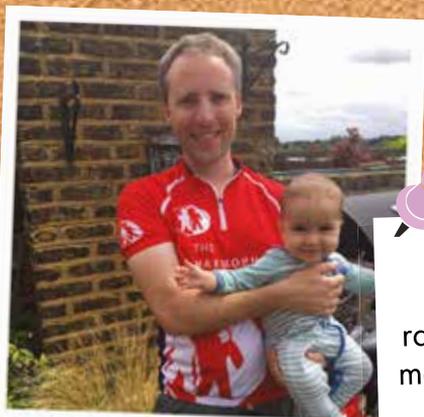
Once again we want to celebrate the efforts of our tireless fundraisers – a huge thank you to you all!



Hannah Brunning and her friends organised a sponsored spin class. Forty people joined the spinathon, raising £887.50!



We had a team of six runners in this year's Royal Parks Half Marathon on 9th October – a first for our charity and an amazing start to an incredible event! Father and son team Nick and Charlie Ashe have raised £3,973.75, Jessica Keegan has raised £570, Sarah Carrol £540 and Sarah Freeman £593 (all pictured). Andrew Vial (not pictured) raised £621.47.



In July Duncan Keysell took part in the 100-mile RideLondon Cycle Challenge, raising £1,866.25 – a wonderful achievement! Duncan is pictured with his son Raffy who has severe haemophilia A.



The importance of information

Our latest booklets and fact sheets are a great hit with members, health professionals and schools

Getting up-to-date and accurate information out to members and the wider community is an essential part of our work. Our two most recent booklets have gone far and wide, so we hope that you've already seen them – perhaps at your treatment centre?

Managing school when a child has a bleeding disorder has been very well received, together with its accompanying A3 poster describing the signs of a bleed and what to do should one occur. Mum Jane wrote: 'These have been so helpful, not only to me as a mum, but to my son's teachers. We all feel more confident and knowledgeable.'

The second booklet, *Understanding von Willebrand disease*, has flown off the shelves so fast we've had to order a reprint! Again, feedback has been very positive. Clare, who has VWD, told us: 'The booklet is very good and I would have loved to have read it years ago!'

Our newest publication, *Understanding haemophilia*, is with the designers and will be available shortly to download from www.haemophilia.org.uk or to order in print.

This booklet gives a general overview of haemophilia A and B. Written for people directly affected by haemophilia and for anyone interested in learning about haemophilia, we hope it will answer your main questions. It's also an ideal introduction for anyone whose child has been recently diagnosed, which we know can feel quite overwhelming at first. The booklet's clear and concise content aims to provide parents with useful, up-to-date information that will stand them in good stead in their child's early years leading up to school.

In addition, we've recently published two fact sheets on the new extended half-life (EHL) treatments: *Extended half-life (EHL) factor XIII* and *Extended half-life (EHL) factor IX*. We've also updated our travel insurance and PIP fact sheets. You can download all of these from the treatment section of our website at www.haemophilia.org.uk

For more information about any of these publications please contact info@haemophilia.org.uk

Meet, learn, share and more... member events 2017

In 2017 we'll be building on our established events, for example with a Youth Weekend, which we hope your children and teenagers will attend. We're also lowering the minimum age for all our youth weekends to six years old. For this age group, and for older children attending for the first time, parents can come too. Taking place near London, the year's first Youth Weekend will feature a very special sports day. Children of all ages will be able to

try out all kinds of different sports, so do encourage them to come along!

New developments to support you in the coming year will include a carers' conference and a family day for those with older children and teenagers. If you or your family would like further details or to come along to any events, please contact Christina or Victoria in Membership (christina@haemophilia.org.uk or victoria@haemophilia.org.uk).

Fit for fundraising? Runs, rides and obstacle races 2017

February

26th: Thorpe Park Half Marathon, Surrey

March

5th: Paris Half Marathon

12th: North London Half Marathon, Wembley

26th: Rocksolid Race – Exeter, Obstacle Race (5K, 10K and 20K)

April

1st: Supernova Run (5K), London

2nd: Lincoln 10K

2nd: Manchester Marathon

8th: Spartan Sprint – London, Obstacle Race (5-6K), South East London

9th: Brighton Marathon

9th: Yorkshire Half Marathon, Sheffield

May

1st: MK Super Hero Run, Fun Run, Milton Keynes

14th: Leeds Half Marathon

21st: Spartan Sprint – Gloucester, Obstacle Race (5-6K), Ashton Down

27th: Edinburgh 5K

28th: Edinburgh Marathon

June

4th: Burnley 10K

17th: Toughest – London South, Obstacle Race (8K), West Sussex

18th: Glasgow Men's 10K

24th: The Gauntlet Games – London, Obstacle/Fun Run (5K, 10K)

July

10th: British 10K, London

22nd: Spartan Beast – Edinburgh, Obstacle Race (19-22K)

22nd: The Gauntlet Games – Cardiff, Obstacle/Fun Run (5K, 10K)

22nd-23rd: London Triathlon

23rd: Spartan Sprint – Edinburgh, Obstacle Race (5-6K)

30th: Ride London 100, London and Surrey, 100-mile cycle

August

5th: Bear Grylls Survival Race – Cambridge, Obstacle Race (5K and 10K)

12th: Mudnificent7, Obstacle Race, Warwickshire



THE
HAEMOPHILIA
SOCIETY

'What a fabulous day we had at the AGM and conference, topped off by the Buddy Awards. We had no idea the charity had come so far in the last three years. Thank you for being amazing and giving us a fabulous day; it's never easy to entertain babies, teenagers and adults in a day and you did it! I feel so much more positive about our family's future, bleeding disorder and all. We will be coming to many more events.'

Your Society: getting in touch

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.

The Haemophilia Society

Willcox House

140-148 Borough High Street

London SE1 1LB

Freephone: 0800 018 6068

Reception: 020 7939 0780

Email: info@haemophilia.org.uk

 [HaemophiliaSocietyUK](https://www.facebook.com/HaemophiliaSocietyUK)

 [HaemoSocUK](https://twitter.com/HaemoSocUK)

www.haemophilia.org.uk

Registered charity no. 288260 (Scotland SC039732)

Company limited by guarantee reg. no. 1763614

Members of the European Haemophilia Consortium and the
World Federation of Hemophilia

Chair: Barry Flynn: barry@haemophilia.org.uk

President: Baroness Molly Meacher

© The Haemophilia Society 2016

The content of HQ is for general information only. If you are experiencing symptoms, or you are concerned about any of the issues raised in the magazine, we advise that you consult your doctor.

Thanks to our corporate sponsors who provide valuable support:

Abbvie, Bayer, BPL, CSL Behring, Gilead, Grifols, LFB,

Novo Nordisk, Octapharma, Pfizer, Shire, Sobi

Copies of The Haemophilia Society's commercial funding guidelines are available on request.