

For everyone affected by a bleeding disorder

HQ

The Haemophilia Society magazine

Summer 2016 edition

Summer's out!

Life stages – perspectives on our services

Members share new treatment experiences

Summer fundraising appeal

Buddy Awards are back!

On wheels and water – members' stories



Welcome to HQ!



It's summer again, and hard to believe it's a whole year since we were celebrating our 65th birthday with many of you at the fabulous arts weekend in Leeds.

As you will see, as well as campaigning on behalf of our members we've been busy developing our existing services and creating new ones. We've had really positive feedback and hope you'll be able to join us at some of our events and services in the coming months. We know how difficult it can be to juggle life, a bleeding disorder and being away from home (or sending your child to a youth weekend, away from you for the first time), but we hope we can entice you to come along. We always have a wonderful time with lots of laughter, and the friendships nurtured when we get together last a lifetime.

We also want to thank and celebrate the amazing achievements of our members who have raised money for us. You've baked cakes, dressed up, run marathons and cycled miles! Without your support we couldn't do what we do, so thank you!

As HQ lands on your doormats, staff members, youth ambassadors and trustees will be in Orlando, Florida at the World Federation of Hemophilia Congress. This is a hugely exciting opportunity for us, especially as we will be hosting the next Congress in Glasgow. Our Congress will be 20th-24th May 2018 – so save the date now! We hope to welcome some 7,000 people with a bleeding disorder from around the world and hope as many of our members as possible will join us, either as volunteers or just to attend the conference, meet old friends and make new ones. If you've ever been to a Congress you'll know what an incredible experience it is to be with so many people who totally understand, learn about new developments in treatment, care and support, and feel part of the global family. If you haven't been before, this is a perfect opportunity!

Liz Carroll, Chief Executive,
The Haemophilia Society

A whirlwind start!

Chair of The Haemophilia Society Barry Flynn looks back on his first nine months in the hot seat...



Well, what a whirlwind it's been! My role began with a bang in late October 2015. Within a month I had taken part in the AGM and met and shaken hands with as many people as I could; spent time with members of our community and specialists from all over Europe; learned about the work of the European Haemophilia Consortium and World Federation of Hemophilia; and gained an appreciation of how the UK landscape comes together around the bleeding disorder community. And that's not to mention meeting local group members, volunteers, youth ambassadors, pharmaceutical companies, treatment centres, regulators and government.

Working with and getting to know The Society's staff, along with my fellow trustees, has been a real privilege. They are a small but dedicated team who work hard in the best interests of the community. I'm sure that getting me up to speed has involved counting to 10 more than once!

Speaking also as someone with haemophilia my initial impressions are threefold:

- While things in the UK are challenging and injustices persist, we are relatively fortunate

compared to most people with bleeding disorders around the world, where lack of provision or recognition leaves young joints chronically damaged and life chances blighted.

- Many committed people, locally and nationally, are working to improve the lives of people with bleeding disorders and their families. Resourceful and resilient, they deserve all the help and support we can give.
- The phrase 'there are none so deaf as those that do not want to hear' could have been written for the Westminster government – past and present. Since losing my brother and sister-in-law to HIV, my feelings on this have run the whole gamut, from grief to anger to disbelief, and from frustration to determination to influence the best outcome practically possible.

To sum up, I've met inspirational people, been frustrated by government and learned much. It has all been hugely rewarding and has sharpened my appetite to put as much into the role as I can in the years ahead.



More than a weekend break!

Hannah Brunning, mum of two-year-old Jake, reports on her family's experience at our weekend for newly diagnosed families at Longleat Center Parcs back in March.

Jake was diagnosed with severe haemophilia A at eight months old. A complete shock! The past year has been a whirlwind, learning as much as possible about the condition, getting his port fitted and learning to administer his prophylaxis at home. It's also been an emotional rollercoaster coming to terms with this life-changing condition.

The weekend for families with a newly diagnosed child came at exactly the right time for us. It gave us the opportunity not only to take time out as a family and reflect on the past year, but also to have a break – and some fun!

We met so many lovely families who shared their experiences with us. For the first time since Jake's diagnosis we didn't feel quite so alone.

Sessions were informal and interactive with plenty of opportunity to ask questions and discuss relevant topics. It was truly inspirational to meet Laurence, one of the charity's youth ambassadors, and a paediatrician, who both have haemophilia. Yes, they've had some tough times, but most importantly they are living life to the full and not letting haemophilia stand in their way.

On day one we already felt better! We came away from the weekend with lots of 'tips', more knowledge, new friends and a network of support. We now feel so much more confident and positive about the future for little Jake – and our family!

It was an amazing weekend and an experience we would thoroughly recommend to any family embarking on this journey.

Claire Fearnley echoed Hannah's thoughts: 'Thank you so much for a lovely weekend! Andy and I came away with such a positive attitude about Thomas' future. The experience was invaluable to us and after a rough few months it really was just what we needed.'



Staying safe at school

New booklet: Managing school when a child has a bleeding disorder

When any child starts or changes school, at whatever age, it can be a difficult time for their parents. For parents of children with bleeding disorders it can be even more so. So in response to many requests we've produced a booklet that can be used by you as parents, as well as being a useful tool for staff at your child's new school.

This new resource aims to help you work with school staff to create an appropriate care plan to meet your child's specific needs. It focuses on the most common bleeding disorders (haemophilia and von Willebrand disease), though any action schools need to take will be similar for all bleeding disorders.

Most teachers will never have come across a child with a bleeding disorder. They will need guidance and support to feel confident about meeting your child's needs while at school.

As parents of children with bleeding disorders, you know how to plan for both the obvious and the unexpected. The booklet emphasises that mums and dads, and often children too, are the experts. For everyone involved, the desired outcome is a happy, healthy and safe child and confident school staff who know enough to act appropriately and seek advice when they need to.

As one parent advises: 'I would say that excellent communication is key. When my son started primary, I discussed his condition with the reception teachers and the teacher who felt most confident with the condition volunteered to have him in her class.'

The information has been checked for medical accuracy by our Clinical Advisory Group, and reviewed by parents on our Reader Panel and some mums and dads who attended one of our weekends for newly diagnosed families. They all found it useful, informative and easy to read. We hope you do too!

Download your free copy from www.haemophilia.org.uk or get in touch (see back cover) to order one.



Volunteering is a privilege

Haemophilia nurse Cathy Benfield has no regrets about giving up her weekends to volunteer with us.

Whenever I see Christina's name (The Haemophilia Society's head of membership and planning) in my email inbox I hold my breath... as it usually involves me volunteering (well, that's what she calls it) to be knee deep in mud, suspended on a high wire or cooking marshmallows around an open fire in the freezing cold! These are some of the fantastic activities the children and volunteers on the Youth Weekends get up to. However, that's only half the story. The real success of these weekends is in seeing each of the youngsters flourish: the independence they experience, the opportunity for informal learning that takes place

while watching others self-infusing or receiving treatment, and the long-term friendships made. It's such a joy to witness the natural support, understanding and care they all show each other.

As a nurse, it is important to know that my patients are in safe hands (often this is the first time a child has been away from their family) and for me to understand how much they gain from the weekend. Whether a young person with a bleeding disorder, a sibling or healthcare professional, not only do we all have a great time but we all learn something new. I take it back... Christina, it's a privilege to be asked!

Hayden's mum Julie said: 'Hayden had an amazing time – thank you! He hasn't stopped talking about it since he got home and he made some great new friends!' And Eesa and Isma-Daisy's mum Sadia agreed – they too had an amazing time.



Talking Red

My name is Hannah, I'm 26, a proud Lancastrian living in London and working as head of business and economics in a school.

Haemophilia first came into my life when my younger brother Jack (a celebrity ambassador for The Haemophilia Society) was diagnosed at eight months old. It would be another 12 years until my diagnosis as a carrier was confirmed.

I've always known we were a little bit different. For example, I've always bruised more easily than my friends and my periods have been a nightmare. But I didn't know this meant that I could be a symptomatic carrier until I attended the Talking Red Conference last January.

Beforehand I was both nervous and excited. For the first time I'd be meeting with young people in the same position; so also for the first time I'd be faced with the reality of being a carrier. I needn't have worried – I found I could air my fears and speak freely about my parents' experiences with my brother. I also met people who had had children recently – children accessing the

latest treatment and living lives that were much more normal compared to my memories of Jack as a child. It was an amazing day – I'd recommend that all young women and their support networks attend.

In the next couple of years I'd like to get married and start my own family – a daunting prospect for someone carrying haemophilia. But I have an incredible partner in David and my support network includes my fantastic mum and dad, who made sure that haemophilia wasn't a barrier to Jack's opportunities or his success. And of course there's Jack too, my everyday inspiration.

I'm less nervous about my future now. Knowing other women going through the same experiences who I can ask for advice, as well as about treatment advances, means I have a much more positive outlook. I can't wait to see what happens next!



Ageing well

Bill Payne and Linda Wild, both in their mid sixties, reflect on ageing with a bleeding disorder.

Bill

What's it like growing older with severe haemophilia B? To be honest, my haemophilia is well controlled with prophylaxis every other day. I've had a PICC line in place for some time, making treatment much easier to administer; and with due care taken at all times, infection hasn't been a problem. A big thank you to the haemophilia team – long may it continue.

As for general health issues, I have high blood pressure, water retention – the usual things that can affect older people. But put together with haemophilia, it gets more interesting. The mention of the 'h' word means that common issues for the practice nurse get passed to the GP – which can mean a wait for an appointment. And if something rightly needs referring to hospital, that's another wait. I'm lucky to have a really good relationship with my healthcare team.

I don't feel any older, though I must be as I'm a proud husband of 45 years, dad and granddad. I've given up smoking, I'm a school governor, adviser to Bristol's Disability Equality Forum and active in my local Labour Party – all of which keeps me mentally fit, if not completely physically so. The future remains to be seen, but with the love and support of those around me getting older is just another of life's little adventures!

Linda

During my life I've been careful and made allowances for my von Willebrand disease without restricting myself too much. The support network around me is a credit to all the medical staff involved. My family, friends and colleagues make my life much richer for their understanding.

As you get older, with the right care and support and limiting yourself to what is right for you, there's no need to feel negative. I feel more positive than ever – especially now we're in touch with The Haemophilia Society, as my husband and I feel we've joined a big, happy family!



Life with an inhibitor

If you have an inhibitor, or are a parent to someone with an inhibitor, then you are part of a very rare group within a rare community! And one that requires additional support. Two members of our inhibitor community tell us about their experiences.

Zoe

Hello, I'm Zoe McGough, I'm 16 and have factor VII deficiency and an inhibitor. I got an inhibitor very shortly after I was diagnosed aged seven. At first it caused a lot of issues, as it was very high. When I was treated with rituximab, this reduced the level of my inhibitor considerably, making life much easier. Having an inhibitor means I need to go to hospital more often than someone who doesn't have one, as I need my levels checked regularly to monitor it. We try to control it by being on factor VII replacement twice daily.

Stephanie

Stephanie, mum of a three year old with severe haemophilia and an inhibitor writes: 'Since we found out our son had an inhibitor right before planning our holiday when he was about eight months old, life has been challenging for our family. Mostly we let him get on with being the active little boy he loves to be, but sometimes it can be hard telling him not to do things he sees other children doing. As a family we've adapted our lifestyle to his needs and try to do the things that make him happy.

When we deal with his bleeds in joints and muscles it can be tough on the family, especially since we are all very active and have a younger child who is too small to understand the two, three or four-hourly treatments our little boy needs to get him feeling better.

Living with an inhibitor has taught us to value life – and the importance of the treatment we receive. Until some miracle happens we are content to deal with our little boy's inhibitor as part of his life that is just as much a part of ours.'

New treatments

As we enter a new era of treatment, particularly for haemophilia and hepatitis, we wanted to share some members' experiences...

New treatments for haemophilia include factor that lasts longer, potentially reducing the number of treatments needed each week. We hope that several of these treatments will soon be available here, including 'extended half-life' (EHL) factor VIII and IX. Trials have shown a significant increase in the number of days between treatments for factor IX, with a lesser effect for factor VIII, though members are very positive about the impact these have had.

Ed: 'Cutting my haemophilia prophylaxis injections down from every other day to every five days has had a real impact. Injecting has become a non-event, whereas it used to be the "elephant in the room". I'd say definitely ask your haematologist about it – it's been really good for me.'



Sarah Jane and Henry: 'Since starting EHL prophylaxis, my two-year-old is able to be a "normal" little boy. If other mums were thinking about this for their kids, I'd say don't hesitate to ask your doctor. It's a no-brainer – more peace of mind, less pressure on friends and family and fewer injections.'



Steve: 'The key things it's given me are confidence and reassurance. I can be more active, stay out for longer and go on holiday with less worry. If anyone asked me whether to switch to this treatment – especially younger patients – I'd say yes, without hesitation.'

Better hepatitis C treatments

Older members infected with contaminated blood in the 70s and 80s are having treatment for hepatitis C with a new generation of drugs. We know how difficult the early treatments were and that some may be anxious about having more, so we thought it might be helpful to share a member's experience of this too. Overall, people tell us that the new treatments are significantly easier to get through, and although there are still side effects, they are nothing like they were before.

Dave: 'I had treatment for hep C with Harvoni, together with ribavirin. Side effects included nausea, which subsided, a splitting headache daily, relieved with paracetamol, and tiredness. But after just two days of treatment, my energy levels increased enormously; I felt so much better. By week four the virus was undetectable, and it has remained that way.'

Read the full stories online at www.haemophilia.org.uk/yourstories

Save the dates!

Together we are amazing

**Please join us at
The Haemophilia Society AGM and Conference
Saturday 5th November 2016
Bristol City Centre**



Featuring the Buddy Awards (see page 19)

We will be holding our AGM and conference in Bristol on Saturday 5th November and hope as many members as possible will join us. Having had two very successful years we know this will be even bigger and better! There will be special activities for children and young adults, as we know the Buddy Awards will be a huge attraction. Whatever your bleeding disorder, age or connection to us, we know you will have a wonderful time. When we come together amazing things happen!



Create

Central London

Saturday 3rd – Sunday 4th September 2016

Join us at our fabulously creative weekend for the whole family!

Whether you love to be centre stage or prefer to hide away there will be something for you! We will be singing, drawing, writing creatively, dancing, filming and much more. A perfect opportunity to have fun with other members of our community, try out new skills and form friendships that will last a lifetime. Get in touch now to book your free place! (Contact details are on the back page.)

Raising the bar

A huge thank you to everyone who has raised funds for us – here's a selection of your amazing efforts!



Our Virgin Money London Marathon team – 24th April 2016. Pictured L-R: Bertie Berger, Stuart Card, Shafique Ladha, Steve Austin, Anne Wareing, Jake Sheader, Graham Pudney. Not pictured: Danny Watson, Ian Turner and Mike King. The team has now raised an incredible £28,120!



Sam Royle (pictured far right with her team) held a pyjama day at work, raising an impressive £110!



Sarah's tea and cake afternoon to support World Hemophilia Day raised almost £3,000!



[Above] L-R: Shafique Ladha, Tilly Gaunt, Duncan Gordon-Smith, Anne Wareing and Robert Dulac.



{Below} Back L-R: Victoria Foster, Dominic Donoghue, Oliver Donoghue, Laura Butcher, Marta Calado and Puvan Suppiah. Front: Rory Donoghue.

A team of 17 runners took part in the Santa run last December, raising £2,500! Our team included one of the youngest runners to take part in the 5km – eight-year-old Rory Donoghue. Brilliant Rory – what an incredible achievement!



Heather Coates took on the challenge of the Yorkshire Three Peaks, raising £155.



Claire Dillon-Thistleton's efforts in the Windsor Duathlon raised £607.



Helen Rogan raised £485 by taking part in the Port Sunlight 10km Run in Liverpool.



Harry Yates and his team at Say Communications decided to do something different for the London Marathon this year and walk the distance as a relay! Pictured is the team before they set off. They have now raised £417.



Amy Vaughan ran the Brighton Marathon for us this year and raised an incredible £1,227! Amy is pictured with boyfriend Anthony White who is supporting us by taking on an Ironman Challenge later in the year.

Summer is the perfect time for running, cycling, cocktail evenings and tea parties – whatever you'd like to do to raise vital funds, we're here to support you. If you'd like to take part in one of our events or hold your own, give the fundraising team a call on 020 7939 0780 or email events@haemophilia.org.uk

Wellies in Wales



Read what youth ambassadors Ria and Matthew learned on a chilly weekend back in February.

Attending the Youth Weekend in Wales from 12th–14th February as youth ambassadors presented us with the opportunity to see how invaluable it is for a group of young people all affected by a bleeding disorder to come together. Over the course of the weekend the kids and teens enjoyed activities outside the usual scope of experience, such as abseiling and a high ropes course. We were immediately able to see the positive impact this had in terms of increasing the young people's confidence and developing foundations for new friendships to blossom.

Another aspect it's important to reflect on is the presence of youth ambassadors at these events. As the haemophilia community is a small one for many, there is sometimes little interaction with others with similar problems and looking up to the older generations who have sadly suffered can be daunting. We felt our being

there created a sense of reassurance because the kids could look at us and know there is nothing to worry about – they can see they have the ability and opportunity to live a 'normal' life.

We had several conversations about the impact of a bleeding disorder on a young person going into adulthood. It seemed reassuring to both the parents and the young people that we had managed our conditions in a way that allowed us to progress into our desired career paths and continue to part take in activities we enjoy. In particular, the kids and teenagers viewed us as people they could relate to and look up to. This meant they felt able to talk about their worries and concerns and ask us the questions that they felt too embarrassed or uncomfortable to ask their parents or doctors.

Great opportunity in Europe



Youth ambassador Laurence Woollard recounts his experience as an intern at the European Patients' Forum in Belgium.

As I write, I'm seven weeks into a three-month traineeship with the European Patients' Forum (EPF) based in Brussels. The EPF is an umbrella organisation that represents the interests of patients living with chronic conditions across Europe, including haemophilia. Their vision is to ensure that the European patient voice is at the centre of the healthcare debate, none more so than the perspective of young patients.

In 2011, the EPF established a Youth Group made up of young patient representatives between 15 and 29 years old from all over the EU to recognise, understand, meet, and effectively represent the needs of young people with chronic conditions through active engagement and empowerment. Thanks to the unwavering support from The Haemophilia Society and endorsement by the European Haemophilia Consortium (EHC), a member of the EPF, I've been fortunate enough to move to the

Belgian capital and support the growing momentum of the Youth Group, with the intention of implementing my experiences to strengthen The Society's youth capacity in the UK.

Being here is giving me invaluable knowledge and insight into young patient advocacy work on an EU level and understanding of the relationship with key stakeholders. Most recently, I facilitated a workshop on young people with chronic conditions accessing the job market at the European Parliament in Strasbourg. This was part of the European Youth Event; a unique two-day platform attended by more than 7,500 young Europeans to discuss the continent's most pressing issues. I am too aware as someone with haemophilia of the difficulties, stigma and discrimination our young community may face finding employment and I'm keen to focus on this important topic with my fellow youth ambassadors.



A sailor's life

Ben Randall competed in the annual Clipper Round the World Yacht Race...

I have mild haemophilia A and chronic osteoarthritis in both ankles. I also contracted hepatitis C through contaminated blood products when I was very young.

At 39, having recovered from treatment in a medical trial that successfully cured my hepatitis, I was feeling a bit lost in life. Then, in late 2013 I stumbled on the Clipper Race and a seed was sown.

This is a 40,000-mile race in a 12-strong fleet of 70ft racing yachts. Designed for amateurs, no experience is necessary! I wasn't a sailor, but the adventure appealed – was it a way to get my mojo back?

After an interview and discussions between the Clipper Race, my consultants and insurers, I was offered a place! Training was four week-long courses off the south coast of England. I also began swimming to improve my overall health and fitness.

During the first week's training we encountered some very rough weather and I was utterly exhausted by the end. But it had been

exhilarating, fun and I'd bonded with a wonderful and diverse group of people.

In late 2015 I flew to Western Australia to join my team. The first of my three races took me from Albany, WA to Sydney via the Southern Ocean and Tasmania. The seas were huge – 15 metres plus! And the storms were severe; one lasting four days with winds over 70 knots.

After Christmas in Sydney and yacht repairs we were hugely privileged to compete in the Rolex Sydney to Hobart Yacht Race. This proved equally testing; the conditions forced a third of competitors to retire. It was an exhausting five days but we did well and it's my proudest achievement.

On 2nd January 2016 we set sail from Tasmania to Airlie Beach, Queensland. From biting cold to sweltering heat, after another 12 days at sea I had completed over 4,500 nautical miles of ocean racing. A true experience of a lifetime, exceeding my wildest dreams!

Read more about my adventure and how I managed my haemophilia on board at: www.haemophilia.org.uk/yourstories



Duathlon silver for Nick!

My name is Nick Latimer and I have moderate/severe haemophilia (4% factor level). I've been lucky with bleeds, only needing to treat myself a few times a year.

Until age 18 I was a competitive runner, but then started to develop hip problems. Having to stop running, I began cycling and I've been racing for nearly 20 years. Without doubt it's strengthened my muscles and that has protected my joints, reducing how much treatment I need.

I'm quite new to duathlon, a mixture of running and cycling. I have to limit the number I do, because haemophilia means I'm still prone to injury when I run. In my first one I came third, so I entered the national championships! Fourth place (in my age group) was enough to see me competing for Great Britain in the 2016 European Duathlon Championships in Germany in April. I came second in my age group (35-39); it was a proud moment to compete for my country and represent people with haemophilia.

Speedy wheels!

Whether it's two wheels or four, haemophilia isn't holding these guys back...

A rally good time!

I'm Alan, last year a 69 year old with haemophilia, bored with golf and wondering what I used to do that really made me feel alive...

... It was car rallying, back in the 70s, throwing my little Imp around Wales. Could I do it again? I bought a Rover 214 Enduro on eBay – not realising it needed new seats, harnesses, fire extinguishers and more! Undaunted, I left 'Brian' at the rally garage while my sons and I went to get our kit and our competition licences.

Second time out at Donnington I was co-driver to son Bill – I hadn't felt so scared, so alive and so wonderful for years! And with The Haemophilia Society branding on the car we talked to lots of people. Some had relatives with bleeding disorders; some just wondered what it was all about.

Should people with haemophilia do dangerous sports? In my view, yes. Take all the safety precautions, assess the risks and plan for them, and then just go and do it!



Read Nick and Alan's stories in full online at: www.haemophilia.org.uk/yourstories

Contaminated blood – campaign update

For haemophilia patients, **#ContaminatedBlood** products carried 4.5-6 times more risk of being infected with HIV and close to 100% chance of infection with Hepatitis C.



I was never told about the risks involved from being treated with commercially pooled plasma. An astonishing amount of my blood records have been got rid of.

Affected community member

#ContaminatedBlood

As we go to press we're still awaiting news on when the outcome of the Department of Health (DH) consultation on reforms to support for those affected by contaminated blood in England will be announced.

We submitted a detailed response to the consultation – visit www.haemophilia.org.uk/contaminatedblood to read it online. We also developed a strong social media campaign with an eye-catching infographic that was picked up by many, with 9.3 million people seeing the messages on Twitter, including tweets from BBC and Sky news. This activity led to several TV and radio interviews for members.

The community really came together with one voice on 12th April, the day of the debate in parliament, protesting outside in large numbers with attention-grabbing activity. Fifty MPs spoke in

support of the community against the proposal in England.

The APPG continues to go from strength to strength in support of everyone affected and has had a meeting with the minister to discuss the consultation. We continue to act as secretariat for the APPG and our new policy and public affairs manager Jeff Courtney is busy working to keep the impact of this tragedy in the forefront of the government's mind.

The Scottish government made their announcement on 18th March to accept the key recommendations of the independent group report, leading to a significant increase in support for most of those affected. In Wales and Northern Ireland uncertainty remains about how any decisions will be made on future support and how this will relate to the DH decision.

Service of Thanksgiving and Remembrance

This year's service in memory of people with haemophilia who have died as a result of contaminated blood returns to St Botolph without Aldgate church in East London where the icon and book of remembrance have been held for many years. The service will take place on Saturday 29th October at 2.30pm and everyone is welcome. If you'd like to attend or ask for someone's name to be added to the book of remembrance, please get in touch (see back page for details).

Returning in 2016 after huge demand...

The Buddy Awards!

Nominations are now open for you to put forward someone who has helped you with your bleeding disorder and been a fabulous buddy. This is the perfect way to say thank you, show how much they mean to you and join them at a special awards ceremony on Saturday 5th November in Bristol as part of our AGM and conference (see page 11). Following the awards ceremony we will celebrate with a Buddy and Bangers Party!

Nominations are encouraged from across the UK, in 12 categories.



To find out more and make your nomination visit our Buddy Awards web page at www.haemophilia.org.uk/buddyawards or call us on 020 7939 0780.

The Buddy Awards are kindly sponsored by Novo Nordisk.





Services news

We've been busy this year ensuring that our services provide support at whichever key life stage you, your partner or child might find yourselves.

All our services, from conferences to weekends for specific groups or written information, have a serious intent. Each event is evaluated to ensure that it is quality assured and tailored to your needs and that the content is up to date. Our Clinical Advisory Group assess all our written material for medical accuracy, backed up by our Reader Panel who check that it's relevant and accessible.

What's been happening?

Back in January we held a Talking Red Conference for women with bleeding disorders and carriers. Over 50 women and their partners attended, covering issues such as relationships and considerations around starting a family. They were also able to share advice and develop a peer support network.

We have held two weekends for newly diagnosed families, which saw 27 families brought together, including 50 children. One mum, Louise, wrote: 'The weekend gave us so much more knowledge and understanding, and the chance to meet other families.'

Three Youth Weekends, including in Wales and in Scotland, have taken place, with over 30 young people taking part in a

variety of outdoor activities. They also had the chance to practise self-treatment and hone needle skills on brave nurse volunteers! These life lessons help young people move from childhood into adulthood. Orlando, 17, said: 'That was a great weekend!' And let's not forget the participants' siblings, who are always welcomed at all Youth Weekends.

We've done a lot of work this year on developing services for our 'ageing' and 'inhibitor' members, including filming interviewees. These films will help us better understand the issues these members encounter every day. Thank you to those who took part in these projects.

Who's involved?

Key to the success of many of the weekends is the attendance of our youth ambassadors. Their reassuring presence helps participants realise that life doesn't have to be defined by a bleeding disorder.

We're also immensely grateful to our wonderful volunteer nurses and physiotherapists, without who many of the weekends and conferences wouldn't happen.



Upcoming member events

As well as two more Newly Diagnosed Families Weekends in September and January (see diary dates on page 23) we have other events you might like to take part in.

Global Family Picnic – Thursday 11th August, London

We want to support members who feel isolated, perhaps because of cultural isolation or not knowing anyone else in your area with a bleeding disorder. Whatever the reason, you'll find a warm welcome at our Global Family Picnic.

Create – Saturday 3rd – Sunday 4th September, central London

A fabulous and fun arts weekend for all the family! (Read more on page 11.)

Ageing Conference – Saturday 17th September

The sessions and content will be tailored to cover the specific issues revealed as a result of the ageing project.

Inhibitors Conference – Saturday 22nd October

As with the Ageing conference, the content for this event will be shaped from the analysis of the year-long inhibitor project.

Contaminated Blood – HIV Event

As part of our aim to further support this often isolated community we're holding an event specifically for members and their families affected by HIV through contaminated blood.

Family Day

In Spring 2017 we'll be holding a family day to bring people together. You might be parents of a young child or a teenager, the partner of an adult with a bleeding disorder or an adult with a parent with a bleeding disorder – all are welcome. The day will include sessions by expert speakers and will also provide the ideal opportunity for you to get together and share stories and experiences.

If you're interested in taking part in any of the events listed please contact Christina:

christina@haemophilia.org.uk. We look forward to seeing you!



Summer fundraising campaign

Thank you for your amazing support in the last few years. Working together, we've been able to develop and grow our services to meet your needs and help you live as actively as possible.

All our services are free to attend, and membership of The Society is free. But to continue to deliver and develop services for you we still need your help. We need to raise at least £15,000 through our summer appeal to ensure we can be here for you whether you are 8 months, 8, 18 or 80!

Here for people like the Davey family, who said of our Newly Diagnosed Families Weekend: 'We feel lucky to have been able to attend and it would be amazing if every newly diagnosed family were also able to have the opportunity as it is so beneficial.' And Ben, 16, who told us: 'I was really nervous about coming to the Youth Weekend as I didn't know anyone and don't really like to focus on my haemophilia. But I had a fantastic time, made great friends I'm sure I will keep in touch with and wonder why me and my mum were ever worried about me going!'

We know we need to do even more to be here for you whenever you need us. For Joe, who said: 'I worry about the future as I get older; who will be here for me when I can't take care of myself?' We want to be able to say, 'We will'. So please help us to help you. Make a donation today, ask your family, friends and colleagues to support our summer appeal and ensure we continue to grow your charity together. Thank you!

It's easy to give using our online 'donate' button at: www.haemophilia.org.uk. Or complete the form below and send it to The Haemophilia Society, Willcox House, 140-148 Borough High Street, London SE1 1LB. If you'd like to make a monthly donation by Direct Debit so we can be confident of a regular income, please complete and return the separate form enclosed with this issue of HQ.



Name & Address

.....

I enclose a cheque for the sum of £..... made payable to: The Haemophilia Society

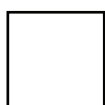
Please debit the following card: Maestro ☐ MasterCard ☐ Switch ☐ Visa ☐ Amex ☐

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I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

Tick here

Member events 2016–2017

July 24th–28th: WFH World Congress, Orlando, USA	August Global Family Picnic various dates and locations	September 3rd–4th: Create Arts Weekend, London 17th: Ageing Conference, London 23rd–25th: Newly Diagnosed Families Weekend, Longleat Forest Center Parcs	October 22nd: Inhibitors Conference, venue TBC 29th: Service of Thanksgiving and Remembrance, London
November 5th: AGM and Conference, Bristol	December 8th–15th: World AIDS Day Event, venue TBC	January 2017 27th–29th: Newly Diagnosed Families Weekend, Sherwood Forest Center Parcs	March 2017 Youth Weekend, venue TBC

Fundraising events 2016

July 23rd–24th: Spartan Race Series, Edinburgh 24th: Colour Vibe 5km Run 31st: RideLondon 100-mile Cycle Challenge	August 6th–7th: London Triathlon 7th: York 10km Run 13th: Mudnificent 7 20th: Bear Grylls Survival Race, Cambridge	September 3rd: Bear Grylls Survival Race, Edinburgh 3rd–4th: Spartan Race Series, Peterborough 4th: Northampton Half Marathon 7th–11th: London to Paris Cycle Challenge 11th: Great North Run 14th–18th: London to Paris Cycle Challenge 24th: Bear Grylls Survival Race, Manchester 24th: Serpentine Swim 25th: Cheltenham Half Marathon 25th: Berlin Marathon	October 1st: Bournemouth 5km, 10km Runs 2nd: Bournemouth Marathon 1st–2nd: Spartan Race Series, Windsor 2nd: Chester Marathon 8th–9th: Bear Grylls Survival Race, London 9th: Oxford Half Marathon 9th: Royal Parks Half Marathon 9th: Salisbury Half Marathon 16th: Amsterdam Marathon 16th: Exeter Great West Run 31st: Zombie Evacuation Race
November 15th: Fundraising events launch, The Haemophilia Society, London SE1 TBA: Vitality WestRun, London	December 4th: Santa Run, Victoria Park, London		



THE
HAEMOPHILIA
SOCIETY

'The Haemophilia Society has allowed me to realise that I don't have to limit my opportunities as a young person, and in fact can expand them further than I would ever have thought.'

Joshua, 18

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.

General contact and legal information:

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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

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Members of the European Haemophilia Consortium and the

World Federation of Hemophilia

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

President: Baroness Molly Meacher

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