For everyone affected by a bleeding disorder

HQ

The Haemophilia Society magazine

Winter 2015 edition

Giving at Christmas: It's in our blood!

Being the best you can be: Annual conference report

Haemo heroes

New treatments update

Meet our new mascot

Welcome to the latest edition of HQ. As a very busy 65th anniversary year draws to a close, there's plenty to share with you in these pages. We hope you enjoying reading HQ, and please get in touch with your feedback and suggestions for future magazines. You'll find our contact details on the back cover. Merry Christmas!

A fond farewell...

Ending my four-year tenure as chair of The Haemophilia Society is an emotional experience.

First, I am sad to be going; it has been a huge privilege to be the chair and to see the commitment from so many people that makes the Society an important resource for its members.

Second, I am delighted that Liz and her staff team are delivering the three-year plan agreed with the board of trustees, and to hear so much appreciation from members for our revitalised services and support.

Third, I am disappointed that we have not been more successful in our advocacy to Government and the health services. With mounting pressure on the NHS, I believe the Society's role in representing your views and interests will be vital in the years ahead.

Finally – and most importantly – I am thrilled to be handing over to Barry Flynn, who I believe is well-placed to lead the Society forwards, including as hosts of the World Hemophilia Federation's World Congress, taking place in Glasgow in 2018.

My best wishes to all of you for the future!

Bernard Manson, Chair of The Haemophilia Society

2011 – November 2015

... and a warm welcome!

It's great to be writing this short message by way of a 'hello' to you all in HQ. I'm thrilled to be taking up the role of chair at such an exciting time for our charity, and determined to do the best I can for everyone in our community.

If you're curious to read more about me, and why I'm stepping up to this role, you'll find more details of my story online at haemophilia.org.uk/trustees

I hope that my first-hand experience of living with severe haemophilia and the legacy of contaminated blood, combined with my background - as a leader, manager, coach, mentor and senior partner with Ernst & Young, and as a dad and husband - will enable me to serve the Society, and our future members, well in the years ahead.

I'm grateful to Bernard Manson for his thoughtfulness in timing my appointment, and for the guidance he has given me during our handover.

I can't think of a better way of using my energy and experience to help improve things for people with a bleeding disorder, and I'm really looking forward to getting started.

Barry Flynn, Chair of The Haemophilia Society

Welcome to HQ!

Our anniversary year has flown by!

We're now providing support that reflects the seven 'key life stages' we shared with you in the last edition of HQ. So far, that's included two newly-diagnosed family weekends, six children and young people's weekends, a fabulous family arts weekend, information days on inhibitors, ageing, and hepatitis C, as well as attending a family day in Northern Ireland.

There's lots more to come; including an information day for carriers and women with bleeding disorders, another weekend for newly-diagnosed families, two more hepatitis C workshops and three children and young people's weekends in Wales, Scotland and Northern Ireland next spring. We're also developing new publications on specific bleeding disorders, dental care and a schools information pack, as well as adding to the information online at haemophilia.org.uk

Over 100 of you came along to our AGM and conference on 7 November in Leeds, taking the opportunity to hear our charity's news, raise questions with staff and board members, meet newly-elected trustees, hear from experts on developments in treatment and have some fun in the lively workshop sessions. Our local groups forum the following day was a fantastic opportunity for our local group members to share experiences, get to know us better and inspire each other.

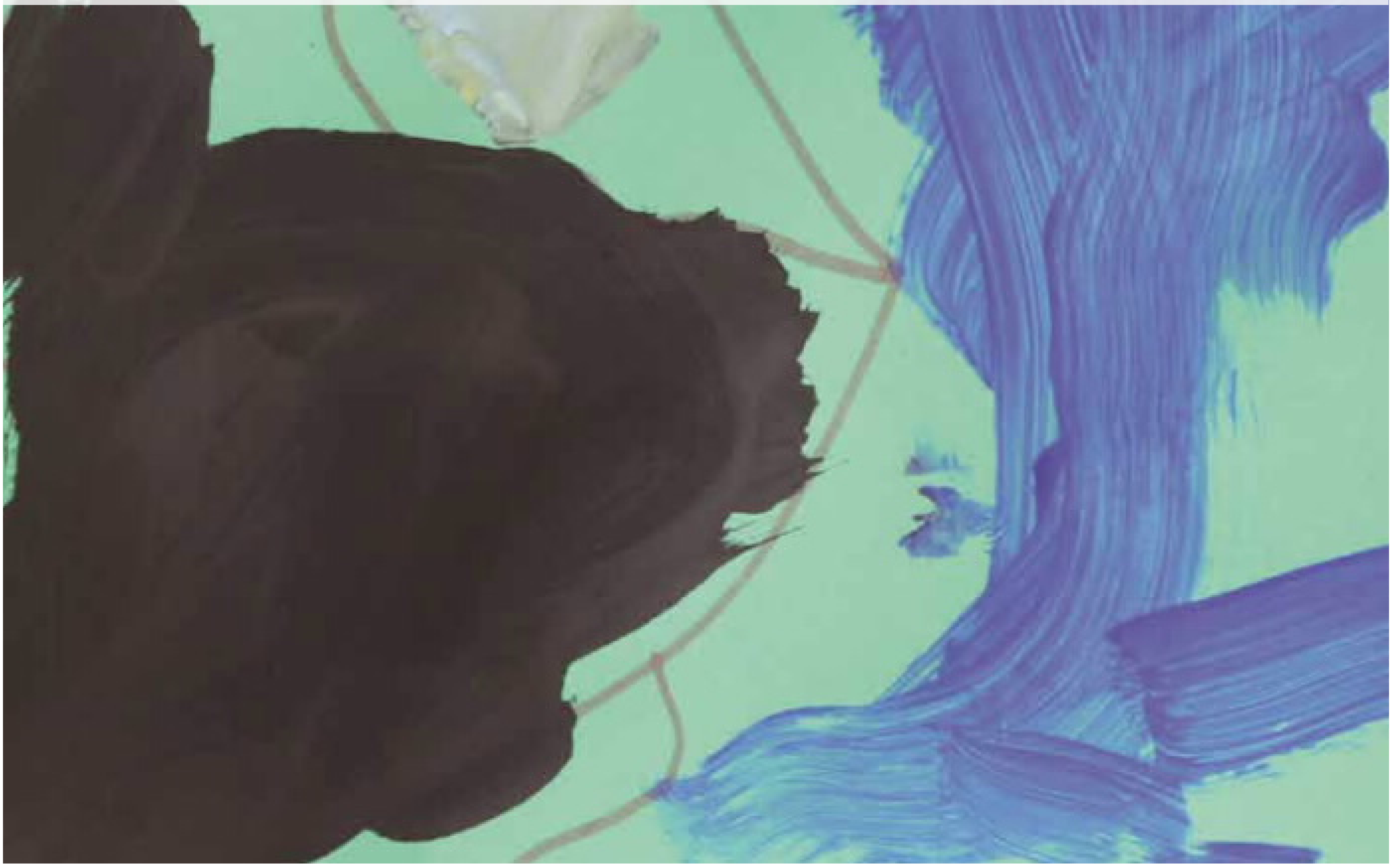
I'm excited to welcome Barry Flynn as our new chair of the board of trustees. Barry is a huge asset to the Society, and I'm sure he will lead us on to bigger and better things. I also want to personally thank Bernard Manson, our outgoing chair, for his incredible support and determination to leave the charity in a much better place than when he joined. We now have a more diverse, sustainable income, vastly improved services and a clear strategy for the future.

We were saddened to hear that our vice-president and founding member, the Reverend Alan Tanner, had passed away in August, aged 90. Alan was instrumental in establishing The Haemophilia Society, and in the World Federation of Hemophilia internationally. For our tribute to Alan, see page 18.

I hope you enjoy reading this, your members' magazine. Without you we wouldn't have a charity, so please join in and help us to be the best we can be.

Wishing you a wonderful Christmas and happy, healthy 2016,

Liz Carroll, Chief Executive of The Haemophilia Society



Supporting you every step of the way

On these pages, you can read more about the support available to you and your family from birth to older age. We provide tailored, practical information and support based around the seven key life stages identified by members:

1. **Supporting newly-diagnosed children and their families**
2. **Starting nursery or school**
3. **Learning to self-treat**
4. **Making the transition to adulthood**
5. **Choosing a career**
6. **Planning a relationship or family**
7. **Getting older with a bleeding disorder**

We also support those who are living with an inhibitor, or feeling isolated, and continue to campaign on behalf of those with contaminated blood.

Life Stage 1:

Giving newly-diagnosed families a break

Eight families, with a total of nineteen children, came together for our third weekend designed to give families coming to terms with a diagnosis the support they need the most.

Held in the fantastic surroundings of Sherwood Forest Center Parcs from 18-20 September, families learned about bleeding disorders and bonded over their shared experiences, as well as having a precious opportunity to relax and spend time together as a family.

'I found the weekend more helpful than I could have imagined and learned so much. Most of all, it was great to meet other families and realise I am not alone.'

As with our two previous events, families are continuing to support each other well beyond the weekend itself. It's these peer support networks, whether face-to-face, over the phone, or online through social media, that are so valuable for parents at this early stage in their child's diagnosis.

Mums and dads alike felt that the weekend would have a lasting impact on their family life: 'Thank you for the time and effort you put in. I truly believe that it will make a difference.'

Thanks to all who made the weekend possible, especially sponsors Bayer, our physiotherapist and three nurse volunteers, and new youth ambassador Hannah Yarnall.

Life Stage 2:

Helping schools to get it right for our children

The Haemophilia Society's eagerly awaited schools booklet will be published early in 2016, designed to give children with a bleeding disorder the best possible start to their education by helping teachers and parents create a care plan to meet their child's specific needs. We hope it will prove a useful tool to guide families with young children smoothly through this crucial stage.

The booklet has been fully reviewed by the Society's clinical advisory committee, a group of mums and a cross-section of members on our reader panel.

One Mum, Anouska, says: 'The booklet reads really well and is easy to understand. It is just as a parent would probably explain, so big thumbs up!'

You'll be able to download your copy from haemophilia.org.uk, or get in touch (see back cover) to pre-order a printed copy.

Life Stage 3:

Life beyond your bleeding disorder: Young people's activity weekends in 2016

Over the years, many younger members have had a first taste of independence, and lifelong friendships have been forged at our outdoor activity and adventure weekends for children and young people.

We're able to offer more places than ever in early 2016, with three weekends taking place in Northern Ireland, Scotland and Wales by popular demand.

Building on the success of previous events, we'll run two separate groups in parallel at each location: one for children aged 8-12, and a second for teenagers aged 13-17. Siblings are also eligible to attend, and our wonderful volunteer nurses, physiotherapists and youth ambassadors will be on hand to help where needed.

Mums and dads are always reassured (and sometimes astonished!) by the boost to their child's sense of independence and self-confidence these weekends bring: from an eight-year-old who has never been away from home, to a 17-year-old on the brink of heading off to college or university.

You'll find full details of dates, venues and how to book at haemophilia.org.uk/events and at facebook.com/HaemophiliaSocietyUK

Talking Red

Talking Red aims to raise awareness of all bleeding disorders in women, including von Willebrand disease, rare bleeding disorders and haemophilia. We want to make women aware of the symptoms of a bleeding disorder – heavy periods, bruising easily and prolonged bleeding after surgery or childbirth.

Talking Red awareness week 2016 – our third – will take place from 18 – 25 June. Get the date in your diary now and visit www.talkingred.org to get involved and find out more.

Life Stage 4:

Understanding how transition affects you: research update

Young people with a bleeding disorder tell us that making the transition from children's to adult haemophilia centre services can be a particularly challenging time.

We've teamed up with Haemnet, a charity that brings together and gives a voice to haemophilia nurses, physiotherapists and healthcare professionals, for a research project to understand more about your experiences of making the transition.

The aim is to capture young people's experiences of this important stage – as well as the perspective of parents who've witnessed their son or daughter making the transition – to identify what haemophilia centres around the UK can do to provide the best possible support in future.

In July, we conducted 20 in-depth telephone interviews with young people and a selection of their parents, led by our fantastic volunteer youth ambassadors Luke, Laurence and Rob.

More interviews scheduled at the end of 2015 will allow us to build the fullest possible picture of your experiences of transition, wherever you live. We'll publish the findings of this research early in 2016.

Life Stage 6:

Carriers and Women's information day

If you're a woman with a bleeding disorder, or your partner is, if you or your daughter is (or might be) a haemophilia carrier, or if you're a single mum trying to cope with your child's condition, then come along to our event in Birmingham on Saturday 23rd January 2016.

It's completely free to attend, and you'll be able to meet other women of all ages who truly understand the emotional and practical issues you face, and gather information and tips from expert speakers on keeping mentally and physically fit and well.

This is your space and your time: you can come purely to listen and learn from others, or choose to share your own experiences along the way.

Partners will be welcome, with a dedicated information session for those considering the possibility of starting a family. And we're offering a section specifically for single parents in response to popular demand.

To find out more, and book your place, get in touch – you'll find our contact details on the back cover.

Life Stage 7:

Getting older?

Your Society Needs YOU!

If you're a Haemophilia Society member aged 35 or over, you should have received a copy of our questionnaire, Getting older with a bleeding disorder. Please do take a few minutes to complete it, and return it to us by 15 January, 2016.

Thanks to modern treatments, today's generation of members can look forward to long and full lives. But as we grow older, new challenges are emerging. We're working to understand these, in detail, to best serve and support the bleeding disorder community in the years ahead.

A group of twelve members spent a productive September day in Birmingham laying strong foundations for this project on ageing, and we've also filmed a handful of in-depth interviews to explore members' expectations, hopes and fears.

In early 2016, a trio of workshops, involving members, healthcare professionals and Haemophilia Society staff, will complete the information-gathering process. We'll share our findings, and the plans that follow from them, later next year.

If you've yet to receive a questionnaire, please get in touch (see back cover) to update your details and request a copy by email or post.

Tackling isolation

When you or a loved one has a bleeding disorder, it's not unusual to feel isolated. These are rare conditions, and many people have either never heard of them, or hold misconceptions about them. For some, other circumstances can make these feelings escalate.

Why we're helping

Children with a bleeding disorder are often 'the only ones like them' at school or in their local area. This is especially true for the relatively few girls and women diagnosed so far.

You may have moved recently, or moved to the UK from another country, and face the challenges of different treatment regimes and medical care approaches.

Cultural differences may make it even harder, particularly if your culture has taboos around bleeding disorders, or if you fear rejection from family or friends, due to a hepatitis C or HIV diagnosis.

'I don't tell many people about my condition because of the consequences within my culture. Once people know, all they see is the bleeding disorder. They do not look beyond it to see the person you are. They whisper about you being abnormal and 'ill'. You begin to doubt yourself and question: Am I really ill? Am I really abnormal? Do I not get the same rights as those without a bleeding disorder?' – Maryam

How we're helping

To support members who feel isolated, we're working with our local groups and haemophilia centres to strengthen networks, put people in touch with each other, and help to ensure that each of our members has someone to turn to.

'I was delighted to have the opportunity to network with others dealing with the same – or similar – issues as myself.' – Orestis

Meeting others at our events and services, as well as at our annual conference each Autumn (this year in Leeds), provides an opportunity to meet others who truly understand how life is for you. Our Global Family events and local groups can also be a great way to meet others, so do join in and get involved if you are feeling isolated.

If you're feeling isolated, whatever the reason, we're here to help. Please get in touch (see back cover).

Our haemophilia heroes

In July's edition of HQ magazine, we invited you to nominate your 'haemophilia heroes': the exceptional people who have made a significant positive change in bleeding disorder awareness, diagnosis, care or treatment and made life better for people affected by a bleeding disorder in the 65 years since The Haemophilia Society began.

We featured the ten shortlisted nominees in a special 'Hall of Fame' at our annual conference. Your overall Haemophilia Hero, as voted by over 100 members on the day, is the late Alf Morris: Lord Morris of Manchester.

Alf Morris was Labour MP for Manchester Wythenshawe for 33 years before joining the House of Lords in 1997. A great parliamentarian and a true friend of the bleeding disorder community, he became president of The Haemophilia Society in 1999, serving our community until his death in 2012.

Lord Morris campaigned tirelessly for justice for those affected by the contaminated blood tragedy. He persuaded Lord Archer to establish his independent inquiry and continued to fight for the cause in every way he could until he passed away.

In 1970, his private members bill led to the Chronically Sick and Disabled Persons Act, made law in the same year. It championed the needs of chronically sick and disabled people, requiring councils to provide information and support including access to sheltered housing, home adaptations, leisure and toilet facilities and concessions on public transport.

As minister for the disabled in 1977, he unveiled the Motability scheme, championed the need for an invalid care allowance and the mobility allowance, exempted the blind from NHS optical charges and more. In the House of Lords, he campaigned for those affected by thalidomide, as well as contaminated blood.

Haemo Heroes: the shortlist

The Reverend Alan Tanner (1925-2015), a founder, former chair and vice-president of The Haemophilia Society whose support and guidance helped countless families over many years.

Katharine Dormandy (1926-1978), a senior haematologist based in London, was awarded The Haemophilia Society's first gold medal in recognition of her outstanding work to improve the lives of people with haemophilia from the 1960s onwards.

Lord (Peter) Archer of Sandwell (1926-2012), who headed the 2007 public inquiry into how 1757 people with haemophilia had been given blood infected with hepatitis C or HIV, giving the infected and bereaved a chance to share their stories.

Professor Ted Tuddenham, whose pioneering research into haemophilia, and now gene therapy, has led us ever-closer to a cure. His efforts are ongoing.

Gordon Clarke MBE, MBA has volunteered his time, talents and personal experience on behalf of people with bleeding disorders over many years: in Northern Ireland, UK-wide, and globally, as a former president of the European Haemophilia Consortium and vice-president of the World Federation of Hemophilia.

Kathleen Holden, aged 90, whose fundraising efforts over many years, together with her late husband Peter and their family, have raised well over £100,000 for the Society through community dances, table and bric-a-brac sales.

Dr Pratima Chowdary, consultant haematologist and clinical lead for inherited bleeding disorders at the Royal Free Hospital, London with more than 30 published research papers on bleeding disorder issues in the UK and internationally.

Debra Pollard MSc, RN, Lead Nurse at the Katharine Dormandy Haemophilia Centre, former Haemophilia Society trustee, member of the clinical advisory group and founding member of our 'Women Bleed Too' project.

Dr Elizabeth Mayne, now retired from Belfast clinical practice, was active in shaping the UK Haemophilia Centre Doctors Organisation (UKHCDO), and her single-handed focus on bleeding disorder care has never been forgotten by our members and their families in Northern Ireland.

For more about your haemophilia heroes,
visit haemophilia.org.uk/haemoheroes

Giving at C

Christmas is a time for families. It's the time when we are able to stop and be with or remember the most important people in our lives. It's the time to share and be generous. It's the time to be thankful for what we have. This Christmas at The Haemophilia Society we plan to have the most wonderful time of our 65th year! Throughout 2015 we have celebrated as a family charity by introducing more services and support to our members than ever before. We introduced our 'key life stages' campaign offering support throughout your life, next year and for your future. With your help we hope to further increase our services for everyone affected by a bleeding disorder wherever they are in the UK.

This Christmas as you enjoy the happiness of the Festive Season please take some time to help support our Christmas appeal.

As a cracker of a Christmas incentive we have a special gift for you to share with all your family and friends. Visit our website and Facebook pages every day of December and find out how you can share the special magic of Christmas by visiting our unique advent calendar. There you'll find a seasonal invitation to support the work of our charity and share it with others.

You might prefer to share the joy of Christmas by donating to our Christmas appeal using the form on page 22. Whether you're carol singing, running in a Santa run, bucket shaking at your local supermarket or organising a fundraising mince pie party, please remember us this Christmas and help us make a difference to families and individuals throughout the UK.

...it

Christmas...

’s in our blood!

Be the best you can be:

AGM and conference 2015

105 members, aged from just 15 weeks old to 75, and from as far afield as Aberdeen and Bournemouth, came along to The Haemophilia Society's annual general meeting (AGM) and conference in Leeds on Saturday 7th November.

This flagship event, held each Autumn, is a popular way to meet other members, staff and trustees, hear more about our work, have your say and ask questions in lively workshop debates.

This year, our theme challenged everyone to 'be the best you can be', as we celebrated 65 years of our charity.

Afternoon workshops were packed, including sessions from Thuvia and Clare (a physio and dietician), incredible motivational speaker Chris Moon, art therapy with Simon Bell and a touch of drumming with Sam!

We revealed our 'Haemo Hero' (see page 9) and the winner of our Swim Around Britain photo competition, and ended the day with a fabulous performance from our young members who had been rehearsing all day, all topped off by a birthday cake and tea.

'We really enjoyed this AGM and conference, we covered lots of issues and it was so welcoming.'

'Thank you. I'm so glad to see the Society is taking a good look at itself and being very positive about the way forward.'

Review of the year 2014-15

At the Society's AGM, outgoing chair of trustees Bernard Manson welcomed his successor, Barry Flynn (see page 2), who many members had the chance to meet and speak with personally.

Liz Carroll, Chief Executive, reported on the progress made in 2014-15. With a new strategy and staff team, this year marked the beginning of a new era of member consultation, services and support, working to shape and implement what members tell us they need most, in an efficient and sustainable way.

We launched our Talking Red campaign, spreading the message via local and national media that tens of thousands of women may have an undiagnosed bleeding disorder.

We enabled 32 families with newly-diagnosed children to benefit from a weekend dedicated to their needs, and built the confidence and independence of 26 young people learning to live with their (or their sibling's) bleeding disorder at our activity and outdoor adventure weekends.

We proposed and supported an APPG inquiry and campaigned for a new package of support for those affected by contaminated blood.

We also launched a 'burden of illness' study (see page 15), and a highlight of our fundraising year saw 11 intrepid volunteers raising £37,000 through Trek Iceland.

Presenting the accounts for 2014-15, our treasurer Simon Mower outlined how, with no government funding, the Society was responding to the challenges we face to ensure the charity's long-term future.

In 2014-15, we successfully reduced fixed costs through an office move and renegotiating supplier contracts. The board's decision to invest more in fundraising staff and activities began reaping rewards despite the challenging financial climate, with an excellent take-up of a wide array of challenge events and other fundraising initiatives by members, families and friends. This was mirrored in positive conversations with past and present corporate supporters regarding ongoing sponsorship (including, but not limited to, the pharmaceutical sector).

Simon explained that trustees had agreed to use some of our charity's reserves – currently healthy thanks to generous legacy donations in recent years – to support activities in 2015-16, returning to 'break-even' from 2016-17.

Members voted to accept the accounts presented and to appoint Wilkins Kennedy as the Society's auditors for 2015-16.

You can find out more about our plans for the next three years at haemophilia.org.uk/ourplans.

Our new trustees

The Haemophilia Society welcomes our new trustees, elected by you, our members. Here's a bit about each of them. You can read full details of all of our board members, and more about the role of the board, at haemophilia.org.uk/trustees.

Lisa Bagley, a haemophilia carrier with two affected children, is an IT consultant and avid supporter of the Society, raising funds through a 10km run in 2015 and Trek Iceland in 2014. Lisa is passionate about the contaminated blood tragedy, developments in treatment, and achieving more consistent care and support for everyone with a bleeding disorder, regardless of their age, location or haemophilia centre.

Liz de Freitas is a business advisor with Ernst & Young, with experience in operational and business development roles. Her husband of 25 years has severe haemophilia A, and Liz hopes to use her expertise and insight into organisation strategy, development and operations to help shape the Society's services and support as we look to the future.

Jamie O'Hara – re-elected for a second three-year term – is director of strategy at a leading health economics consultancy, a senior lecturer of health economics at the University of Chester, and has severe haemophilia A. Jamie led the 'burden of haemophilia' study (see page 15), is the health economics lead on the European Haemophilia Consortium's data and economics committee, and a steering committee member of the European Patients' Forum, advising charities on patient care and policy development.

Collette Pigden is a carrier of haemophilia A with three adult children: a carrier daughter and two sons, one of whom has severe haemophilia. Her father died after being infected with HIV through contaminated blood. As a nurse, Collette specialises in haemophilia research at St. Thomas' Hospital, striving to improve life for people with bleeding disorders through new therapies and improved treatment options.

Clive Smith is the youngest of three brothers, all with severe haemophilia A. As a qualified barrister practicing criminal law, Clive brings legal expertise to the board, and is passionate about raising awareness within the bleeding disorder community of what is possible. Despite arthritis in his ankle, Clive has recently run the Brighton Marathon in aid of Great Ormond Street, competed in triathlons and completed two Ironman challenges in two years!

What's in a name?

A lively discussion about whether our charity should consider changing its name took place: thank you to all who shared their views. The debate began with two speeches from members with opposing opinions, and was then opened up to the floor.

As anticipated, there are strong feelings and opinion is divided.

Many members who have a bleeding disorder other than haemophilia feel very excluded, and took years to find us because our name suggests we're not relevant to them. Even those who know about our services often feel 'second best' to those who have haemophilia.

Others feel that our long history is more important, and that our heritage as the world's first Haemophilia Society, or our charity's profile, might suffer if we change our name.

We will continue talking and listening to your views in the months to come, and come back to you with further thinking as the year progresses.

New treatments: in brief

Treating haemophilia: new products edge closer

New, more effective treatments for both haemophilia A and B are expected to be available in the UK by 2017.

These 'extended half-life' (EHL) recombinant factor products could improve quality of life for many of our members, either by increasing factor levels for the same number of injections, or by enabling a similar, or higher level of factor cover with less frequent injections.

Results have been especially promising for adults with haemophilia B, with the potential for a single weekly or even fortnightly injection to provide similar levels of factor to existing treatments.

These products may not be suited to everyone, and in particular, the research needed to establish their effectiveness for babies, children and previously untreated patients is not yet complete.

While the prospect of fewer treatments is appealing, the greatest benefit of these new products may lie in their ability to raise levels of factor in the blood, helping people with haemophilia to lead more active lifestyles, safely.

Read the full article, based on the presentation at our recent annual conference, at haemophilia.org.uk/hq/treatments

Hepatitis C: new treatments now widely available

October brought good news for many of those infected with hepatitis C through contaminated blood, when NICE approved three new combinations of new-generation drug treatments for hepatitis C. While NICE guidance applies to NHS England, we know that Northern Ireland, Scotland, Wales are likely to apply the same principles, or even slightly enhanced access.

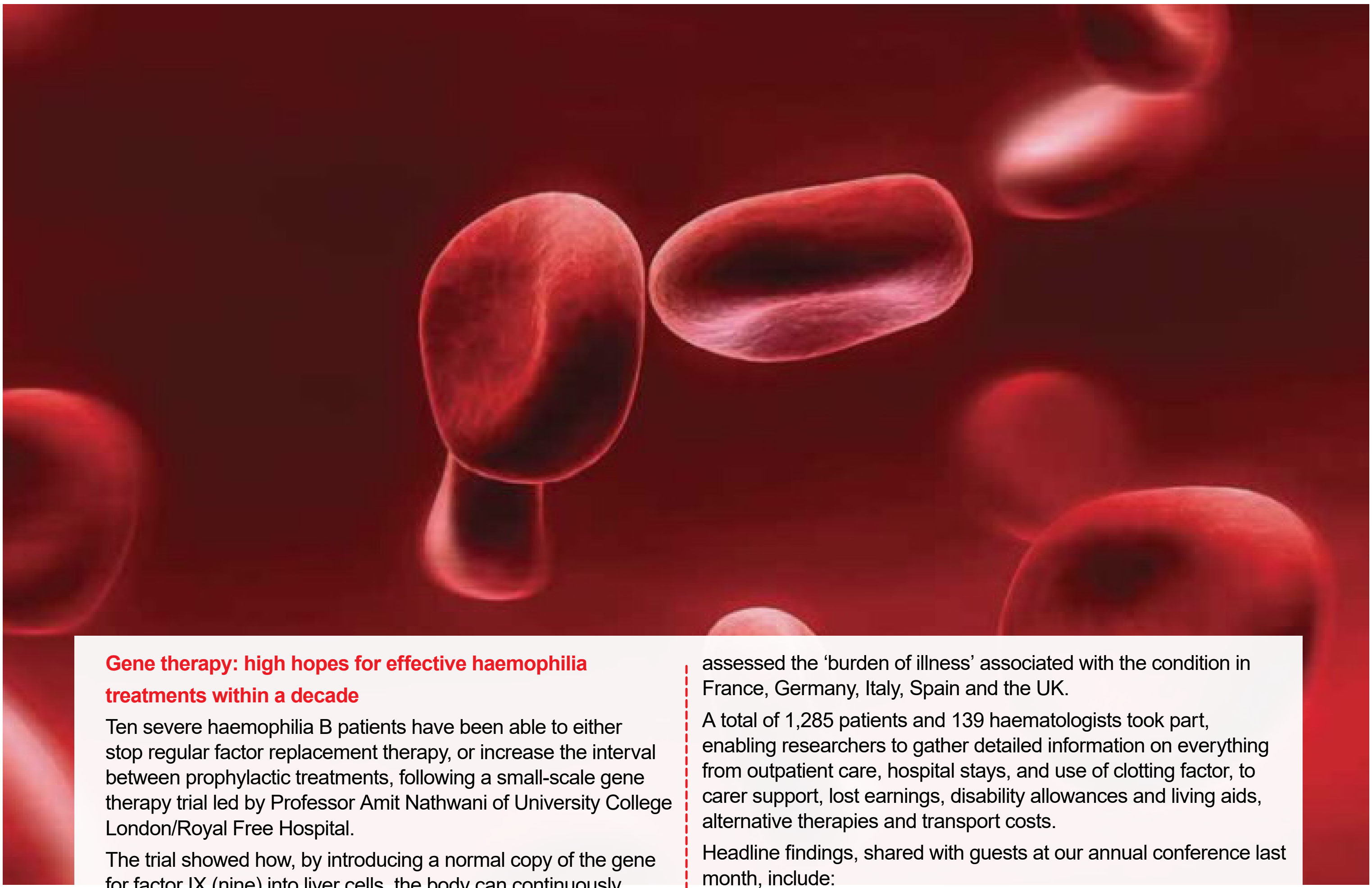
Everyone with liver cirrhosis or advanced fibrosis should now have access to one of the new treatments. All treatment must be approved by a hepatologist, and be approved through a registered 'hub centre'. Local hospitals, particularly in England, aren't able to prescribe these new drugs directly without approval from the hub.

It's likely that new drug combinations will be approved for treating people with earlier stage liver disease in the near future, so even if your hepatitis C infection hasn't progressed, it's really important to get a referral for an appointment with a hepatologist to discuss whether one of the new treatment options could be right for you in the near future.

The three new combinations are Daclatasvir (Daklinza®), Ledipasvir–Sofosbuvir (Harvoni®), and Ombitasvir–paritaprevir–ritonavir (Viekiraz®) with or without Dasabuvir (Exviera®) and ribavirin.

With excellent success rates and fewer side-effects than previously, we are hopeful that our community might be free of active hepatitis C virus in the near future.

For further information, see the NICE website or partner charity Liver4Life's useful summary of treatment options by genotype.



Gene therapy: high hopes for effective haemophilia treatments within a decade

Ten severe haemophilia B patients have been able to either stop regular factor replacement therapy, or increase the interval between prophylactic treatments, following a small-scale gene therapy trial led by Professor Amit Nathwani of University College London/Royal Free Hospital.

The trial showed how, by introducing a normal copy of the gene for factor IX (nine) into liver cells, the body can continuously produce normal factor IX protein at levels similar to moderate or mild haemophilia.

One participant says: 'It's been amazing. I've had no side-effects and I don't have to inject myself twice a week, which was not pleasant. My factor IX levels have increased and stayed constant. When I cut myself shaving, for example, the bleeding just stops – which wasn't happening before.'

Professor Nathwani says: 'For most people with severe haemophilia B, increasing factor IX levels to above 5% constantly would reduce joint disease, chronic arthritis, deformities and other problems as they get older. So far we are seeing stable, long-term expression of the new copy of the gene: for more than four years in humans following a single gene therapy treatment.'

Other approaches for both haemophilia A and B are being evaluated in the UK and further afield, with pharmaceutical companies now developing their own gene therapy programmes. This is a very positive sign of the level of investment needed to bring the potential curative benefits of gene therapy to more people with haemophilia, in the UK and worldwide.

Read the full article at haemophilia.org.uk/hq/treatments.

The true costs of severe haemophilia

Results of the largest ever study into the socio-economic costs associated with severe haemophilia have now been published.

Commissioned by The Haemophilia Society, and led by trustee Jamie O'Hara in partnership with the University of Chester, the three-year research project, known as 'CHESS' (the Cost of Haemophilia across Europe: a SocioEconomic Survey) has assessed the 'burden of illness' associated with the condition in France, Germany, Italy, Spain and the UK.

A total of 1,285 patients and 139 haematologists took part, enabling researchers to gather detailed information on everything from outpatient care, hospital stays, and use of clotting factor, to carer support, lost earnings, disability allowances and living aids, alternative therapies and transport costs.

Headline findings, shared with guests at our annual conference last month, include:

- More than 95% of the overall costs of severe haemophilia are the costs of drugs used to treat the condition.
- Of the remaining costs, around 60% are indirect costs shouldered by patients and their caregivers, such as loss of earnings.
- People with severe haemophilia are experiencing other linked conditions, and in particular, levels of anxiety and depression are up to 50% higher along this community.
- Nearly one-quarter need a carer – usually a family member – to help them with daily activities.
- One-third had been hospitalised for a bleed, and one in five had had surgery on a target joint, within the previous 12 months.
- Nearly one-fifth had experienced work-related problems in the last three months, and 12% had to stop working or retire early.

With more analysis, the research can help us to understand people's experience of haemophilia in different countries, and to identify which approaches to care, treatment and support work best. We can then use the evidence to influence and improve the UK's approaches, to be the best possible for our members, while showing healthcare leaders that investing in high quality care can reduce the overall long-term costs to the NHS and society.

What we learn from the data will help us develop our support for members at each of the seven key life stages (see page 4), including services for members as they age, for carers, and supporting young people struggling with their treatment regime. We're also considering how to ensure that our services take account of the risks to mental health, at every life stage.

Your stories: It's in our blood

In our summer anniversary edition of HQ, we invited you to share your stories and memories of The Haemophilia Society over the years. Here are the first two of your stories shared.

Missing factor VII

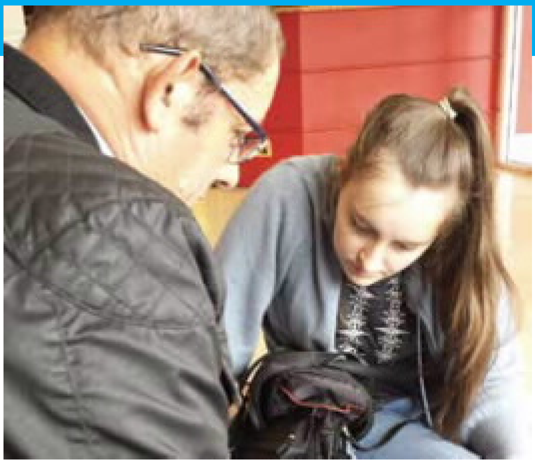
My name is Zoe, and I'm 16 years old. When I was seven, I was diagnosed with a factor VII (seven) deficiency – a rare bleeding disorder caused when I inherited an affected gene from both of my parents. I went on to develop an inhibitor and other complications that made treatment tough at times.

When first diagnosed, I wasn't really aware of the consequences of a simple injury or missed factor treatment, and I struggled to understand the need to be careful when my friends were happily jumping on trampolines and bouncy castles.

Since then, I've learned to approach things with caution: I've learned the hard way that it's much quicker to take the sensible approach than to endure the longer-lasting consequences of 'overdoing things'. That said, I try not to let my condition limit me too much, and do occasionally push the boundaries of medical advice to do the things that mean a lot to me: I love dancing, and have completed my bronze Duke of Edinburgh award.

Now I'm in year 11, my most recent problem has been missing school due to gynaecological complications. I've had support from my haemophilia centre and social worker, providing extra home tuition to keep me on target for my GCSEs.

Over the years, I've learned to view my bleeding disorder as not all bad. I've met so many interesting people, and had lots of opportunities I never would have had if it wasn't for my missing factor VII.



If you can relate to Zoe's story, you may like to attend our Women and bleeding disorders / Carriers' Information Day in January (see page 7)

£65 at 65

We challenged a thousand of our members, volunteers and supporters to collect £65 in a special anniversary moneybox.

A huge THANK YOU to each and every one of you who has returned your box already – if you've still got yours, please return it to us by the end of January 2016!

World Hemophilia Day – 17th April 2016

Can you help us to 'Go RED' – at home, in your local community, at work, school, college or uni, in a bigger and better way than ever before? Look out for your fundraising pack coming soon!

Meet our new mascot!

Baggins is a gorgeous two-year old English cocker spaniel who - rarely for his breed - has haemophilia A. We're pleased to welcome him to The Haemophilia Society as our very special pet mascot!

Members of our Facebook group online have been regaled with heart-warming tales of Baggins' adventures, mishaps and general naughtiness, thanks to owners Paul and Wendie Sutton, from Redditch, who joined the group this summer. Paul says:

'Baggins isn't on permanent medication, but if he has an internal or joint bleed, he's given Vitamin K injections and Metacam, a painkiller that helps to reduce swelling.

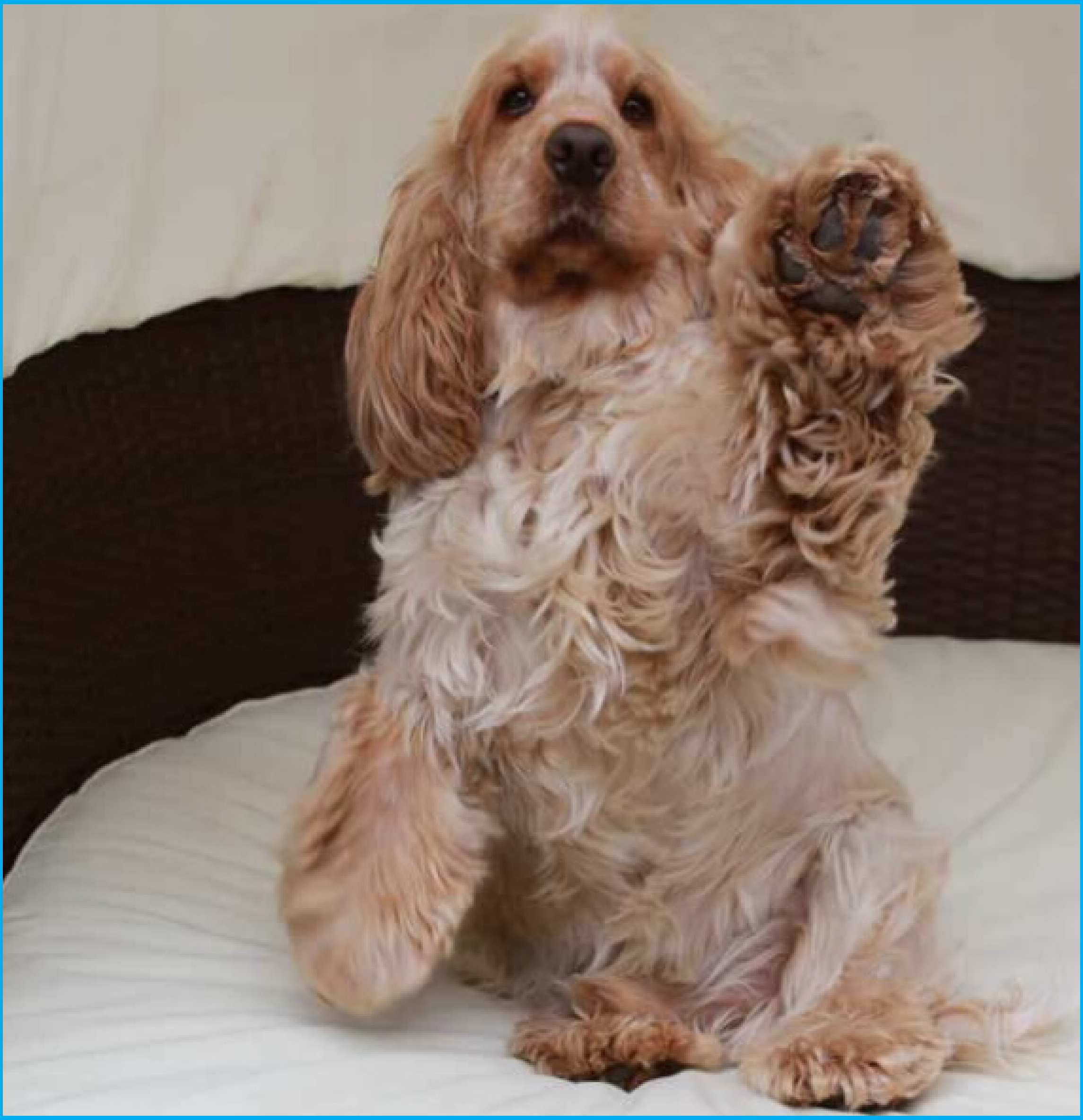
'So far, he's cut his paw and his tongue, and once vomited blood during a stomach bug. Fortunately, he's a tough little character and after a couple of Vitamin K injections and antibiotics, he's been back to his normal naughty self fairly quickly.

'When a cut to his tongue bled for five days, Baggins received a cryoprecipitate transfusion from the Pet Blood Bank, which we never knew existed!

'Our vets are amazed by Baggins as they've never encountered the condition before. Luckily, I'd taken out good pet insurance before he was diagnosed, which obviously really helps!

'Baggins shows us all that even with a bleeding disorder, you can do your best to just get on with things.'

Baggins has already proved very popular with our younger members. You can read his full story online at haemophilia.org.uk/hq/yourstories and see updates on his progress at facebook.com/haemophiliasocietyUK



The All-Party Parliamentary Group

The APPG on Haemophilia and Contaminated Blood is a cross-party group of MPs and Peers, aiming to raise awareness of haemophilia, bleeding disorders and the contaminated blood tragedy in Parliament, and to influence policy and legislation in a way that improves the lives of those affected.

Diana Johnson MP and Sir Peter Bottomley MP are co-chairs, and as an independent charity, The Haemophilia Society provides the secretariat to the APPG.

APPG news in brief:

Members of the APPG were disappointed when the promised statement on a new financial and healthcare package for those affected by contaminated blood was not forthcoming before Parliament's summer recess. In recent months, the APPG has written to the Prime Minister and met with Minister for Public Health, Jane Ellison MP, and as we went to print, we are still awaiting a concrete announcement on this critical issue.

Please visit haemophilia.org.uk/appg for the latest news on the Group's activities and membership, or call us with your questions (see back cover for contact details).

In memoriam: the Reverend Alan Tanner

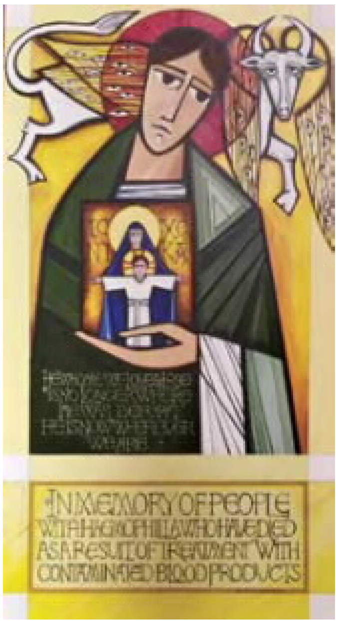
We are sorry to share the sad news that the Reverend Alan Tanner passed away on 5th August this year after a short illness, aged 90.

Born in 1925, Alan – whose son Mark was diagnosed with haemophilia and later died as a result of contaminated blood – was a founding member of The Haemophilia Society and a staunch lifelong supporter of our charity and our community.

Having chaired our board of trustees for 22 years from 1975 to 1997, and arranged and led the annual service of thanksgiving and remembrance for nearly 25 years. Alan played a huge part in the lives of so many of you, guiding and supporting families through some of the darkest times of life.

Alan also served as chairman of the World Federation of Hemophilia, and – in their early days – of The Macfarlane Trust and the Eileen Trust. He remained as our vice-president until his death.

The Society will always be immensely grateful to him, and his daughter Mary-Ann, for supporting so many of our members over the years.



25 years of remembrance

Every year, we take time to remember loved ones who have died from HIV or hepatitis as a result of treatment with contaminated blood products at the Service of Thanksgiving and Remembrance. More than 100 people gathered at the Charterhouse in London on 31st October to remember family and friends.

This year's service was especially poignant: not only did it mark a quarter of a century since the first service in 1990, but – sadly – this was to be the first service without the Reverend Alan Tanner, who established and led this most important event in the Society's calendar.

Another member, the Reverend Richard Donoghue, stepped in to lead the service. Beautiful music composed by Andrew March, with text adapted by Sue Threakall, added something extra to the traditional readings, hymns and prayers.

Candles were lit in memory of each of the lost members of our community, as their names were read aloud.

Next year's service of thanksgiving and remembrance will take place in the City of London on Saturday 29 October, returning to the church of St Botolph's Bishopsgate, where the Book of Remembrance and memorial icon (pictured here) are on permanent display.

Creativity: It’s in our blood!

A lively mix of members made our first ever arts weekend a huge success, as well as proving to be the perfect way to celebrate our 65th birthday. Held in July, at the Northern Ballet in Leeds, people of all ages got involved and worked together.

Members could choose from dance/drama, art, photography or singing workshops, all culminating with moving, uplifting and emotional performances in the theatre! For a flavour of what you missed, look at our video clips online at haemophilia.org.uk/events

Linda Wild, who has von Willebrand disease, shared her 65th birthday with our charity: 29th July 1950, joined us as guest of honour.

One member, Jane, commented: ‘An awesome weekend with some great people, having experiences outside our comfort zones. Looking forward to the next event!”

The arts weekend is set to become an annual event and we plan to return to the same venue in Leeds again in summer 2016 – we can’t wait!

Please get in touch (see back cover) if you’d like to register your interest for 2016.

Going local in Leeds: local groups forum 2015

25 representatives from 7 of our 11 local groups came along to our dedicated forum following the AGM and conference In Leeds.

An informal meal on the Saturday evening gave everyone – especially new staff and trustees – a much-needed opportunity to meet and get to know each other.

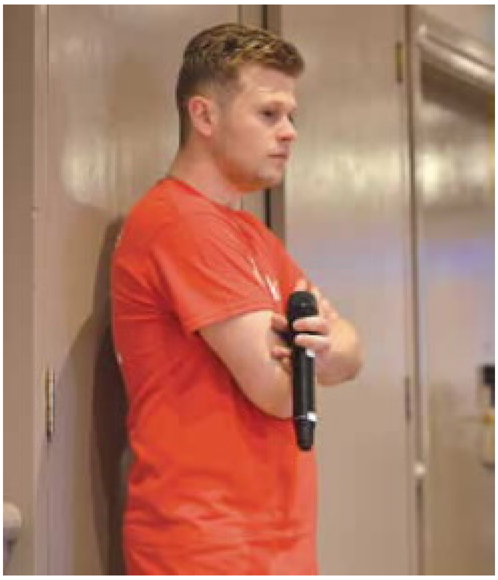
Sunday's forum was a chance to share concerns and discuss issues – both local and national – as well as comparing notes on the highs and lows of running a local group.

We're planning a Local Groups residential weekend on 5-6 March 2016, to take forward all the ideas and issues raised.

New chair Barry Flynn's closing comments echoed the view that we need to strengthen relationships between local group volunteers, staff and trustees and improve communications and practical support for local group activities.

If you'd like to be put in touch with a local group in your area, or help to start one, please get in touch (see back cover).

Youth Ambassador Update



Our five talented youth ambassadors: Rob Barnard, Luke Pembroke, Ria Peake, Laurence Woollard and Hannah Yarnall have all taken to their new roles with gusto, being on hand at our regular weekend events, including the recent AGM and Conference, as well as representing us at major conferences in the UK and overseas.

Ria says: 'Being a youth ambassador means I get the opportunity to share a positive message to show that there is always light at the end of the tunnel and that you can achieve your dreams.'

Hannah agrees: 'Becoming a youth ambassador has been such a rewarding experience, it is enriching meeting families and learning their stories. The Society has such a warm atmosphere and I love how every day with them guarantees fun and new challenges.'

Luke adds: 'The EHC Youth Leadership Conference in Belgrade gave me a whole new perspective on how I live day-to-day with haemophilia. Not only did I meet some inspiring people from our European community, but it was also an eye-opening experience that left me humbled and feeling extremely fortunate.'

Rising to the challenge

Thanks to everyone who has done their bit for our charity in 2015 – you are all heroes to us. Here are just a few highlights to share.

Tanya Grey, her daughter Lola, aged eight, and four-year-old Finlay who has mild haemophilia B, raised £345 in the Market Drayton 10km (Tanya) and fun runs in May. Tanya says: 'The Society does such a great job, educating people that this condition can be managed… people with a bleeding disorder can do anything they want to and nothing should stand in the way'.

A team of supporters from our corporate partner Baxalta raised £5,057 in the London to Paris cycle challenge in July. Nicole Farmer, Baxalta UK's managing director, says 'It has inspired our people to achieve something that maybe they didn't think was possible – and have some fun along the way'.

This year's British 10km run team raised an impressive £6,172 between them. Laura-Jane Butcher, whose fiancé Frankie has a bleeding disorder said: 'I enjoyed every minute of the race and loved the opportunity to fundraise for the Society again and give some help back!' Back: Robert Dulac, Sebastien Ricard, Alice Howe, Richard Bagley, Laura-Jane Butcher, Carreen McCay, Lisa Valentine-Grebius, Ian Mobey. Front: Lisa Bagley, Jules Ricard. Not pictured: Dominic Donoghue

Pravina Patel, her fiance Suki and Paul Cox raised £670 in the Yorkshire Three Peaks Challenge as part of their ongoing fundraising efforts with the support of their employer, corporate partner Sobi.

Skydive 65: 12 brave souls jumped out of a plane during our 65th anniversary year, raising a fantastic £7,857. Pictured here are Elliot (L) and Wyatt (R) Ko from Bournemouth, whose cousins Cassius and Jonny both have haemophilia, raised £1,076 and loved every minute: 'It's not jumping, it's falling with style!'

Can you help?

As a charity, we receive no government funding and rely on generous support from our wonderful members, fundraisers and friends, all over the UK.

There are a variety of ways you can give back to our charity:

Anytime:

- **Online using the DONATE button on our website at haemophilia.org.uk**
- **By text message from your mobile phone: just text HAEM25 £?? [insert your chosen amount of £1, £2, £3, £4, £5 or £10] to 70070.**
- **By phone or post: call or write to us using the contact details on the back cover.**

Regular giving by Direct Debit

A small amount can go a long way. Regular donations, where we know what we're likely to receive and when, help us to plan our work and channel funding to the projects and services that need it the most, developing new or priority activities as well as sustaining the best elements of what we already do.

No matter how big or small, regular giving helps the Society sustain our work for the long term. And don't forget, if we can claim Gift Aid on your donation, the Government will give us 25p extra for every £1 donated.

Payroll giving

Did you know that you can donate to our charity easily and effectively from your pre-tax pay? The Haemophilia Society is very lucky to receive donations through payroll giving, where people choose to set up regular donations through their employer. Because of Gift Aid, a donation of £10 only costs £8 after tax for basic rate taxpayers. We would like to say a big THANK YOU to all of you who do this; your ongoing support is greatly appreciated by everyone who receives the help they need.

The gift of a lifetime

Remembering The Haemophilia Society in your will is perhaps the most special gift you can make to people affected by a bleeding disorder. Legacy donations are important for many charities, including our own, and leaving a legacy to The Haemophilia Society will enable us to support future generations throughout their lives. Please contact us (details on the back cover) for more information.

Giving at Christmas: It's in our blood

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 ☐

Card number: ______________________ Security code: ____________

Expiry date: __________ Issue number: __________ Issue date: ____________

Signature: ______________________ Date: ____________

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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

January 23rd - Carriers' & women with bleeding disorders Conference Birmingham 28th - International Rare Disease Day Youth Ambassadors Residential Training Weekend Kids & Teens Weekend Northern Ireland	**February** Ageing projects workshops x3 Inhibitor project workshops x3 Kids & Teens Weekend Wales	**March** 5th-6th - Local Groups Forum Residential Weekend 18th-20th - Newly diagnosed families weekend Longleat Center Pards Kids & Teens Weekend Scotland	**April** 17th - World Hemophilia Day Newly diagnosed families weekend Teen Weekend - venue TBC	**May** Ageing with a bleeding disorder conference Kids Weekend - Venue TBC	**June** Youth sailing weekend
July 24th-28th - World Federation of Hemophilia World Congress Orlando, USA 28th - World Hepatitis Day	**August** Arts Weekend Leeds Kids Weekend - Venue TBC	**September** Inhibitors Conference Newly diagnosed families weekend	**October** Service of Thanksgiving and Remembrance London KidsWeekend - venue TBC	**November** AGM - Venue TBC	**December** 1st - World Aids Day

Fundraising events 2016

January New Year New You We are dedicating the whole month of January to any new challenge that you set yourself. Why not help our charity if you are planning a new year's fitness regime?	**February** Coventry Half Marathon	**March** Paris Half Marathon North London Half Marathon	**April** Manchester Marathon Brighton Marathon London Marathon Plymouth Half Marathon	**May** Milton Keynes Marathon and Half Marathon Run Hackney Edinburgh Marathon	**July** British 10k RideLondon Colour Vibe Series
August Mudnificent 7 London Triathlon	**September** Berlin Marathon Run to the Beat Northampton Half Marathon Great North Run Cheltenham Half Marathon	**October** Bournemouth 5km, 10km races Bournemouth Marathon Zombie Evacuation Race Royal Parks Half Marathon Amsterdam Marathon	Salisbury & Yeovil Half Marathon Chester Marathon Oxford half Marathon Bristol & Bath Marathon Exeter Great West Run	**November** Vitality West Run London	**December** Santa Run

Throught the year
May - Sep - Spartan Race Series
May, Jul, Sep - London to Paris Cycle
The Countrywide Great Tour 2016 Cycling event - all year
May, Jun, Aug, Sep - Bear Grylls Survival race 5km, 10km and 30km
Skydives - Various locations throughout the country

Thanks to our corporate sponsors who provide valuable support:

Abbvie
Baxalta
Bayer (newly-diagnosed families)
CSL Behring (women and carriers)
Period Box (Talking Red)
Grifols
Novo Nordisk
Octapharma
Pfizer (Women / Carriers)
Sobi (children and young people, AGM and conference)
Superdrug (Talking Red)
Virgin Money Giving.

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

abbvie Baxalta BAYER CSL Behring GRIFOLS novo nordisk PERIODBOX octapharma Pfizer sobi Superdrug Virgin money giving

THE
HAEMOPHILIA
SOCIETY

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 for your centre, friends or family.

The Haemophilia Society staff are:

- Liz Carroll, Chief Executive
- Christina Burgess, Head of Membership and Planning
- Stephen Wilkie, Head of Fundraising
- Lorna McKay, Fundraiser
- Serena Lindsay, Services Coordinator
- Cynthia Creavalle, Finance Officer
- Fiona Donoghue, Chief Executive's Assistant and Office Manager
- Victoria Foster, Receptionist and Office Administrator

To contact a member of the team, please call 0207 939 0780 or email [firstname]@haemophilia.org.uk

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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 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.

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