

Haemophilia Society

Introduction

We are the only UK-wide charity for everyone affected by an inherited bleeding disorder, a community which includes family members, healthcare professionals and other supporters. Since 1950 we have campaigned for better treatment, been a voice and a source of information and support, and have helped members to lead fulfilling lives and inspire others to do so.

Around 26,000 people in the UK have a diagnosis of an inherited bleeding disorder. Approaching 7000 are males with haemophilia, but there are also around 2000 females registered as carrying a defective gene who also often have low levels of factor VIII and have haemophilia. The largest proportion of people who have an inherited bleeding disorder have Von Willebrand Disease, but there are many rarer bleeding disorders that affect both men and women.

This year The Haemophilia Society celebrated its 65th year. We celebrated by hosting our first ever arts weekend where families could come together, be creative and have fun together while exploring what a bleeding disorder means for them. We were joined by member who were still toddlers to some of our longest standing member. Our special guest was member Linda Wild who was 65 on the same day as The Society.

This was a year of significant development and growth, particularly for our services and members support. Early in 2015 we published our three-year strategy and plan outlining how we will develop new services, increase our funding and strengthen our governance to ensure a sustainable future for the organisation that is relevant to our membership and forward thinking. This led to the development of our 7 Key life stages strategy. This identified 7 key times in our members' lives when they felt the need for additional support and information. Our services and activities are now focussed at these points. In addition to these 7 key life stages we identified other groups or situations where our members looked to us for support. This included people with an inhibitor and women with bleeding disorders. We worked with our members to prioritise areas to focus on and what services should include.

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 our community, 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.

Key risks and uncertainties (I would put this much further down the order)

Financial

Significant reliance on charitable contributions from members, corporates and other sources, and lack of certainty over the sustainability and security of these sources of funds.

Governance

Managing the risk of non-compliance with relevant legal and regulatory requirements.

Reputation

Managing reputational risk which could be impacted in any various ways, such as, perceived failure to represent specific member(s) views on a particular issue; failure to successfully influence government or NHS decisions on key issues; failure to safeguard a vulnerable adult or child at one of the Society's events or services.

Each risk was carefully monitored and mitigation procedures put in place to reduce the likelihood and impact of the risk. The Board of Trustees reviewed the risks and mitigation quarterly.

Development and service delivery.

Life Stage 1 Newly diagnosed families

Members told us a child's diagnosis is often traumatic and a lonely time. Many of our families also experienced suspicion that bruising was caused by violence facing very difficult situations before a diagnosis was finally made. Many families talked of isolation and fear. In light of this we developed our Newly Diagnosed Families weekends further and for the two week-ends carried out this year a total of 27 families including 48 children attended. Weekends include sessions on 'What does your bleeding disorder mean to you' and 'What do Dads think Mums think?'

The weekend exceeded expectations and more: a massive weight has been lifted. To be with other families who actually 'get it' made the world of difference. I cannot recommend this enough to other parents.

Key life stage two Starting nursery and school

It is often nerve wracking for parents when their children start nursery or school, but when your child has a bleeding disorder this is heightened. Many schools and nurseries are unsure of how to care for a child with a bleeding disorder and many parents find it difficult to provide the information the school needs. This year we supported many families in this situation and spoke to nursery and school staff reassuring them that children should be treated as any child would be as long as precautions are taken and staff are aware of what to do in case of injury or a bleed. During the year we worked with parents and teachers on the content of a new school's booklet that will be available in 2016.

Key life stage three Learning to self-treat

With so many UK haemophilia centres promoting home treatment children are beginning to learn to do their own treatment from the age of 8. However, it isn't easy to treat yourself

so we encourage all of our younger members from 8 - 18 to attend our youth weekends. We held 4 weekends this year with 37 young people attending including supporting 13 children to attend Barretstown in Ireland, a sailing weekend, an Arts week-end, a Shropshire week-end and one in Wales. At the weekends, as well as having lots of fun abseiling and climbing, serious conversations and learning took place. Each weekend is attended by haemophilia nurses and physios as well as some of our youth ambassadors. Everyone attending has their treatment together, under the supervision of our nursing volunteers. They share techniques, discuss worries and challenges and learn from each other. Our youth ambassadors share experiences of their own and talk about the importance of having treatment regularly and what happens if you miss a treatment. As you reach teenage years and become more responsible for your own treatment it is easy to forget or skip treatment, because you have never had a problem and forget that this is mainly due to your regular treatment. Teenagers of ten tell us they don't realise how important it is to keep taking your treatment until they miss it and experience the pain of a spontaneous bleed. We hope by hearing from our youth ambassadors our younger members will understand and remember their treatment regularly, however focussed they are on other activities.

Having had several conversations at the week-end about the impact of bleeding it seemed reassuring to the young people that we had managed our conditions in a way that allowed us to progress in our lives. Ria Peake, Youth Ambassador

Key life stage four Transition to adulthood

Just as you are finally getting to grips with life with a bleeding disorder and you have survived your early teens, it is time to move from children's care to an adult haemophilia centre. For some this is very smooth and painless, but for others it can be a very difficult time. We have been working with the organisation Haemnet to undertake some research into the challenges of transition and what we can do to support members at this time. Our youth ambassadors spent time phoning families to understand their experiences and as a result we recruited two new youth ambassadors to join the team. As we understand more about this, we will look to develop resources or services to support members at this time.

Key life stage five Choosing a career

Whether you have a bleeding disorder yourself, or care for someone who has, your career options can be affected. We have been sharing members' stories and helping people make appropriate choices and ensure they understand how the law can help when you have a bleeding disorder.

Key life stage six Relationship planning

When you are in a relationship or thinking about a future with a partner the prospect of your children inheriting your bleeding disorder can have an impact. This year we held a conference for women with bleeding disorders including carriers where 50 women and their partners came to together to discuss the concerns and challenges of living with or being a genetic carrier of a bleeding disorder. The day included sessions on 'Emotional impact' and 'What medical choices are available to me?'

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 parent's experiences with my brother. I'm less nervous about my future now.

Key life stage seven Ageing with a bleeding disorder

As you age life can feel uncertain as previous generations often didn't make it to older age, the specialist health teams are learning with you about how people with bleeding disorders experience the everyday challenges of getting older. This year we began a major new project to look at ageing and bleeding disorders. This began with an ageing Information Day and has led on to us filming members of our community and their family to fully understand the impact this has. We have also filmed health professionals and are using this information to help shape our services and advocacy work in the future. The films will be available in 2016 and will lead the way in ensuring our older members receive the service and support you need in the coming years.

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!

Living with an inhibitor

Life can be tough with an inhibitor with more bleeds, more pain and more treatment. We know it increases hospital visits and has a huge impact on the whole family's life. Our focus has been to dig deeper into what this means for you and how we can support you through the challenges you face. We started with an inhibitor Information Day bringing together 23 members and their families who live with an inhibitor. We have developed a film to better understand members' experiences. This is just the start of a long term project, but has already helped reduce the isolation so many of our members affected by an inhibitor feel.

When we deal with his bleeds in joints and muscles it can be tough on the family, especially since we are all very active. 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.

World Haemophilia Day

This year we undertook some market research to understand the public's perceptions of bruising. We know many of our members experience difficulties when people see their bruises, jumping to conclusions. Whether you are a parent accused of abusing your child or a woman hearing comments about how you must be being beaten, it is often enough to make members feel uncomfortable and self-conscious. Our Bruised not abused radio and newspaper campaign reached almost 48,000,000 listeners on via radio stations across the UK. Our members also took on the challenge of raising awareness by holding events around the UK and raising funds too.

Talking Red

Our Talking Red awareness campaign went from strength to strength this year with even more women taking part in events and raising awareness of women and bleeding disorders. This year Celebrities Gok Wan, Emilia Fox and Carol Smillie supported the event. Emilia Fox said *'Talking Red encourages women to be able to talk about bleeding disorders. Just one cation could help them reach someone currently suffering in silence because they think their symptoms are normal'*.

Advocacy and influencing

This has been a frustrating and busy year continuing our campaign to bring about a fair resolution for our members who were infected by contaminated blood products in the 1970's and 1980's.

Early in the year the long awaited Penrose Report was published in Scotland. Despite this being delayed by many years the outcome was a disappointment to many. Although a great deal of evidence was clearly documented in the report, no useful recommendations were made and many of our members were left feeling angry and disillusioned. The Society reviewed the evidence and published a response to the report and continued to work with governments across the UK to bring about a fair settlement for those affected by each devolved government. In May 2015 we wrote to the Prime Minister setting out what we believed needed to be done to bring about a fair settlement. We continued working with our colleagues from Haemophilia Scotland who were able to engage very effectively with the Scottish Government, who were open to discussions. It was harder to achieve this level of open dialogue with the Department of Health in England. In October 2015 The Department of Health established a reference group to inform the development of a consultation on support for those affected which we were able to attend with others from the community. Unfortunately, the recommendations from the reference group were not reflected in the consultation that was launched by the Department of Health in February 2016.

Throughout this time we have continued to act as the Secretariat for the APPG (all party parliamentary Group on Haemophilia and Contaminated Blood) and have worked very closely with MPs to ensure this issue remains high on the political agenda and MPs are informed of the impact government proposals and activity have. Details of our work are available on our website.

This has also been a year of significant change for our members affected by Hepatitis C. With the introduction of a new class of treatment with high levels of success and few side effects than previous treatment, there was the real potential for our community to finally receive effective treatment. We were able to respond to several NICE consultations and were hopeful that treatment would be quickly made available. This became reality in Scotland Northern Ireland and Wales. However, NHS England challenged NICE and requested a delay in treatment starting and introduced a phased treatment plan, meaning many of our community would not receive treatment in a timely way. We continue to work closely with the commissioners and APPG to call for access to treatment.

Worldwide connections

We have strengthened our relationships with the UK Haemophilia Centre Doctor's Organisation (UKHCDO), Haemophilia Nurses Association, Haemophilia Physio's, The European Haemophilia Consortium (EHC) and World Federation of Hemophilia (WFH). We are members of the Clinical Reference Group providing advice to NHS England on treatment for bleeding disorders and are an active member of the Factor Tender panel who make recommendations on treatment access and availability. As the host nation for the WFH Congress in 2018 we have already started making plans and have been working with the WFH team to ensure we have a positive presence at the next Congress in July 2016 in Orlando Florida.

CHES study

As the Chair of the Steering group for this research study Liz Carroll has been working closely with HCD Economics who undertook the research and analysis to ensure the data can support our work in calling for improved treatment and care in the UK, as well as enabling our partners in the four other European nations to do the same. The study is the largest ever undertaken into the burden of severe haemophilia and had produced some fascinating data to support our activity. Our thanks go to our Trustee Jamie O'Hara for all his work on this study.

Local Groups

Our local groups continue to grow and provide an invaluable support to people in their local communities, providing information and support as well as fundraising and awareness. Without our local group volunteers, we wouldn't be able to provide the local support so desperately needed.

AGM and Conference

Over 100 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 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 a physio and dietician, incredible motivational speaker Chris Moon, art therapy with Simon Bell and a touch of drumming with Sam!

We revealed our 'Haemophilia Hero' the late Alf Morris: Lord Morris of Wythenshawe who was voted by our members 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.

A lively discussion about whether our charity should consider changing its name also 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 our members in the months to come.

'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.'

Fundraising

This year our fundraisers have been even bigger and better with more of our community than ever before running marathons, jumping from airplanes, climbing mountains. Cakes have been baked and events planned. Without our community fundraisers we couldn't achieve anything like the amount we do, so one of our biggest thank you's goes to our amazing fundraising teams.

Volunteering

This year we have had some incredible support from volunteers, both in the office and out and about across the UK, however one or two volunteers have given above and beyond and we would like to thank them personally. Dave Gort has worked with us to improve our website and publications and never tires of us asking for one more change to make it a bit better. It's a work in progress, but we are getting there. Keith Colthorpe has also travelled up and down the country taking photographs of our service and events to ensure we can share images with our members and bring our service to life.

We also know we couldn't run most of our services without the incredible nurses and physiotherapists who volunteer at all our newly diagnosed family weekends, youth weekends and conferences. One particular nurse Cathy Benfield has given up more than her fair share of weekends to volunteer for us. Thank you Cathy.

Youth Ambassadors

This year we created our Youth Ambassador programme and recruited 6 youth ambassadors. Four young men and two young women all with a bleeding disorder. As a team they have attended services, talked about their experiences with members, and supporters and have attended training sessions to enable them to support us on the development of the charity and bring a younger person's perspective to the work we do. We would like to thank Rob Barnard, Luke Pembroke, Ria Peake, Laurence Woollard, Hannah Yarnall and Matthew Minshall for their tireless enthusiasm and energy.

We remember

We remember our members, friends and volunteers who have died during the year: they have left us with hope and determination; hope that we can support our members to live full and positive lives and to ensure the tragedies of the past are resolved and will never happen again.

Future plans

In 2016-17 we will continue to develop and grow our services, with a particular focus on delivering services as a result of our work this year on inhibitors and ageing. Using the knowledge gained we will create new services and information in partnership with our members. We will also develop and publish booklets and factsheets on the key issues faced by our members and ensure these are available online, and where possible in print.

We will continue to act as the secretariat to the APPG and will look to bring final resolution to the longstanding issues faced by our community affected by contaminated blood, but also begin to address other issues impacting haemophilia care and treatment such as access to new drugs and benefit access.

We also aim to increase our support to our Local groups with new ideas and opportunities to bring the local face of the Society to communities across the UK.

In our fundraising we will expand our offer and work with a greater range of companies and offer more events to diversify and increase funding again. We aim to ensure a balanced income and expenditure in 2016-17.

We will also continue the discussion on whether our name and logo are fit for the inclusive modern charity we are today. We will ask members to decide if our name and logo should change to ensure everyone with a bleeding disorder feels welcome and included in our organisation.

Liz Carroll
Chief Executive Officer, The Haemophilia Society
October 2016