

## Haemophilia Society

We are the only UK-wide charity for everyone affected by an inherited bleeding disorder; a community of individuals and families, healthcare professionals and supporters.

For 65 years we have campaigned for better treatment, been a source of practical information and support, and enabled people living with long-term conditions to:

- lead fulfilling lives
- make informed choices about their treatment and care
- support and inspire others to do the same.

We also continue to advocate for a fair settlement and access to the best possible health and social care for those members of our community affected by the contaminated blood disaster. Membership of The Haemophilia Society is free and open to all.

Almost 26,000 men, women and children in the UK have a diagnosed inherited bleeding disorder. Of these, around 10,200 have von Willebrand disease and around 6,800 have haemophilia. There are also around 1,800 carriers of haemophilia who are recorded in the National Haemophilia Database as having low levels of factor; they may experience bleeding themselves. The balance is made up of people with rarer bleeding disorders.

This has been a year of substantial progress for the charity, building on the changes started last year. The new management team under our CEO Liz Carroll is now fully in place, and we have agreed a strategy developed after consultation with members and begun work on a three-year plan. The Trustees' Report details services we have delivered during the year, and demonstrates our increase in activity since 2013/2014.

In recent years the charity has had an excess of expense over sustainable income, but as reported in the Financial Review we have diversified and increased sustainable funding despite the ending of our annual government grant, while at the same time the move to new premises along with a review and renewal of all of our supply contracts has substantially reduced our fixed cost base. We have professionalised our measurement of the impact of our service provision, and this has already had a positive effect on the willingness of funders to support our projects. In the current financial climate, fundraising continues to be a core issue for the charity, but we are confident that we are on a path to increase income to fully cover expense by 2016/2017; meanwhile we have adequate reserves to cover the budgeted shortfall for next year.

A disappointing feature of the year has been the late delivery of the Penrose Report into Contaminated Blood and its unsatisfactory conclusion contradicting the detailed evidence the report itself presents. This has contributed to delay in the Government acting on the Prime Minister's promise to review the settlement for those suffering the impact of contaminated blood.

The Society continues to advocate for a speedy review and revision of the settlement, based firmly on independent analysis of the needs of those affected.

An important initiative this year has been our initiation of a Burden of Illness study into the cumulative impact of severe haemophilia across all aspects of life. This will be by far the largest study of its type and will become an important resource for economic analysis of treatments when it reports in the third quarter of 2015.

As Chair, I have had the opportunity to see how many people, paid and unpaid, have contributed to the work of the Society. I would like to thank all of them, including our staff, who work far beyond what we could reasonably expect, our trustees, member volunteers in many areas, clinicians who support events, review articles or provide advice, MPs who support the work of the APPG, our President Baroness Meacher, those who are helping plan the Glasgow WFH Congress, those who have raised funds for the charity and those who have donated, and our many commercial sponsors. Without the contribution of all of these people we simply could not function.

## **Our Vision, Mission and Values**

***Our vision:*** Wellbeing for everyone with a bleeding disorder.

***Our mission:*** For all those affected by bleeding disorders, we will provide information and services; build community and mutual support; influence government health and welfare policies, including advocating for those impacted by contaminated blood; and involve people in making decisions about their own care.

***Our values:*** We relate everything we do to the needs of everyone affected by bleeding disorders; act with integrity, honesty and transparency; make the best use of our resources; and are inclusive and independent.

## **Public benefit statement**

The Haemophilia Society's services are available to everybody affected by inherited bleeding disorders in the UK. We have almost 5,000 members; membership is open to all, with no charge, and services are open to members and non-members alike. We provide social, psychological, and practical support, complementing the care given by the NHS and bringing people together to reduce the isolation many of our community experience. We advocate to ensure levels of NHS service are maintained and improved, and encourage patients to become involved in decision making about their own treatment. We are recognised by the government as a key patients' representative promoting informed patient involvement in monitoring and developing services.

## **Specific activities providing public benefit include:**

- Providing information, services and support on all aspects of inherited bleeding disorders, enabling people to live well and make informed decisions about their own treatment and care. Information is provided at service events, by phone and email, and through a website, very active Facebook pages, leaflets on specific aspects of bleeding disorders, a network of local groups, and publications.
- Running day and residential events for different groups of people with bleeding disorders in order to provide social support and education. For example, during the year we ran two weekends for parents with children newly diagnosed with bleeding disorders and weekends for children and teenagers with bleeding disorders, and held our first public awareness campaign for women with bleeding disorders. We also held an information day for people infected with Hepatitis C by contaminated blood products in the 1970s in 1980s.
- Ensuring that the patients' viewpoint is heard in key NHS and Department of Health forums, for example on the Clinical Reference Group for Haemophilia.
- Escalating issues of provision of care to the NHS government health teams.

- Advocating for fair treatment and support for those impacted by the contamination of blood products supplied by the NHS in the 1970s and 1980s.
- Commissioning research with the intention of benefiting those with bleeding disorders, for example the Burden of Illness study on the impact of haemophilia which was initiated during the year.

## Services and Activities

### *Newly diagnosed weekends*

This year we were able to build on the learning from our pilot services in 2013 to improve our weekends for newly diagnosed families. We held two weekends, bringing together 32 families comprising 62 adults and 64 children.

The weekends enabled families to learn from each other and from haemophilia experts. Each weekend gave the opportunity to hear from a haemophilia consultant, a physiotherapist, and a specialist paediatric haemophilia nurse. Topics included what a diagnosis means, living with a bleeding disorder, treatments and the importance of physiotherapy. There were also opportunities for mums and dads to separate and have a facilitated discussion about their feelings, coping strategies and the issues they face following the diagnosis of their child. Common themes emerged: for mums, feelings of guilt for passing on an affected gene or not spending enough time with the rest of the family, or frustration over having to stop working and always be on call. There were also discussions about being constantly on guard and fearful of anyone else looking after their child. Dads discussed feelings of isolation and uncertainty about the future, as well as sadness about how their relationship with their son or daughter may be affected by their diagnosis. The weekends were held at Center Parcs to take the event away from a hospital setting; families could feel part of normal life, children could be cared for and parents could relax.

For many families the weekend was the first time they had dared to stay away home following their child's diagnosis and for almost every mum, the first time someone else had looked after their child. The highlight of the weekend for many was the involvement of our new Youth Ambassadors. The Youth Ambassadors all have a bleeding disorder themselves and were able to talk about the ups and downs in their life, as well as showing parents how they gave themselves clotting factor treatment.

### *Activity weekends*

Some children with a bleeding disorder experience isolation, and parents can struggle to have the confidence to let their children be active and participate in certain school activities. Some children and parents find it difficult to cope with learning to self-treat. We ran two activity weekends this year, one for children aged 8–13 and another for teenagers. Twenty-six young people attended our weekends; this included siblings as well as those with a bleeding disorder. A diagnosis has just as big an impact on brothers and sisters and we know it is important to invite them too. The first weekend for the younger children was in Preston where the children took part in abseiling, archery, and go-karting, and got thoroughly soaked during a raft building and sailing finale to the weekend.

However, the biggest impact came in the quieter moments. At the campfire session the children were encouraged to talk about what it feels like to have a bleeding disorder and to ask any question they wanted. The session was facilitated by specialist nurses and the

conversations ranged widely, from 'how do you describe it to your friends?' to 'who do you tell?' and 'why do I bleed differently to you?' There was an interesting discussion about the difference in clotting between haemophilia and von Willebrand Disease.

We also encouraged the children who didn't already treat themselves to have a go. Everyone had treatment together, sharing tips, discussing techniques and learning from each other. We also asked the children a few questions before and after the weekend which showed that the event clearly had a positive impact. Mitchel (8) summed up the weekend as "My best holiday ever!!"

At the beginning of the weekend 40% of the children didn't know what bleeding disorder they had compared to 28% at the end of the weekend.

Before the weekend 84% would tell someone if they had a bleed (those that didn't said it was so they could keep playing or do sport). Afterwards 99% said they would tell someone as they understood why early treatment was important.

The 'Big Teen weekend' had a similar impact. For example, Josh (15) commented: 'it was so much better than sitting at home watching Netflix'. During the weekend the teenagers worked together as a team, gaining new skills, supporting each other physically and emotionally and growing in confidence, joined and encouraged by a Youth Ambassador.

## **Global family get together**

During the summer our 'Global family' met. Global family is our service for families who feel particularly isolated due to their bleeding disorder. This may be due to belonging to a community where any ill health is seen as unacceptable, or where someone lives far from their relatives or is a single parent. The (indoor) picnic to bring people together in a safe environment was a riot of food, colour, fun and games. For many of the children attending this was the first time they had been able to speak with anyone else about their bleeding disorder, and for parents a first opportunity to share their concerns and feelings.

## **World Haemophilia Day**

We celebrated World Haemophilia Day with a radio campaign to raise awareness of bleeding disorders and with The Buddy Awards. The Buddy Awards enable young people to nominate someone who has helped and supported them through tricky times with a bleeding disorder. Brothers and sisters, teachers, nurses and friends were all nominated. Two hundred guests attended and celebrity children's entertainers Dick and Dom presented the awards. The Buddy Awards are a fantastic opportunity to recognise and thank the people who support our community.

## **Talking Red**

We know that hundreds of thousands of women in the UK may be living with a bleeding disorder and not know. Symptoms can include easy bruising, heavy menstrual bleeding or frequent nose bleeds. In June we launched our first Talking Red Campaign, where we encouraged women with a bleeding disorder to talk about it with family and friends, and launched an awareness media campaign. Women across the UK shared their stories on social media, painting their nails red and joining in our awareness-raising Red Knicker night. Our press coverage for the campaign reached people across the UK with lots of stories in local papers and The Daily Mail. The campaign had a direct impact, as evidenced by women who contacted the Society having seen the stories, took the information we had shared to their GP and were referred to a haemophilia

centre after many years of being told their symptoms were normal. Some were subsequently diagnosed with a bleeding disorder.

## **Contaminated blood**

Many of our older members were infected with multiple viruses including Hepatitis C and HIV through their NHS treatment in the 1970s and 1980s. We continue to work with the community affected to support them in living with complex multiple conditions. We continue to advocate on their behalf to government, the Department of Health and the NHS to ensure they receive the support and care they deserve and need. This year we held our first Hepatitis C information days in partnership with the Hepatitis C Trust. For many of those infected, the stigma of infection and fear of others' reaction leads to isolation and lack of support. Our information days enabled the participants to meet in a safe environment and learn more about living well with hepatitis C and haemophilia. The day included information on nutrition and maintaining your health, with excellent evaluations. The participants had often not spoken about their infection to others and built relationships over the events that have since continued.

The Society is also the secretariat for the APPG (All Party Parliamentary Group) on Haemophilia and Contaminated Blood and we work closely with them to ensure the voice of those affected by contaminated blood is strongly heard in parliament. The Society and MPs frequently hear from people who have struggled to negotiate the complex and often distressing system of Trusts set up to provide financial support to the people affected. This year we encouraged and supported the APPG to undertake an inquiry into the current support for those affected by the contaminated blood scandal in the UK. The Society funded the survey and report publication and has used the findings to advocate to government. We worked closely with Diana Johnson MP and Jason McCartney MP, then co-chairs of the APPG, and with the Rt Hon Alistair Burt MP who has been particularly supportive and influential in bringing about positive steps towards a new and improved package of support for the community. The report was launched in parliament in January, followed by a three-hour backbench debate, where MPs from across the House showed their support and commitment to the community. The report is available on our website.

## **The Society online**

During the year we launched our new website, which we continue to develop and update. The website has information on living with a bleeding disorder, including benefits, travel insurance, personal stories and information about our events and activities. It also provides information approved by our clinical advisory group on medical aspects of the different bleeding disorders. [www.haemophilia.org.uk](http://www.haemophilia.org.uk)

Our social media presence continues to grow, with over 6,000 participants on our three Facebook pages and groups. The pages are very active, with members sharing experiences, seeking and giving support and sharing thoughts on the work of the charity.

## **Worldwide connections**

We continue to work with government and with the NHS, particularly with the UK Haemophilia Centre Doctors' Association (UKHCDO) and the Haemophilia Nurses Association. As members of the NHS Clinical Reference Group, NHS Tender procurement groups and Department of Health Blood Safety Consultative Committee, we are able to influence decision making about quality and safety of care as well as to ensure the patient voice is represented.

We are also active members of the European Haemophilia Consortium (EHC) and The World Federation of Hemophilia (WFH). During the year, staff and trustees attended WHF events, including the WFH Congress 2014, where we heard from experts about developments in treatment, care and support across the world; feeding into our activities on behalf of our members. These events also provided opportunities to build relationships with other Societies across the world and learn from others' experiences, for example in relation to our Talking Red Campaign and new Youth Ambassador Programme. EHC training events have enabled staff and trustees to learn about particular issues such as von Willebrand Disease, inhibitors and economics of health technology. In October we were fortunate to host the EHC annual conference in Belfast, thanks to the hard work of Gordon Clarke, a leading member of EHC and WFH over many years. Gordon's dedication to the community enabled us to sponsor two members from mainland UK to attend as well as sponsoring places for 50 members from Northern Ireland. The conference was a huge success and provided inspiration for our strategy development at our AGM in November.

### **Burden of Illness study**

In 2013 we started work on the Burden of Illness study on haemophilia. In 2014 we reached agreement with an academic partner and the study was named CHES: The 'Cost of Haemophilia across Europe: a Socioeconomic Survey' and will be by far the largest study of its type. Liz Carroll chaired the steering group for the study, which included colleagues from the Societies in the other EU countries where the study was undertaken (France, Spain, Germany, Italy). Chester University led the study and employed Health Care Decisions (HCD) Ltd. to undertake the research. This was not the Society's first choice of partner, as trustee Jamie O'Hara is a Director of HCD; however the Charity Commission approved the decision to partner with Chester University and agreed the Society had acted appropriately and had not provided any personal benefit to our trustee. Recruitment of patients was well underway as the year ended in March 2014. Our thanks go to Jamie O'Hara for driving this study forward including sourcing the funding and enabling the Society to initiate such an important research study for our community. Results are expected to be published in summer 2015 and we hope to use these to influence key decisions on health and social care, as well as contributing to the world's understanding of the true impact of severe haemophilia.

### **Local Groups**

Our Local Groups continue to grow and develop with many holding social, fundraising and educational activities during the year. These ranged from the 'Nippy Dipper' in Grampian – an annual Boxing Day fancy dress dash into the North Sea – to a family fun day to bring families with bleeding disorders together for support in Bournemouth. Our thanks go to the volunteers who run our local groups; the support and encouragement they give to members in their local communities is invaluable.

### **AGM and Conference**

The 2014 AGM and Conference was our largest for many years, with over 100 members of all ages attending. The AGM dealt with the formal business of the Society and was followed by our 'Fit for the Future' conference. Members heard from our new celebrity ambassador, Paralympic swimmer Jack Bridge, and our Celebrity Supporter gold-medallist cyclist, Alex Dowsett. Both Alex and Jack have severe haemophilia and are role models for many members of the bleeding disorder community. The conference enabled members to attend workshops on ageing and



haemophilia, Talking Red – women and bleeding disorders, sticking with treatment even when you don't want to, learning to self-treat and singing for your soul. There was also a chance to swim with Jack and cycle with Alex. During the day we asked members to help us prioritise the services they felt we should focus on in the next three years; this helped shape the long-term plan we finalised later in the year.

## **Fundraising**

With no government funding and an increasingly challenging fundraising environment, the Board of Trustees approved increased spending on fundraising staff and activities; this is already enabling us to diversify our funding streams and to increase our income in a sustainable way. This year we extended the range of fundraising activities for our supporters to take part in with our very first Challenge event – Trek Iceland – where 11 trekkers braved high winds and freezing temperatures to raise £37,000 for the Society. We also had a significant increase in the number of people running marathons, cycling and holding community fundraising events; these included an exceptionally wet Ride London 100-mile cycle ride and a very chilly Santa Run. Investing in fundraising has been an important decision this year, which we believe will improve our financial sustainability. Thank you to everyone who has pushed themselves to their limits, raised funds, organised events and sponsored our activities. Without your support we would not be able to provide the much needed information and support we do.

## **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 provide information and support for our members to lead positive lives and determination to ensure that the tragedies of the past are resolved and will never happen again.

Liz Carroll  
Chief Executive Officer, The Haemophilia Society  
October 2015