

Haemophilia Society

We are the only UK-wide charity for all those affected by a genetic bleeding disorder: a community of individuals and families, healthcare professionals and supporters. For almost 70 years we have campaigned for better treatment, been a source of information and support, and raised the awareness of bleeding disorders.

We:

- Raise awareness about bleeding disorders
- Provide support throughout members' lives
- Influence and advocate for the community on health and social care policy and access to treatment

Our peer support - through local groups around the UK and our online community - offers friendship and a listening ear when needed, as well as enabling people to share their views and experiences. By bringing people together for information and support at events tailored to all life stages, we amplify their voices to reduce isolation and influence government, welfare and health care policy. Our community is at the heart of everything we do - we work collaboratively with members and health professionals to ensure we make decisions influenced by their valued input and direction.

WFH Congress 2018

The year began by hosting the World Federation of Hemophilia (WFH) Congress in Glasgow from 20-24 May 2018. Congress was a huge success, with 5,110 delegates from 132 nations attending. Delegates included people with a bleeding disorder, healthcare professionals, allied health professionals, pharmaceutical industry staff and charity staff from across the world. Our role included shaping the programme, recommending speakers, promoting the event, training Glasgow city tourism representatives and recruiting almost 100 volunteers to support Congress activity over seven days, including hosting a treatment room for those who didn't have access to treatment in their own county. This was a huge piece of work collaborating closely with WFH, Haemnet, People Make Glasgow Welcome and SECC.

This was a unique event for our members, giving them the opportunity to meet friends and colleagues from across the world, hear about advances in treatment and support, and share experiences and make memories that last a lifetime. We were able to share examples of our services and publications as well as introduce our mascot Buddy, who proved to be very popular. We can't thank our amazing volunteers and colleagues enough for the incredible energy and vitality they brought to the event.

Newly Diagnosed Family Weekends

Hearing that your child has a bleeding disorder brings with it a huge range of emotions. For those who know they have a family history it often brings guilt for passing on the gene, or fear that your child will go through some of the devastating consequences you, your father or brothers experienced. For others the news is totally unexpected and comes along with questions about unexplained bruising, social services involvement and fear for your baby and your family life. Our free weekends enable new parents to learn more about what to expect, meet others who are experiencing the same emotions and spend time hearing from and talking to experts, helping them build a foundation of knowledge and support as they start their journey as a family. Specialist bleeding disorder physios, nurses, doctors, psychologists and social workers facilitate sessions alongside our local group representatives and Youth Ambassadors. This year we held four weekends for families with a newly diagnosed child, with one focusing specifically on mild and moderate bleeding disorders, while the others focused on children with a severe bleeding disorder. This year, following feedback from

members weekends have developed to include psychological support for parents and distraction techniques for children while having their treatment.

Youth activities

This year we focused our youth activities for younger children at summer camp in the Lake District that reduced the isolation of living with a bleeding disorder, recognised the impact on siblings and raised confidence levels in our younger members. From learning to give your treatment for the first time and understanding what your condition really means for you, to understanding how teamwork and determination can help you make huge leaps (literally in some cases), the campers loved every moment.

During the year our Youth Ambassadors had been working on developing events for young adults. This culminated in Lads and Dads and Mums and Daughters weekends in the Brecon Beacons over very wet weekends in March, where parents were pitted against their children in archery, quad biking, canyoning and more. The final activity for both groups was an invigorating - for that read very cold water - morning canyoning at the National Park's waterfalls, with a breath-taking white water and rapids ride. This concluded brilliantly with a seven-metre jump into a waterfall!

Youth Ambassador engagement

Our Youth Ambassadors are fundamental to our work. They attend many of our events and services, sharing their experiences, demonstrating treatment and offering a role model to younger members as well as reassurance to parents that a severe bleeding disorder won't hold you back in life. This year two of our Youth Ambassadors decided it was time to move on, but before they stepped down helped us shape a new development programme that has led to the recruitment of seven new Youth Ambassadors. We have also sponsored two young people to attend the EHC youth leadership programme and another to attend their leadership weekend. Our thanks go to Rob Barnard and Luke Pembroke for their passion and commitment to our community.

Talking Red programme

Talking Red this year focused on raising awareness of bleeding disorders with women in universities and our conference events that enable women to come together, talk about the challenges of living with a bleeding disorder and find support from others in similar situations. It can be incredibly isolating when you don't meet others who understand the daily challenges you face, be that not being able to leave the house due to heavy periods, waking up with a nosebleed, or having to manage daily life where bruises are questioned, and pregnancy planning becomes a complex multi-agency conversation.

Ageing

Following our member surveys and conferences in the last few years we have been developing our 'living well' resource pack for members as they get older. Many are concerned about social care as they become less able to care for themselves and live with multiple complex diagnoses. This new resource pack aims to guide people through the issues they may face and ensure they can access the support they need. At the ageing information day this year members fed back on the draft pack, enabling us to ensure it provides the essential information and support they require.

Inhibitor project

Living with an inhibitor long term or hearing that your child has been diagnosed with an inhibitor is often a highly stressful and emotional time. Knowing that the treatment usually given to treat your condition won't work and that you need to embark on intensive treatment that may require multiple treatments a day for several years is daunting. We know that the care people receive in the NHS is

excellent, but the emotional support and day-to-day tips that come from others who are currently living with or have successfully achieved treatment tolerization is invaluable. We are able to bring families together, ensuring they have support and up-to-date information on treatments and know they are not alone. This year we have focused on developing an inhibitor resource pack, working with members who live with an inhibitor, as well as hosting an information day looking at what care and support people can expect when coping with the huge challenges of life with an inhibitor.

Volunteering

We couldn't function without our incredible volunteers. Throughout the year over 30 healthcare professionals supported us at our events, volunteering either for a day or an entire weekend. This is in addition to the hundreds of members who run our local groups and helped organise events across the country, while Youth Ambassadors and Talking Red Ambassadors have also volunteered at our events and education days. Across the UK we have some incredible volunteers who run our local groups, arranging events and raising funds to support members in their local community. We have been working with our local group volunteers to better understand their support needs and are working on developing better support for them.

Advocacy

This year we have continued to advocate for access to new treatments for people with bleeding disorders, responding to NICE consultations and as part of the NHS Tender Boards for treatment and home delivery. As members of the Clinical Reference Group in England we bring the collective patient voice, along with two patients, to provide advice to the decision makers in the NHS on what matters to our members about treatment, care and support. This included access to innovative new treatments, access to specialist nursing and physio care, and sharing people's experiences of their haemophilia centres.

We have also represented patients' views on the Welsh Inherited bleeding disorder project board, which is redesigning care for people in Wales with a bleeding disorder. We also worked closely with the Department for Work and Pensions (DWP) to highlight concerns over benefits, particularly for those with a bleeding disorder who are routinely being refused Personal Independence Payment (PIP) but are successful on appeal. Our work has identified gaps in assessors' knowledge and recommended expert advisers to support a fairer system. We have also worked closely with EIBSS and the APPG on Haemophilia and Contaminated Blood to challenge decisions on support for those affected by contaminated blood and called on government to end the disparity between nations.

Throughout the year we have been patient advocates on numerous working groups including the haemophilia centre peer review audit development facilitated by the West Midlands Quality Review Service as well as the James Lynd Alliance research questions development project (Stop the Bleeding).

Public inquiry into infected blood

Following the previous year's announcement of a statutory public inquiry into infected blood we employed staff to work on the Inquiry to support our members and prepare for evidence. This included a communications expert to ensure the community was informed of the activities of the Inquiry and had access to information in a consistent and balanced way. We welcomed Sir Brian Langstaff's consultation on the Terms of Reference. Having using a range of channels, including a new social media group, we gathered opinions to inform our response to this consultation. The opening of the Inquiry hearings in late September was both welcome and emotional for everyone affected.

Fundraising

Our fundraisers continue to amaze us with their imagination, time and energy. From to running marathons to cake sales or hosting one of our new fundraising Buddies Who Brunch events, we couldn't do it without you. We have also seen increased support from community groups such as rotary clubs and schools. We know how busy our members and friends are and appreciate every event you do to help support our work. In the coming years, we will need to significantly increase our community fundraising activity so we can continue to provide information and support to our members free of charge, so are working on new ways to engage with our community and the wider public. This year we held our biggest Big Red London Bridge Walk to date, with over 100 walkers dressed in our fabulous red T-shirts. This was an amazing event that not only raised important funds, but also built new friendships and shared experiences participants will remember for years to come.

Liz Carroll,
Chief Executive, The Haemophilia Society
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