

# 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

More than 36,000 men, women and children in the UK have a diagnosed bleeding disorder and the number rises every year. Membership of The Haemophilia Society is free and open to all.

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.

As bleeding disorders are rare, many people will never encounter The Haemophilia Society; we are largely invisible beyond the communities we serve. So, we must work doubly hard to raise both awareness and understanding of bleeding disorders and vital funds needed to give those affected the services they deserve and need to live the best life they can.

## Activities

### *Members Conference*

This year we held our members conference in Liverpool with almost 400 people attending over the two days. There was a packed agenda as always with updates in new advances in services and treatments as well as sessions on women's issues and health and wellbeing.

We held a gala dinner with a lively auction and the chance to socialise with other members and build connections to others in the community. Children's activities included a trip to Chester Zoo and bowling on Sunday.

### *Newly Diagnosed Family Weekends*

Our weekends for parents of recently diagnosed children are free to attend and enable new parents to learn more about what to expect when raising a child with a bleeding disorder. It is a chance to 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 physiotherapists, nurses, doctors, psychologists and play specialists facilitate sessions alongside our trustees and Youth Ambassadors.

This year we held three 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 we have included information on women with bleeding disorders, recognising that the needs of girls ought to be highlighted and addressed at an early stage.

### *Youth Activities*

This year our younger children attended summer camp at a dedicated outdoor activity centre in Surrey. Attending camp reduces the isolation of living with a bleeding disorder and raises the confidence levels of our younger members. Siblings are invited to attend as it is important that the impact of living with a brother or sister who has a bleeding disorder are understood and managed.

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 and in some cases learn new skills such as those who learnt to ride a bike for the first time this year.

### *Youth Ambassador Engagement*

Our Youth Ambassadors have attended two training weekends to enhance their skills in communication and storytelling, learning about clinical trials structure, personality types and teamwork. They have been developing three works teams concentrating on mental health, exercise and wellbeing and women's bleeding disorders.

They continue to support us at all of our events talking about their experiences, engaging with the community and helping staff deliver services as well as engaging in social media and advocating for our community.

Two of the Youth Ambassadors attended the EHC Conference, one as part of the Youth development programme and one representing us at the inhibitor working group. We also had one youth ambassador attending the EHC new technologies workshop.

Additionally, they organised the 'Lads and Dads' activity weekend in the Brecon Beacons continuing the friendly rivalry between parents and their children across a range of outdoor events and activities.

### *Talking Red Programme*

This year we held two Talking Red conferences in Belfast and Birmingham with tailored sessions from a range of health care professionals talking about the challenge's women with bleeding disorders face, from diagnosis and dentistry to periods, pregnancy and childbirth.

These events allow women living with bleeding disorders to connect with others who understand their challenges and provide a safe environment to share their experiences, reducing the isolation some people feel.

We surveyed women to understand more comprehensively the issues that were important to women living with bleeding disorders and the issue of 'period poverty'. The findings were to be presented at our third Talking Red event scheduled for March 2020 but due to COVID-19 this had to be cancelled and rescheduled for 2021.

### *Family Days*

We held 7 family days at various fun locations across the UK from Zoo's and Aquariums to Science Parks. These were attended by over 250 people and is a great way for families to get to know each other share experiences and build support networks over lunch. Some of the families had met previously at newly diagnosed weekends and had the chance to meet up again a few years later to compare their journeys.

### *Service of Thanksgiving and Remembrance*

With the start of the Inquiry hearings and it was of particular importance this year to remember those who could not be with us and lost their lives through contaminated blood. The personal testimonies heard this year have been deeply moving and for many have brought back many painful memories so therefore it was not surprising that we had 150 people attending this year to honour lost friends and family.

### *Publications*

We produced this year new booklets on dental care for adults, sex and bleeding disorders as well as factsheets on applying for PIP. An updated version of the understanding VWD was released and work started on a series of rare disease factsheets.

### *Volunteering*

As always, we rely on the generosity of so many volunteers to help us run our events and support us in a range of amazing ways. Without the help of the many healthcare professionals who give up their time to speak at events for us, the Youth Ambassadors and newly appointed LGBTQ Ambassador, local group volunteers, reading panels and a whole host of volunteers who rise to the challenge we would not be able to deliver the range of services we do.

This year we began a plan to expand our volunteering process to offer a larger range of opportunities, however due to COVID-19 this process was put on hold at the end of the financial year and will be initiated again in the future.

### *Advocacy*

This year we have continued to advocate for access to new treatments for people with bleeding disorders, responding to NICE consultations, NHSE consultations on new treatments and as part of the NHS Tender Boards for treatment and home delivery. As members of the Clinical Reference Group in England (which is attended by Welsh and Scottish clinicians' representatives too) 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.

Issues highlighted 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 DWP to highlight concerns over benefits, particularly for those with a bleeding disorder who are routinely being refused PIP but are successful on appeal. We have worked with DWP on developing training for providers and with the assessment providers to improve education.

We have also worked closely with EIBSS (and the associated devolved nations support organisations) and the APPG on Haemophilia and Contaminated Blood to challenge decisions on support for those affected by contaminated blood and called on governments to end the disparity between nations.

We have worked with the APPG to investigate the challenges people living with bleeding disorders face whether access to improved treatment, access to quality service or disparity of services across the UK. This has been collated, however launch was postponed due to timings with Brexit, General election and the COVID-19 situation.

### *Database and Processes*

We have been working hard this year to examine our background processes and database and ensure we have a solid foundation to move forward from. It is vital for us that we have good procedures in place and the right information to allow us to engage effectively with our community. This work is ongoing to help us become more efficient in the future and provide the right information to our members.

### *Public inquiry into infected blood*

This year saw the start of the hearings of the Statutory Public Inquiry into Infected Blood. We heard from personal witnesses across the devolved nations. It was both heart-breaking and yet inspirational to hear the experiences of people and their families of living through the impact of contaminated blood and losing loved ones. No one attending could help but be moved by the bravery of those who spoke out, vividly bringing to life the tragedy they had lived through.

We have continued to keep our members updated via a dedicated section on our website, producing newsletters and articles in HQ, daily updates on social media during the hearings and meeting with people attending the hearings around the UK. We have ensured all our documentation was provided to the Inquiry and have waived legal privilege on all of our documents. We have inputted to the experts reports and attended the hearings of these in February.

We continue to campaign for increased expert psychological support for those affected by contaminated blood and to support our members through these difficult times.

### *Fundraising*

Our fundraisers have been active throughout the year organising sports days, baking, knitting, hosting brunches and initiating a range of fun activities. We welcome your feedback about different activities and stories of success, especially with the ongoing challenges of COVID-19.

We are grateful that people are running, walking, cycling and swimming to raise money for us and we thank you all for your commitment and the personal sacrifices and hours of training you have put in.

We have launched our virtual shop so you can buy merchandise from us including Christmas cards and are looking to expand this in the future to include our publications. Thank you to all who have contributed to our campaigns so we can continue to provide information and support to our members free of charge.

This year we held our Big Red Glasgow Bridge Walk but unfortunately had to cancel our Big Red London Walk due to COVID-19 lockdown restrictions. This was a real blow for us as it

was such a great event attended by so many the year before. We hope we can reinstate this event.

Debra Morgan & Kate Burt,  
The Haemophilia Society  
October 2020