

Haemophilia Society

WFH Congress 2018

Much of this year was dominated by preparations for hosting the World Federation of Hemophilia Congress in Glasgow from 20-24 May 2018. Congress was a huge success with 5110 delegates from 132 nations attending.

Newly Diagnosed Family Weekends

Hearing that your child has a bleeding disorder brings 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 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 physio's, nurses, doctors, psychologists and social workers facilitate sessions alongside our local group representatives and youth ambassadors.

Youth Activities

This year we focussed our youth activities in summer camp in Surrey 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, even the torrential rain!

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.

The first social for people aged 18-29, a trip to a comedy night in Leeds only attracted a few people but gave the foundations for the survey conducted slightly late to understand and increase youth involvement.

50 participants responded which the youth ambassadors used to evidence their request for funding for increased activity in 2018.

A youth ambassador also sits on the board now to regularly update the board on the work they have been doing.

Talking Red Programme

We began our Talking Red programme for women with bleeding disorders in 2014. This year almost 50 people came together at a weekend conference in Birmingham.

We discussed periods, surgery, nose bleeds and relationships. We shared an update on our first university Talking Red focus groups and the work of the EHC women's committee.

We also had a rallying cry from Talking Red ambassador Linda Wild, a social worker discussed support for women affected and held a breakout session for partners.

We had a stand at the fresher's fair at University of Sheffield and had a footfall of 3,000 people.

Ageing

This year our aging project looked at how we could support our members with HIV and Hepatitis better, as well as focussing on staying well as you get older. Our conference looked at maintaining activity levels when you age, ensuring good dental health, as well as giving updates on new developments in HIV and Hep C treatment.

Inhibitor Project

We know that a diagnosis of an inhibitor takes a family from someone having a rare bleeding disorder that impacts daily life to an overwhelming situation where normal life seems far away and treatment, hospital trip and anxiety levels soar.

Our residential weekend in Leicester enabled 8 families of a child with an inhibitor and 3 adults with inhibitors to come together and hear from physiotherapists, psychologists and youth ambassadors as well as facilitated peer to peer sessions to share experiences and coping mechanisms. As members of the EHC inhibitors group we enabled one of our families to attend the European inhibitor summit. We also have a new inhibitor liaison rep who will be working with us to develop our services and advocacy as well as support other families with inhibitors.

Volunteering

We just 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, alongside 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 educational days.

Advocacy

This year was dominated by our work focussed on access to new treatments for people with bleeding disorders. 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. This included access to innovative new treatments, access to specialist nursing and physio care, and sharing people's experiences at their haemophilia centres.

Public inquiry into infected blood

After so many years of campaigning, the community welcomed the announcement in July that there would be a full Statutory Public Inquiry. Our campaigning continued to

ensure the responsibility for the Inquiry was removed from the Department of Health and Social Security and eventually this was changed to the Cabinet Office in late 2017.

The Trustee Board committed to funding of dedicated staff from a legacy, and subsequently a full-time position of Public Inquiry Lead was appointed and a dedicated Sub Committee of Trustees was formed to oversee the work on the Inquiry. A series of Roadshows was held with members around the UK to understand their expectations of the Inquiry and how they wanted to be represented by The Society.

Sir Brian Langstaff was appointed as Inquiry Chair on the 8 February 2018. A consultation was opened on the Terms of Reference and using a range of channels, including a new social media group, we gathered opinions to inform our response to this Consultation.

Fundraising

Our fundraisers have continued to do amazing things for us this year, from hosting dinners to running marathons right through to abseiling down the Orbit Tower in the Olympic Park and golf days. We have also seen increased support from community groups such as the Freemasons (via donations and Ladies Nights). However, we are seeing a decline in people taking part in activities and hosting their own events. If we are to continue to provide the activities that we do, we hope to find new ways to engage with our community and the wider public and look to our members for new ideas and advice.

Liz Carroll,
Chief Executive, The Haemophilia Society
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