

Haemophilia Society

I've had the privilege of being CEO of THS for just over 12 months, and there have been both highs and challenges. The global pandemic has been the backdrop affecting us all, and as we emerge into a changed world, we are seizing the opportunity to look at the way we work; challenging our approach to supporting the bleeding disorder community, collaborating more effectively, and finding new ways to generate income so that the organisation can thrive.

We've looked at our brand identity and voice, and in November will be launching membership cards and improving our website. We are redoubling efforts to support a national network of local groups linked to Haemophilia Centres, and are also strengthening collaborations, including renewing relationships with colleagues in other nations across the UK and signing new partnerships with Little Bleeders, Haemnet and the HepCTrust.

A big shout out has to go to the West Yorkshire Local Group who came up with the idea of the "Race Around the World". Commencing in March 2021, the aim was for participants to run, swim, cycle, and walk enough miles to cover the distance around the world. The aim was to arrive back in Yorkshire in time for World Haemophilia Day, on 17 April 2021. The Yorkshire group delivered ahead of schedule and made it a significant way around again! The Race Around the World raised £5,000 to go towards point of care ultrasound equipment. With many people being more sedentary during lockdown, we intend to run this as a national event in 2022 and have even bigger plans to get others involved.

It's been exciting to finally be able to attend events including our summer 2021 Youth Camp in Derbyshire. The July and September weekends for our newly diagnosed families in Essex and Manchester were also highlights. It was a privilege to meet families face to face at last and hear their experiences. I could also see first-hand just how precious the opportunity was for many families to have the chance to chat with others who just 'get it.' Thank you to the healthcare professionals from Haemophilia Centres who gave up their precious weekends to support these events, we can't run them without you. In September I also visited Charlie Hay and his team - due to COVID the first opportunity to see a Haemophilia Centre's work and it was a great and very informative day. I hope to be able to visit many more centres in the coming months.

Like many of you, I have been following the Infected Blood Inquiry closely and attended several, emotional hearings. We continue ongoing reporting from the Inquiry and will respond to the government's Compensation Framework Study after consulting with our members.

We have launched an innovative symptom checker for women with potential bleeding disorders and I'm looking forward to continuing to build momentum around this important campaign at Talking Red Live in March 2022. I hope to see some of you there, and at other events, in 2022.

Kate Burt,
CEO, The Haemophilia Society
October 2021