



It's been a busy year for Haemnet!...



2019 has been a busy year for the Haemnet team, running workshops, educational courses and research projects for the community of healthcare professionals working within haemophilia. It is thanks to the support of our industry partners that we have been able to do this, whether you have sponsored the annual HNA meeting, funded a research project, or donated funds to support our courses or online journal. In the past year, we have been supported by CSL Behring, Grifols, Novo Nordisk, Roche/Chugai, Sobi, and Takeda.

As we wish you happy new year, we thought we'd give you an update on how over the past year your support has helped us to make a difference to clinical teams, and ultimately to people with haemophilia.

Our educational programme keeps rolling on

Our first big event of 2019 was the annual HNA conference. As popular and engaging as ever, this year's event once again featured a number of industry sponsored workshops. The biggest complaint we saw on our feedback forms was that people wanted to attend more than just one of the three workshops on offer. The motivational interviewing workshop proved so popular that, in association with Sobi, we were able to continue these workshops through the year with a series of centre-specific workshops.

The ASPIRE programme continues to be popular and in-demand among members of the haemophilia MDT, enabling participants to recognise their leadership skills and to facilitate development of their abilities during this time of significant change.





The ASPIRE 2019 cohort met for the first time in June and have now completed three modules and participated in three “action learning” sessions. At the third workshop, they decided who would take a lead in facilitating the industry-sponsored workshops at the HNA 2020 conference. They also identified the difference they want to make that will enhance haemophilia care through creating opportunities to share experiences that leads to standardisation of practice and raising the profile of bleeding disorders to improve the experience of patients across the care pathway.

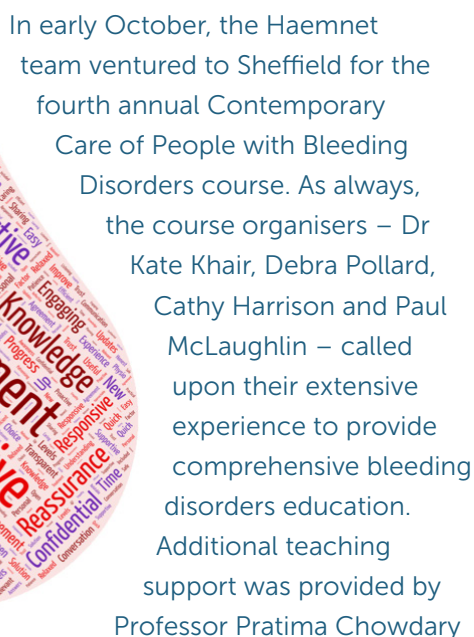
We asked our 2019 graduates what they would say to potential ASPIRE participants:



‘It’s what I hoped for and so much more’, ‘Come and discover a whole world of tips that will help you in your journey to leadership’, ‘Well worth it! A very enjoyable and insightful course. Techniques used to demonstrate leadership with constructive feedback and guidance throughout’, ‘Be open minded! Taking part in ASPIRE has been thoroughly enjoyable, inspirational and has influenced me and my career in a wholly positive way’ and ‘Really fantastic content’.

ASPIRE is about helping people to “find their voice”. Talk to colleagues of those who’ve been through the programme and you’ll see the impact it has had. Not surprising then that The Haemophilia Society invited us to take elements of it into the patient community. At their AGM in Liverpool in November, we ran a plenary session entitled “Constructive Consultations: Be heard, get what you want and live well”. It was great to have a conversation with the people present and to hear the words they would use to describe a successful consultation, captured in the word cloud. We plan to use this in the programmes we run with members of the care team.





In all, 16 nurses and 4 physiotherapists attended, covering a vast amount of content that will prepare them well for the future of working in haemophilia and bleeding disorders. We are sure they won't forget the friends they made or the day they spent in leg braces, slings and elbow supports courtesy of @paulthephysio.

Inbox - mike@haemnet.com

15 October 2019 at 11:34

Details

RE: Contemporary Care course, Sheffield, 6-10 October

To: Mike Holland, Cc: Luke Pembroke, Kate Khair, Cathy Harrison & 2 more

Hello All,

Hope you have recovered from all the hard work put in during the course last week and have had opportunity for R&R.

I wanted to take the opportunity to extend my gratitude to you all for your time spent to invest in us all and ensure we have the very best start to our career in Haemophilia (possibly you didn't have the same when you first began).

Mike- Your investment into putting all the logistics together and ensuring it all ran to clock work really did shine through. Thank you for ensuring we knew what to expect, where to be and what to do in advance. Your hospitality through it all enabled us to feel relaxed, well fed and cultivated an environment for us to get the very most from the course.

Debra, Kate, and Cathy- Thank you for creating and investing in legacy. There is nothing more incredible than when we have the opportunity to stand on the shoulders of those who have gone before us. It is evident you have fought and championed for nurses to have a seat at the table and be valued in the world of Haemophilia care. Your passion, knowledge and experience passed on has truly impacted me and inspired me to want to achieve great things in the future.

Luke- Thank you for your genuine, fun, and open approach to sharing your life with us during the session you delivered. It is a privilege to have you share with us and you are/shall continue to be an inspiration to those you share with. Thank you for capturing all the moments of the course on camera and sharing it, leaving a digital footprint of what truly was a special course.

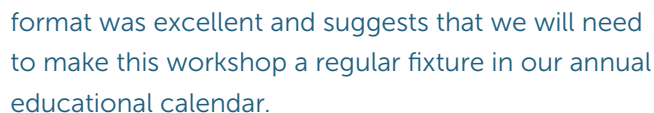
Paul- Last but not least... Thank you for sharing all your wonderful wisdom on the Physio side of Haemophilia. Working in a centre that doesn't have a fixed post Physio, having you teach on the course has really helped me greater understand the A+P and a broader perspective of how to assess my patients. Your passion for what you do really shows.

Sorry lengthy but I just wanted to honour you all and Thank you ☺

See you hopefully at HNA if not before!

Kind Regards,

Specialist



Behind the scenes

In the past few months, we've published articles about Haemnet research in *Haemophilia*, from the HOPE study (doi: 10.1111/hae.13803) and the BBC Study (doi: 10.1111/hae.13736 and doi: 10.1111/hae.13684). Our own journal, *The Journal of Haemophilia Practice*, continues to grow, with the publication this month of a proceedings supplement based on the EHC's recent conference on women and bleeding disorders (available at www.haemjournal.com).

In 2018 Haemnet ran a series of regional HNA one-day workshops designed to give haemophilia nurses around the country a chance to have a say in updating the HNA Competency Framework. The outputs from those meetings have now been incorporated into a revised Competency Framework for haemophilia nurses that we believe will provide a strong practice-based foundation for specialist haemophilia nurses to continue improving services for people living with haemophilia and their families.

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also help us to plan the educational activities based on the needs at a national and regional level. You can expect to see more on this topic at the HNA meeting in Birmingham in March 2020 and – all being well – before then in *Haemophilia*.

Haemnet in Uganda...

At the end of 2019 the Haemnet team were able to visit Uganda and offer some educational support to the Haemophilia Foundation of Uganda. When she was at Great Ormond Street, Kate Khair led a WFH twinning programme with Mulago Hospital in Kampala. With diagnostic capability now established in Mulago, WFH is now sending factor to allow bleed treatment. But Uganda is a huge country and those outside the capital can sometimes travel for days to get treatment. So we are supporting the HFU to raise awareness of haemophilia in some of the more distant towns, linking them into the existing networks. In December, we travelled to Kampala and spent time meeting families who live with haemophilia. We also took a 7-hour drive to Lira, a small town in northern Uganda, where we ran a teaching workshop for healthcare professionals and helped the HFU to run a patient awareness camp, where more people were diagnosed, which will mean they are able to access treatment. While we were there, we undertook interviews and captured film footage so Luke Pembroke can make a documentary on the lives of people with haemophilia in Uganda.

We also have some “news” of our own to share...

Haemnet was established as an education and research-based charity and we are now turbo-charging both aspects of our “offering” with two key appointments:

- Dr Kate Khair has stepped down as a trustee of Haemnet in order to become our Director of Research. Her experience will be invaluable in designing and directing research into the lived experience of people with bleeding disorders.
- Debra Pollard will take on the role of Director of Education with Haemnet for one day a week under a secondment arrangement between Haemnet and the Royal Free Hospital.

Although both Kate and Debra have been closely associated with Haemnet for many years now, we believe this more formalised arrangement will help us to take us to a whole new level.

In addition, we have signed a contract with Oxford University Hospitals, under which Haemnet will support Simon Fletcher through his PhD, funding his post on a one-day a week basis enabling him to undertake the necessary research for the project. Kate will be one of his PhD supervisors and much of the work will be based on the patient-experience based studies we are able to conduct.

Your support of Haemnet and our activities over the past few years has allowed us to create an engine for future growth and development in haemophilia care. We are incredibly grateful for your on-going support and look forward to continuing our working relationship with you in 2020.

