

Haemophilia Nurses Association



Committee

Elected 2012

Kate Khair	Chair
Anna Farrell	Vice-chair
Emma Franklin	Secretary
Cathy Mumby	Treasurer
Martin Bedford	
Helen Greensmith	
Jayne Keaney	
Anica Phillott	

The Haemophilia Nursing Association (HNA) is the specialist group representing nurses involved in the care of people with bleeding disorders in the UK. The HNA held a very successful AGM in February 2014, at which the first HNA research bursary winners were announced. Two members are now undertaking short projects investigating why patients participate in CTIMPs when they already have access to recombinant products and the patient/parent benefits of participating in long acting factor trials.



The HNA continues to use Haemnet (www.haemnet.com) as our main means of communication and as a platform for national research. SO-FIT, the first ever nursing and physiotherapy collaborative research project, across 16 haemophilia centres which started in 2014 has recruited nearly 100 young people with haemophilia to assess self-reported functional assessment and quality of life vs. physiotherapy joint health care assessment

Haemnet has supported individual nurses with research grant applications and execution of research projects including development of an educational film scripted with patients that is to be launched at EHC in October 2014. We are also working with an academic GP group at the University of Birmingham to examine the diagnostic pathways of women with bleeding disorders. We are working with the University to deliver a CPD-based training course for GPs in November 2104 on bleeding disorders in women.

We heard from nurses and allied health professionals that they learnt from discussing case studies to enhance patient care though best practice, but that publishing in the main stream journals was becoming more difficult especially for individual cases or small series. Conversely publishing long qualitative research was also complicated due to limits on word numbers and so on. This prompted us to develop and launch *The Journal of Haemophilia Practice* (JHP), an international, on-line journal freely available at www.haemjournal.com. The third edition is about to be published. We have published case studies, reviews, qualitative research, outcomes studies and opinion pieces, where leaders in the field of haemophilia give opinions of past, present and future haemophilia care. Although it developed as a nurse initiative, this journal is not limited to nurses/allied health providers; every edition so far has had a medical author paper published too!

Three members will step down from the HNA committee this year, and the new committee will be announced at our AGM in March 2015. We continue to encourage applications for a growing number of research bursaries and to encourage nurses to publish their work.

Kate Khair
Chair, Haemophilia Nurses Association
September 2014