

# Haemophilia Nurses Association



## Committee

Dr Kate Khair	Chair
Cathy Harrison	Vice-chair
Sarah Johns	Secretary (from December 2014)
Emma Franklin	Secretary (to December 2014)
Jayne Keaney	
April Jones	(from December 2014)
Jenna Stanley	(from December 2014)
Martin Bedford	(to September 2015)

The Haemophilia Nursing Association (HNA) represents specialist nurses involved in the care of people with bleeding disorders in the UK. We held a very successful AGM and conference in 2015, at which two more nurses were awarded Haemnet research bursaries; we are leading the way for evidence-based haemophilia nursing globally.

All nurses in the UK will soon be entering new territory, as we are required to seek revalidation. HNA is no longer running the Essentials and Advancing haemophilia courses, but in 2016 will initiate a new course designed to meet the needs of today's nurses (and the NMC). In addition, we are working to ensure our study days and courses meet NMC requirements for revalidation. We will be looking to UKHCDO centre directors to ensure that haemophilia nurses are supported in both time and money to attend our meetings and courses.

HNA continues to use Haemnet ([www.haemnet.com](http://www.haemnet.com)) as a platform for communication and for coordinating research. SO-FIT, the first ever nursing and physiotherapy collaborative research project in the UK, recruited 127 young people with severe haemophilia assessing self-reported functional assessment and quality of life vs. physiotherapy assessed HJHS. Early results won a poster prize at EAHAD this year; data analysis continues and we hope to share full results of the study in 2016.

We have two national research studies currently underway looking at the lived experience and outcomes in children and young people with long-standing inhibitors (the SO-HEROIC study) and with platelet disorders (the SO-LIFE study). In addition, Haemnet is coordinating Transforming Transition, a nurse-led initiative to improve transition for young people with bleeding disorders funded by the Burdett Trust for Nursing. This action-research project aims to deliver and evaluate a nurse-led development programme by reviewing current practice, capturing patient experience and agreeing outcome measures.

Our open-access on-line journal, The Journal of Haemophilia Practice ([www.haemjournal.com](http://www.haemjournal.com)) continues to grow and is increasingly receiving submissions from medical authors. Since our first issue in January 2014, we have had 10,503 sessions by 8,408 users, who have registered 25,671 page views from people in 120 countries.

Our most recent issue is a celebration of 50 years of haemophilia care at the Katharine Dormandy centre at the Royal Free.

Dr Kate Khair  
Chairman, Haemophilia Nursing Association  
September 2015