

## Haemophilia Nurses' Association

### *Membership*

Cathy Harrison  
Simon Fletcher  
Shaun Emmitt

Chair  
Vice-Chair  
Secretary



Clare Forrester  
Sarah Johns  
April Jones  
Jenna Stanley  
Anne Wareing  
Dr Kate Khair (stepped down May 2018)

The Haemophilia Nurses Association (HNA) represents specialist nurses who care for people with bleeding disorders in the UK either through direct clinical practice or research. The last year has been exhilarating, and dominated by the WFH 2018 congress, held in May. HNA members participated in the treatment room and enjoyed meeting and treating people living with bleeding disorders from across the world and found collaborating with each other and with multidisciplinary peers a very rewarding experience.

As a consequence of WFH taking place in Glasgow, we chose not to run our annual conference in 2018, but instead convened a short AGM in the treatment room after the nurses' day of the congress. We plan to hold a series of smaller, regional meetings throughout the autumn, giving us the opportunity to review topics presented at WFH, and to reassess the haemophilia nurse competency framework, which needs to be updated given the changing treatment landscape. The meetings will also focus on offering nurses peer review training. The new peer review process is due to start this Autumn/Winter and represents a vast change from the previous audit process. The review paper has been supported and developed with a multidisciplinary approach and represents a transparent review of the services provided by each centre. HNA members were involved in its development and are training and signing up to be reviewers with a good representation from across the UK.

The HNA was initially formed in the mid-1980s because nurses were experiencing the trauma of HIV/AIDS diagnoses and deaths. The HNA remains an organisation designed to support our members and provide forums for reflection and discussion. With the infected blood inquiry now underway, and at a time when staffing resources are tight across the UK, we recognise that our members are again working under stress. Therefore, in March 2019 we will again run a full annual conference, designed around a theme of wellbeing and resilience.

HNA meetings and courses are run by Haemnet, our education/research charity. In October 2017, the Contemporary Care of People with Bleeding Disorders course trained 16 participants from the UK and Ireland, and in October 2018 a cohort of 24

multidisciplinary professionals will head to Sheffield for the next course. This course is a unique, practical, hands-on educational opportunity developed and delivered by nurses and physiotherapists from key UK centres, supplemented by invited experts. It is the only course for nurses and physiotherapists specialising in the care of people with bleeding disorders.

Also, in 2017 the ASPIRE clinical leadership development programme saw the second cohort of 6 nurses and allied care professionals from centres across the UK participate in three modules throughout the year. Other initiatives designed to enhance the level of practice and professionalism of nurses currently practising in the UK have included events designed to share experience with extended half-life products, and collaborative work on subcutaneous administration techniques. In addition, our members have participated in the Haemnet Horizons events, which facilitate collaborative work among nurses across Europe. We also have several on-going studies underway and hope shortly to begin collaborating with UKHCDO members on a study looking at pain.

We strongly believe that participation in our events greatly enhances the sense of community among HNA members and will go some way towards ensuring a happy, well-educated and sustainable haemophilia nurse establishment for the future. We recognise, however, that in recent years, many nurses have experienced difficulty in securing funding or study leave for educational courses and meetings. As a result, we have moved towards a model of centralised funding for our programmes, allowing us to keep the costs of attending courses down to a very low level, and where possible we make no charge at all; for some meetings we are also able to cover nurses' travel costs, but we cannot do anything about study leave. We would strongly urge all centre directors to support their nurses in attending the educational opportunities that we are able to offer.

HNA members are key stakeholders in the ongoing care of people living with bleeding disorders; our members are playing an active role on new initiatives within the UK haemophilia treater community; including the CRG, CMU, the peer review group, and various UKHCDO working parties. The HNA committee wishes to thank all of the nurses who represent their colleagues on these groups. HNA members continue to bring passion to their roles, ensuring the national voice of haemophilia nursing is represented. Representation at Glasgow WFH 2018 showed the world what an amazing, passionate group of nurses we are. I am proud to be one of them.

Cathy Harrison,  
Chair, Haemophilia Nurses' Association  
September 2018

Dr Tina Biss,  
Co-Chair, Prophylaxis Task Force  
September 2018