

WFH in Melbourne: the long march of the haemophilia nurse continues

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The World Federation of Hemophilia's world congress in Melbourne offered haemophilia nurses from across the world an opportunity to meet and share knowledge and experience in a friendly and supportive setting.

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From 11-15 May, 110 nurses representing at least 21 countries descended on Melbourne, Australia, for what is arguably the largest global conference for nurses caring for patients with bleeding disorders – the World Federation of Hemophilia's (WFH's) World Congress. Held every two years, this meeting attracts nurses from around the world who generally work in haemophilia treatment centres (HTCs) providing comprehensive, multidisciplinary care to patients and families with a variety of bleeding diatheses. This year's congress was an overwhelming success.

The WFH Nurses Committee selects nursing topics and speakers for the WFH World Congress. This committee is comprised of ten nurses who work in HTCs and represent four geographic regions of the world as established by the WFH: Asia and the Pacific nations, Africa and the Middle East, Europe and the Americas. Representatives on the committee who helped plan for the congress in Melbourne include:

- Kuixing "Jessica" Li from China, and Robyn Shoemark from Australia, who represent Asia and the Pacific nations
- Bongsi Mbele from South Africa, and Mahmoud Abu-Riash from Saudi Arabia, who represent Africa and the Middle East
- Kate Khair from the United Kingdom, Anu Laal from Estonia, and Virginia Puliga from Italy who represent Europe
- Ana Claudia Acerbi Vrabic from Brazil, Georgina Floros from Canada, and Jim Munn from the United States who represent the Americas.

Session development and speaker nominations occur after each congress and every attempt is made to have global coverage within the developed programming.

Sessions for nurses at the Melbourne congress were conducted over the course of the week with the first day's presentations centered around the theme "From Triage to Triumph". Advances in technology coupled with the desire to provide real-time care for patients have transformed the typical definition of triage from a face-to-



face interaction to one that utilizes the social media age and state-of-the-art equipment to enable assessment of patients from various angles. Telephone triage is essentially the norm for nurses practising in haemophilia and the first presentation addressed using a telephone triage protocol developed in Canada. This particular session, presented by Lori Laudenbach, a Nurse Practitioner from London, Ontario, is featured elsewhere in this issue, which will highlight the details of the protocol and illustrate its use.

Continuing with the triage theme, Joanna McCosker, a Clinical Nurse Consultant from Queensland, Australia, presented on using telemedicine to provide real-time assessment, diagnosis, treatment and outcomes evaluation by use of technology that allows for audiovisual interaction between a remote site and the home treatment centre. She is able to reach patients with bleeding concerns who would otherwise have to travel many kilometers over several hours to reach her HTC. The use of telemedicine allows for faster assessment, and ultimately faster delivery of patient care, and can be established between the HTC and a variety of outlying hospitals and clinics closer to the patient's home.

Social media explosion almost has required that HTCs provide a way to interact with patients on a whole new

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WFH Nurses Committee

The WFH Nurses Committee aims to improve the quality of care to patients with haemophilia and other bleeding disorders throughout the world by enhancing nursing practices and making nursing an integral part of a multi-disciplinary health care team. It has six goals:

- To improve the quality of care to people with bleeding disorders throughout the world
- To provide education
- To stimulate an interest in hemophilia care
- To provide tools to improve nursing services
- To enhance communication
- To advocate for nursing to be an integral part of multi-disciplinary teams

level. Use of electronic treatment logs has flourished and Robyn Shoemark, a Clinical Nurse Consultant from Sydney, Australia, summarised the growing range of e-logs in use by patients and families living with haemophilia. Each HTC will have to decide the appropriate use of e-logs and how this mode of interaction is to be utilized in their clinics. It is clear the HTC should not bury its head in the sand with respect to these devices and apps that patients have on their phones and computers. Change will inevitably continue in this arena and haemophilia nurses must find ways to stay proactively on top of them.

Several free papers were presented during the first day's programme including:

- How to sustain haemophilia nursing positions in today's activity-based funding environment
- A multi-centre study in Europe on the use of port-a-caths in children with haemophilia
- Thrombosis encountered in patients with von Willebrand disease (VWD).

Each of these free papers was selected from abstract submissions to WFH so I encourage all nurses to consider submitting an abstract to future WFH congresses.

The first day closed with presentations on the nursing training kit that has been developed by the WFH Nurses Committee in collaboration with several nurses from the haemophilia community, as well as the WFH staff. A presentation on the history, development and initial use of the training curriculum was followed by a discussion of the cultural and regional approach to nursing education, teaching strategies and practical aspects of training delivery given by Anne-Louise Cruickshank, a Haemophilia Nurse Coordinator from Cape Town, South Africa (who can also be found elsewhere in this issue of *The Journal of Haemophilia Practice*). The session concluded with information from Jennifer Laliberte, Director of Education and Public Policy of the WFH, about the development and roll-out of the first nurses training utilizing the newly developed kit. The training was conducted in Nairobi, Kenya, in June 2013. The training kit has since been used for nurse training in Mongolia and Jordan. The kit will continue to be refined and updated with new information germane to the treatment of individuals with bleeding disorders and the nursing care received by these persons.

Nursing sessions also were conducted throughout the

WFH meeting. On Monday 12 May there was a session dedicated to clinically focused care and what is being done around the world to address specific needs of the bleeding disorders community. Speakers discussed clinics developed for their patients that included a nurse-led clinic for patients with von Willebrand disease (VWD), age-grouped clinics for boys with haemophilia and new parents that were generated to address specific learning needs of young boys and psychosocial concerns of parents that arise with a new diagnosis, clinics developed to address pain and physiotherapy needs of patients with joint problems, and information about including genetics counseling and information for all patients and families.

On Tuesday 13 May, vein health was discussed in a nursing session. Presentations were given on how to maintain good access in the clinical setting, the use of central venous access devices (CVADs) and arterio-venous fistulae (AVFs), the process of teaching venepuncture to patients and families, and finally, needle phobia and teaching factor administration beyond the clinic or home setting. Venepuncture remains the single best way for patients with most bleeding disorders to receive therapy to treat their condition and it was apparent from this session that knowing how to do this well reduces stress for all involved.

The nursing sessions concluded on Thursday 15 May with lectures dealing with family dynamics. Several nurses spoke about sibling issues, adolescents and parents, educating patients and parents in sports and physical activity, and ageing and partner issues. Tips and tricks were offered on how to address life course concerns for patients, families and spouses. Advances in care have presented new issues for our patients that in the past did not exist on the same scale as are seen today. This session highlighted the need to recognise issues early and address individual concerns at all levels of the life span.

Planning for the next WFH World Congress has already begun. The WFH Nurses Committee encourages suggestions for sessions for each congress and uses evaluations from past conferences to provide education that is comprehensive, up-to-date and covers all aspects of haemophilia nursing. We look forward to seeing more nurses at the next WFH World Congress that will be held in Orlando, Florida, USA, in July 2016.