

New developments in haemophilia nursing

Megan Walsh

I was very fortunate to be selected by the Australian Haemophilia Nurses group to be supported to attend the **17th Annual Congress of the European Association for Haemophilia and Allied disorders (EAHAD)** in February 2024. It has been over 7 years since I have attended an overseas conference and it was so exciting to see what new developments have been happening in the haemophilia sphere.

The Congress took place over 4 days with over 2000 delegates. This is a snapshot of some of the sessions I attended.

IMPACT OF NEW THERAPIES

The first day commenced with a multidisciplinary session with physiotherapists, nurses and psychologists discussing the experiences with the new subcutaneous treatment product emicizumab (Hemlibra®) for haemophilia A. It was interesting to hear we were all seeing similar experiences in patients using this product – for example, that a lack of adherence was causing significant muscle bleeds and children were complaining that the subcutaneous injection stings. Several interesting case studies were presented by a nurse, a physiotherapist and a psychologist and discussed by the group.

LATEST RESEARCH

There was also a SLAM session where five nurses who have submitted posters were selected to speak on their research. Topics covered included training staff on reconstitution of clotting factors, looking at an adult transition program, an analysis of an electronic health record used for recording health data by patients in clinical trials, and analysis of nursing practices in HTC's in France.

There was a focus on the need for more psychology input for the bleeding disorder patients undergoing new treatment trials. Speakers emphasised shared decision-making, especially when discussing

enrolment in trials or commencing new products. There was an interesting panel discussion around treatment choices and what multidisciplinary support was required to help in patient decision-making.

Assessing health literacy of patients and tips for dealing with patients with general low literacy were also discussed. The session explored what aids were required and that visual aids to explain complex information were often useful and what they would look like.

WOMEN

The needs of women with bleeding disorders, their diagnosis and management were also highlighted. It was noted that there are at least two potential carrier females related to each male with haemophilia and there are also women with other types of bleeding disorders, but Haemophilia Treatment Centres are not seeing the numbers of women that would be expected. There was discussion around how to encourage these women to seek diagnosis and treatment at Haemophilia Treatment Centres.

ARTIFICIAL INTELLIGENCE

The session on Artificial Intelligence (AI) was interesting and many examples of the uses of AI in different fields were presented. AI can be a powerful tool. It is starting to be used in diagnosis and individualizing patient treatment in some diseases. It potentially can analyse a lot of data quickly and identify trends or patterns so it may be useful for clinical trials and research. It was interesting to hear all articles submitted to medical journals are now scanned for AI input. Speakers also showed the other side of AI, where fake news and non-existent people could be created. AI brings many ethical challenges around privacy, data protection, societal impact and even its use in medical care.

NEW TREATMENT PRODUCTS

There were presentations on clinical trial results for many new treatment product studies, including one for recombinant VWD, a once-a-week extended half-life recombinant factor VIII, and second generation gene therapy trials. Among other novel therapies discussed were another product called mim8 which mimics factor VIII much like emicizumab, but more potent, along with fitusiran, concizumab and SerpinPC, which are all new subcutaneous drugs that prevent bleeding, targeting different parts of the clotting pathway and rebalancing it. Several of these trials involve Australian patients.

MILD HAEMOPHILIA

Mild haemophilia was another area discussed. It was noted patients with mild haemophilia tend to present late for treatment or not at all and thus were living with complications of bleeds. We do see inhibitor development in this group of patients as there are specific genotypes that are associated with a higher risk of inhibitor development. So in this session there was an emphasis on the need for patients to have their factor levels checked and genetic testing to identify inhibitor risk, and also to present earlier for treatment of bleeds.

EAHAD 2024 was a very stimulating four days and a great experience, and certainly very beneficial for my practice.

Australian haemophilia nurses were assisted to attend WFH World Congress through funding from a variety of sources. For more information, see page 12.



Abi Polus and Megan Walsh at EAHAD

Photo: Abi Polus

Megan Walsh is Clinical Nurse Consultant at the Ronald Sawers Haemophilia Centre, Alfred Health, Melbourne