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From the President

WFH WORLD CONGRESS

The WFH World Congress brings the worldwide community together, which I think is enormously important. I was privileged to attend the 2024 WFH Congress in Madrid. It was exciting to hear updates on what's happening worldwide - with women, clinical trials, gene therapy, you name it. As you will read in this issue of *National Haemophilia*, Australia was well-represented at Congress and our speakers and delegates acquitted themselves well.

With floods in Dubai, my flight was delayed by a couple of days and I was disappointed to miss the Global National Member Organisation (GNMO) Training workshop that was held before Congress. The plan had been for me to present the HFA poster about the Bleeding Disorders Roundtable and then join a panel to discuss collaborating on future directions. Fortunately, the poster made it to the Training, even if I didn't. It described how HFA is bringing together representatives from HFA and all the health professional groups for roundtable discussions: the Australian Haemophilia Centre

Directors' Organisation (AHCDO), and the nursing, physiotherapy, psychosocial worker and data manager groups. The Roundtable meets three times a year to discuss current issues from the perspective of each discipline and has been a great opportunity to collaborate.

Together with Natashia Coco, HFA Executive Director, I also attended the WFH Cornerstone Initiative lunch during Congress.



The Cornerstone Initiative aims to close the gap in treatment by providing support, expertise, and training to countries with minimal levels of care. The Initiative is currently active in Tanzania, Mozambique, Benin, Mauritania, Madagascar and Tajikistan. It was great to hear stories form these countries and how the program is assisting so many in the bleeding disorders community. HFA has supported this program financially.

World Haemophilia Day is one way of supporting WFH initiatives like these. Thank you to everyone who supported World Haemophilia Day – we had over 80 locations turn red to raise awareness.

RESEARCH

To make sure people with bleeding disorders have a voice in their future treatment and care, HFA regularly promotes relevant research studies. With several new therapies currently going through the process to become available in Australia, you may have noticed that you are being invited to participate in quite a few. HFA will also launch a more detailed study on treatment goals and preferences in haemophilia in a few months' time. I would encourage you to take the opportunity to take part in some of these studies, if possible, and give your opinions and insights.

HEPATITIS C

The release of the report from the UK Infected Blood Inquiry has raised questions in the Australian community about HFA advocacy relating to hepatitis C. We have outlined the continuing work on our hepatitis C strategy in the article about the UK Inquiry and Australia in this issue of *National Haemophilia*. We understand that revisiting these experiences may be an upsetting time for some people in our community. Please reach out for support if this is the case for you – suggestions for support are at the end of the article.