

Gavin Finkelstein is President, Haemophilia Foundation Australia



FROM THE PRESIDENT

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2020 WFH WORLD CONGRESS

The 2020 WFH World Congress will be held in Kuala Lumpur, Malaysia from 14-17 June.

Australia has a long history of involvement in the Congress and was represented at the very first World Federation of Hemophilia Congress in 1963. The Congress is held in a different country every two years, which is decided through a bidding process. It seems so long ago now that our bid 'a la Olympics' style was successful in Buenos Aires, Argentina in 2010. Australia stood proudly as the co-host with WFH in 2014 when the World Congress was held in Melbourne. It took a solid four years of planning and we were delighted to be involved.

After the Melbourne Congress people told me how that Melbourne meeting had helped them: so many people took time off work and away from their families to join the camaraderie of the global meeting in Melbourne to hear and learn more about living with a bleeding disorder, and to find out about the new treatment pipeline.

It is a great time to go to another Congress – and with the June meeting in our own region there is the benefit of shorter travel times, lower costs and time away.

Importantly, the KL meeting comes at a very important time in the development of treatment and care for haemophilia. Never have we known so many new treatments in development which promise better outcomes for our health. It is important for us to realise some of the trial drugs may not reach the market in the long run because they do not end up being safe and effective, or they will not be practical from a commercial point of view, but we can expect a range of different types of treatments to become available over the next few years. It is important that we take personal responsibility for staying on top of our future treatment options. Congress is a great way to hear about these developments and how they will improve our lives.

CONNECTING TO OUR GLOBAL COMMUNITY

For those of us involved in representing the bleeding disorders community, the Congress puts it all in perspective. We see 'up very close' just what the issues are around the world for people with bleeding disorders and the ways we can step up our efforts to influence care

and treatment in Australia and other countries. We can learn from the advocacy experiences of others, and pick up on emerging issues that might later become barriers to treatment access. In Australia in the last few years our community has not had timely access to new treatments and we need to find ways to improve this.

We also look forward to using the Congress opportunity to meet with our Myanmar Twinning partners. Sam Duffield, an HFNSW member, and Leonie Demos, President of HFV, have met with the Myanmar patient group to explore ways HFA and Myanmar can work together to improve treatment and care in Myanmar and to help the patient group there to develop new skills in advocacy and representation. Our joint application to WFH to become formal twinning partners in the WFH Haemophilia Organisation Twinning Program has recently been approved so we can use the opportunity to make forward plans.

THINKING OF ATTENDING?

Congress program details can easily be found on the WFH Congress website - www.wfh.org/congress/

Note that the regular registration period ends 17 April 2020, and after that you will need pay for a late registration. HFA or your local Foundation may be able to assist you with financial support for your registration fee so do think about whether you can attend.

At the time of printing, there is still global concern about coronavirus (COVID19) and you are encouraged to get advice from relevant authorities and your doctor. The Australian government provides details at **Smart Traveller** - www.smarttraveller.gov.au/news-and-updates/coronavirus-covid-19.

