

Gavin Finkelstein is President, Haemophilia Foundation Australia

FROM THE PRESIDENT



Gavin Finkelstein

2019 CONFERENCE

It is hard to believe the Conference is over and it is December already. In this publication you will read my Conference reflections and the reports of some of the sessions presented. We are grateful for the Conference Program Committee, chaired by Dr Liane Khoo, and the speakers, chairs and others who made the Conference a success. If you missed out on getting to the Conference you can read many of the presentations on the HFA website. We haven't yet decided where the 2021 Conference will be located but will let you know as soon as we can.

HFA AWARDS

The HFA Awards Program recognises special service given to the bleeding disorders community in Australia. It was my great pleasure to announce three important Awards during the Conference dinner on 11 October.

HFA Volunteer Awards were given to Donna Field and Cheryl Ellis. Donna is a member of Haemophilia Foundation Victoria. She lives with her family live in Neerim South in country Victoria. Donna started a bleeding disorders awareness campaign there ten years ago for Bleeding Disorders Awareness Week. She called it **Paint the Town Red**. Donna and her family and friends bake red cakes and sell them along with a sausage sizzle to raise funds and community awareness about the impact of bleeding disorders on families. Further, through her work with the Bendigo Bank she has partnered with work colleagues to raise awareness and funds that have been channelled to the community for family camps and peer support. Donna was not present at the Conference, but her Award was later presented by Sharon Caris and Natasha Coco at a dinner held for Donna and her family with HFV representatives on 18 November.

The second HFA Volunteer Award was presented at the Conference dinner to Cheryl Ellis. Cheryl has served on the Haemophilia Foundation Western Australia (HFWA) management committee for 14 years and as the Vice President for ten of those. She has completed over 800 hours of voluntary service and has been a tireless fundraiser for HFWA. Both Donna and Cheryl are wonderful volunteers and have made a great difference in our community.

The HFA Ron Sawers Award is given to a doctor or scientist who has made a significant contribution towards

improving the quality of life for people with bleeding disorders through dedicated work promoting and supporting clinical excellence or undertaking significant research. It is named after Dr Ron Sawers, who developed and championed high standards of haemophilia care throughout his 40 years of service at the Alfred Hospital in Melbourne. It was my great pleasure to present this award to Dr Simon McRae, Director of the Haemophilia Treatment Centre at the Royal Adelaide Hospital, for his leadership in South Australia and nationally as the Chair of the Australian Haemophilia Centre Director's Organisation (AHCDO) for several years.

2020 WFH WORLD CONGRESS 14-17 June 2020, Kuala Lumpur, Malaysia

We had a very special time in Australia when we hosted the 2014 WFH World Congress in Melbourne. The 2020 Congress is not in Australia, but it is close by. If you haven't made it to a World Congress and want to get to one in our region, why not think about attending the Congress in Kuala Lumpur. HFA will reimburse the registration fee for the first five community members who have registered for the Congress, and do not have any other funding support.

TREATMENT PRODUCTS

I am disappointed that the National Blood Authority (NBA) has not yet announced the outcome of tenders for clotting factor products which was called earlier this year. Following the recommendations of the Medical Services Advisory Committee (MSAC), extended half-life factor VIII and factor IX were included in this process and we have people awaiting the outcome and opportunity to use them for their treatment. The first of these products were registered for use in Australia in 2014 by the Therapeutic Goods Administration (TGA) yet they are still not available as a clinical choice for all who could benefit from them.

Fortunately, the NBA agreed to an expanded access program which enabled limited access, but there are many people who would benefit but do not have access as yet. There is no news either about Hemlibra which is a non-clotting factor registered in Australia for people with haemophilia A with and without inhibitors to factor VIII. This treatment has made a significant difference to the lives of many already through clinical trials or compassionate access, and HFA has made submissions to MSAC and directly to the Health Minister to seek funding. I truly hope this has been resolved before the next publication of *National Haemophilia*. ■