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## From the President

### RAISING AWARENESS

On 17 April we join the global community in celebrating World Haemophilia Day. This is an important opportunity for the bleeding disorders community worldwide to come together to raise awareness about bleeding disorders. In Australia the Light It Up campaign has been very successful, where landmarks around the country are lit red at night. I encourage you to share photos of your local landmarks on the HFA Facebook Page so that we can share the day and its significance with each other and those who are connected to us.

This year the World Federation of Hemophilia (WFH) has given the event the theme of *Access for All*. It is a timely reminder that much of the world's population of people with bleeding disorders doesn't have access to diagnosis and effective treatment. We feel very fortunate to live where we do and in these times of new haemophilia treatments and HFA is committed to supporting the WFH programs to bring change worldwide, including the Twinning Program.

In February we also celebrated Rare Disease Day. Haemophilia is considered a rare disease, but some of our community members have very rare bleeding disorders, such as rare clotting factor deficiencies and very rare types of VWD, and it is important to raise awareness about the diversity of experience in our community. Our thanks to Adam, Simoni and Belinda who shared their personal stories for Rare Disease Day this year.

### WORLD NEWS

WFH has announced that the World Congress will take place as scheduled in Montreal, Canada on 8-11 May 2022, both face-to-face and with select sessions available through their virtual platform. Registration is now open. Like the Australian Conference, there is a mix of community and expert health professionals and a dynamic and exciting program, covering the

latest information and issues. If you have attended a World Congress before, you will know the excitement of meeting together as a global community and sharing experiences, catching up with old friends and being inspired by what is being discussed.

I am sad that we farewelled a great leader and friend from our global network when Val Bias passed away in December 2021. Val was the former CEO of the National Hemophilia Foundation in the USA. Val had severe haemophilia but didn't let it stand in the way of his impressive work to bring the US chapters together and in national advocacy, fundraising and support for young people. On the global stage he was very active in the WFH Twinning Program. We will miss him and pass on our condolences to his family and former colleagues.

### EDUCATION RESOURCES

Throughout the COVID epidemic, we have continued our work on education resources – not only the COVID-19 vaccine FAQs, but other resources for our diverse community. I would like to thank our community members and expert health professionals, who contribute their experiences, expertise and feedback to the development of these resources. Our health professionals at the HTC's have been particularly generous, giving comments and advice when they can, although many have been in other roles to manage the impact of COVID in their hospital.

You may have seen new information on financial planning and aged care and disability services on the Getting Older Info Hub and updated sport information for young people on Factored In. We are nearing the completion of the resources on haemophilia testing in women and girls, exploring the complexities of genetic testing and diagnosis, and encompassing recent changes. Now that the HTC's have had some experience with new haemophilia treatments, we will be updating our haemophilia resources – and there are other resources in the pipeline. Watch this space!