



**Gavin
Finkelstein**

President,
Haemophilia
Foundation
Australia

From the President

NATIONAL CONFERENCE VIDEOS

We are pleased that you can now view most of the sessions from the 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders on our website. It was HFA's first virtual national conference, held over 8-9 October 2021, and we were grateful for the work put in by the Conference Program Committee to develop such an interesting program. When you watch the sessions, if you haven't already done so, you will see the invited speakers made a concerted effort to give lively and challenging presentations.

WFH WORLD CONGRESS

It is always exciting that no sooner has the HFA Conference taken place than we are looking forward to the WFH Congress. WFH held a hybrid congress this year during 8 -11 May 2022, making it possible to attend face-to-face in Montreal or virtually. You may have joined the Congress and associated meetings virtually as I did.

I was grateful that Shauna Adams from HFACT attended the Congress in person, and that she agreed to be the face-to-face presence for HFA, joining me as HFA representatives at the WFH General Assembly on 7 May 2022. This is the WFH Annual General Meeting and it is important to HFA that we participate. Shauna had been awarded a Youth Fellowship for the Congress which was to be held in Kuala Lumpur, Malaysia in 2020. Fortunately, this was carried over for the Montreal meeting and Shauna was able to attend.

You will hear from Shauna about her reflections on the Congress in the September issue of *National Haemophilia*, along with other reports of Congress sessions attended virtually by Australian community members and specialist health professionals.

AND FOR THE FUTURE

We finished the national Conference on a high. There is so much to look forward to and there is now considerable knowledge about the impact of some of the new treatments already available and others around the corner.

But significantly, the HFA Treatment Policy was affirmed. We learned how important it is that our community continues to have access to a range of treatment products, even the older ones which are effective and necessary for some people in our community. We will continue to advocate in support of the national framework established under the National Blood Agreement that means all Australian governments, federal and state/territory, share the cost of our treatments and that these are managed and supplied at no cost to patients by the National Blood Authority. We do not take this system for granted as we know how many of our global bleeding disorders friends do not have the surety of supply and ongoing treatment. As new therapies for bleeding disorders, including gene therapy for haemophilia, come to market we will be advocating to our governments for early access.

It is a critical time in our health system. The government policies for evaluation and assessing new treatments are being reviewed and HFA looks forward to participating in the National Medicines Review and the review of Health Technology Assessment. These reviews are both fundamental to access to medicines in Australia and the bleeding disorders community has considerable experience with this. We know the consequences of delays in access to available new treatments. We can also share in a constructive way the importance and value of new therapies to both individuals in our community and the Australian community generally, with case examples showing the benefits of new treatments. We look forward to early opportunities to meet with the new government to share some of these experiences. >>

<< REPRESENTING OUR WHOLE COMMUNITY

We are particularly mindful that there are no formal community organisations for bleeding disorders in either South Australia or Northern Territory, but there are informal connections and representation nevertheless.

Community members in South Australia should watch out for news about the next information evening to be arranged by the Haemophilia Treatment Centres in Adelaide.

We are very keen to make sure our community members have a say in HFA activities regardless of where they live and I invite you to contact HFA if you have ideas or concerns about your treatment or the work that HFA does. Feel free to phone HFA on 03 9885 7800 or email hfaust@haemophilia.org.au.

Damon Courtenay Memorial Endowment Fund Funding Round Open

The Damon Courtenay Memorial Endowment Fund (DCMEF) was established by Haemophilia Foundation Australia in 1994 with financial support from the late Bryce Courtenay and the late Benita Courtenay in memory of their son, Damon.

Small grants are available to individuals or patient support organisations for the care, treatment, education and welfare of people affected by haemophilia or related bleeding disorders.

WHO CAN APPLY?

- Anyone with a bleeding disorder or affected by a bleeding disorder who resides in Australia may apply for a grant
- Patient support organisations in Australia, however preference will be given to the needs of individuals with high needs

WHAT CAN THE GRANTS BE USED FOR?

An amount of \$20,000 is available for distribution. Applications will be considered on merit by a panel.

There is no limit on the amount that you may apply for, however activities up to the amount of \$2,000 are more likely to be successful.

Funding may be used for projects, services and/or care, or an activity aimed at improving the physical and emotional wellbeing and independence of recipient/s such as:

- medical appliances and equipment to help people live more independently
- career development
- training, education and coaching
- personal development
- conferences or workshops
- peer support activities/camps

HOW TO APPLY

The relevant application form must be used. Application form and guidelines available:

- HFA website www.haemophilia.org.au
- Request by email hfaust@haemophilia.org.au
- Telephone HFA on 1800 807 173

Applications close 30 August 2022