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From the President

As I write my update for *National Haemophilia*, I can't help but think about where things will be at for HFA and our community next year at this time or the following years. Our community should be excited about the future, with new treatment options coming to the global market. Some of these will bring less onerous treatment, better health outcomes and improve quality of life and productivity for people who use them.

TREATMENT ADVOCACY

We encourage treatment product sponsors to work hard to bring their innovative treatments to Australia. The products need to be registered and funded by governments before they are available for our use, but I assure our community that HFA wants to play its part to ensure the treatments people need are available to them in the future. Our treatments represent a high cost for governments. Our engagement with our community is important so that we understand treatment preferences and can advocate for the treatments and care our community needs. We want to be able to work with governments to make sure the right treatment products are available at the right time for our community and that they are provided as cost effectively as possible.

The Federal government is undertaking a review of the government's health technology assessment process, which is the evaluation process used to assess the quality, safety, efficacy, effectiveness, and cost-effectiveness of health technologies – this includes our treatment products. We can contribute community expectations and preferences, based on the lived experience of people living with a bleeding disorder to these processes, so when treatment products are evaluated, the process is more 'patient' focused, and relevant questions are asked about how the treatment will impact or benefit from the point of view of patients.

HFA FUNDING

Some of you are aware that HFA faces a challenging financial situation. HFA has always relied on different sources of income: we have fundraising campaigns throughout the year, that you may generously contribute to by making donations, and we seek sponsorship from the corporate sector and charitable grants for some activities, and government grants. Our fundraising is transparent, ethical, and accountable.

We have taken significant steps over the last 5 years to strengthen our financial situation and establish a reliable source of income so that we can operate self-sufficiently and continue to respond to the needs of the community. But we are a small community, and many in our community have complex needs. Further, it has become more complex to operate, and to keep up with community expectations for digital communications and our website capabilities. HFA has always received Commonwealth government funding grants to enable it to operate as the national peak body, and so we can connect with our community, and provide advice about the treatment and care needs of our community to governments, and for the cost of some of our education and digital communications activities. HFA is an information provider to HealthDirect, which is funded by Australian governments to provide a national health information service to all Australians.

We are grateful for the Federal government funding that has enabled HFA to do its work, and we cannot operate without this funding. We have never taken this funding for granted, but in return for these grants over many years we have delivered. The Australian government has been able to rely on HFA to work as the national peak body, to produce high quality education resources and represent its community through submissions and balanced advice about treatment and care. We can only do this because

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our connection with our community is strong and what you tell us about your experience of living with a bleeding disorder, your needs and the needs of your families and carers informs everything we do.

HFA is part of a broad 'blood sector' stakeholder framework that comes together so all Australians living with a bleeding disorder have the care and treatment they need to live full and active lives. This occurs with the support of different levels of government. HFA's national work is only possible because of the network of community members and health professionals who contribute in a voluntary capacity to work with our staff to make sure governments get value for their investment in our treatment products.

HFA's federal government grants have reduced significantly and without reinstated funding, HFA will not be viable going forward. We want government to recognise the value of the HFA input. I can assure you that HFA remains solvent as a business now, but our continued input into the national blood sector about our treatment and care needs will require a commitment from the Federal government to the costs of HFA's peak body and education activities.

Our pre-budget submission before the recent Federal budget was unsuccessful, but we will continue to discuss the needs of the bleeding disorders community with the Federal Health Minister, the Hon. Mark Butler, and Department of Health officials. We know many of our members will share my concerns and may wish to approach their local Federal Member of Parliament to explain why they believe our community representation and participation is important. Please feel free to contact me or Sharon and the team at the HFA office for further information.

In the meantime, HFA has been operating in line with our workplans and while we have needed to curtail some planned future activities, we have very important work to keep going so we continue to meet current

grant deliverables and other activities not funded by grants, including our committee work and collaborations with other organisations. Our education work includes new information on the HFA website www.haemophilia.org.au and the youth website www.factoredin.org.au and a very shiny new education resource to add to our suite of resources for women and girls, A **Guide to haemophilia testing in women and girls** which was published in April. We also have new information on the Getting Older Hub - please take a look at it.

NATIONAL CONFERENCE

The **21st Australian Conference on Haemophilia, VWD and rare bleeding disorders** in August 2023 is our most important and valuable meeting. It is held every two years and we hope you are making plans to attend.

The Conference is unique; it brings together all stakeholders in the blood sector - patient and families, their treating health professionals, industry and policy makers together to discuss treatment and care from the perspective of the experts including from people who live with a bleeding disorder and their carers as experts. The focus is on improving the health and quality of life of people living with a bleeding disorder. It is always a vibrant meeting where every delegate learns more.

We urge you to come to Melbourne for the Conference in August. This is our first conference since we moved to a virtual conference during the COVID-19 pandemic and we know how valuable it is for our community to come together and share their experiences face-to-face.

It is also a great opportunity for us to time to show our solidarity and actively demonstrate our contribution to the blood sector.

The Conference is supported by corporate sponsorship specifically for the conference, and we have no doubt it will be a great meeting. Please contact HFA or your local Foundation if you require financial assistance to attend. We look forward to seeing you in August.