

#### Gavin Finkelstein

President, Haemophilia Foundation Australia

# From the President

As we head towards the end of the year, it's an important reminder to stay connected with your Haemophilia Treatment Centre - and if you have an annual review, have you been booked in for 2024? We as people change all the time, and sometimes your treatment also needs change and adjustment.

### BLEEDING DISORDERS AWARENESS MONTH

Bleeding Disorders Awareness Month is coming up in October. This is a time for our community to raise awareness about bleeding disorders – it might be about your experience or sharing the stories of others. I'm always impressed to see the work of kids and their families in these activities – holding stalls or speaking to their class at school about their bleeding disorder and what it means. It's a really effective way to increase understanding in the wider community. With the theme NEW POSSIBILITIES over the month, we will share stories and a lot of information and facts. It's not too late to order promotional materials.

#### GENE AND EMERGING THERAPIES

We continue to monitor updates about gene therapy in haemophilia and watch the space overseas. Over the coming months we will be producing information and resources on gene and emerging therapies. Gene therapy for haemophilia is currently being evaluated by government, with gene therapy for haemophilia B being the most advanced in the process. Visit our website for information about gene therapy and listen to the webinar recorded in May 2024 with Dr Michiel Coppens.

HFA is working with a highly respected research company CaPPRe on a study about patient treatment preferences in haemophilia. This is important research for our future directions in treatment and we would like to hear what you have to say. We have chosen to undertake this research independently and it has been funded by the Haemophilia Foundation Research Fund. The survey will be launched soon. Keep an eye on your e-news if you wish to participate.

## **REVIEWING THE YEAR**

HFA Council will hold our Annual General Meeting in October and look out for our Annual Report at the end of November, which will show our work and its impact over the last financial year. Most local Foundations will also host their AGMs around this time. If you would like to know dates and get involved, visit your local Foundation website.