



Gavin  
Finkelstein

President,  
Haemophilia  
Foundation  
Australia

## From the President

Another exciting year ahead and the staff have hit the ground running in 2024. I am happy to share that HFA funding has been reinstated by the Department of Health and the National Blood Authority until 2027. This is a big relief for HFA, our stakeholders, community and health professionals.

### WFH WORLD CONGRESS

Australia will be well-represented at the World Congress in Madrid in April 2024. A number of our Haemophilia Treatment Centre health professionals will be attending and presenting. I will be attending the National Member Organisation training in the days leading into Congress and the General Assembly, as well as attending Congress. HFA Executive Director (Acting), Natashia Coco, will also be attending Congress and Suzanne O’Callaghan, Policy Research and Education Manager, has been invited to speak on *Creating supportive networks and advocacy initiatives* in the Women and Girls with Bleeding Disorders track on Tuesday 23 April 2024. We look forward to hearing the reports from Australian delegates in the next edition.

### WORLD HAEMOPHILIA DAY

Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. The 2024 international theme is **Equitable access for all: recognizing all bleeding disorders**.

Australia has a number of sites lighting up in red on the day. See [www.haemophilia.org.au/WHD](http://www.haemophilia.org.au/WHD) for a list of sites.

### RARE DISEASES

In this issue of *National Haemophilia* we also feature Rare Disease Day and personal stories that two community members with Glanzmann thrombasthenia have generously shared with us. Some bleeding disorders are very rare and people affected can feel very isolated. We are grateful to Allison and Elizabeth for explaining the challenges they and their family live with and highlighting the work that still needs to be done around rare diseases.

### HFA WEBSITE

The new HFA [www.haemophilia.org.au](http://www.haemophilia.org.au) website went live in January 2024. The site features improved navigation, and it is much easier to find many of our resources. Your local Foundation sites have also had a makeover and gone live recently. Please bear with us as the staff fine tune a few aspects of the site.

### DON’T FORGET THE PROBE STUDY

HFA is building evidence about the needs of men and women affected by haemophilia in Australia with the PROBE Australia Study. This is an important study on the impact of haemophilia and we would really appreciate your help, particularly as we enter a time of further advocacy around new treatments. For good credible data, we need several hundred survey responses. Please consider participating, if you haven’t already, and perhaps inviting your family and friends to complete the survey – we also need equal numbers of people without a bleeding disorder as a comparison group. See page 12 for details.