

Gavin Finkelstein is President, Haemophilia Foundation Australia

# FROM THE PRESIDENT

*Gavin Finkelstein*



## COVID-19

As we approach the mid-year reporting time for HFA, I wonder what our future members will think about the very unusual year of 2020. We finished 2019 with a very exciting national conference and feeling very upbeat. We had new treatment products to look forward to, our community was feeling strong and engaged and we had many plans for community events. As the terrible situation resulting from COVID-19 started to unfold around the world, we were soon to discover we were living in a pandemic that would bring the world to a halt in so many ways. We hope you and your families have stayed well during this time. For Australians with a bleeding disorder there has been an ongoing supply of treatment products and medicines but we know that hasn't been the case for everyone globally, and our thoughts are with National Member Organisations whose members are finding it harder to get treatment and support.

We are grateful for the extra work done by our Haemophilia Treatment Centre staff in extraordinary circumstances to keep connected and to be available to help their patients, whether it's been via telephone or internet, and to manage the difficult situations which have arisen because people needed to attend hospitals for treatment. The National Blood Authority has kept us up to date and assured us the existing plans will meet treatment product needs.

## TREATMENT PRODUCT TENDERS

We are still waiting on the outcome of the government tender process for the supply of treatment products. We have many people desperately waiting for a new treatment and we hope we will soon be in a situation in Australia where best practice clotting factor and other treatments is a reality. At the national conference and at our meetings

and events we have heard from clinicians and the those who have had the chance to use a new treatment in a clinical trial or compassionate access program just how life changing some of the new options can be. Everyone in our community should have access to an improved treatment which helps them lead a healthier and more fulfilling and productive life. You will read about young Christopher in this publication and share our delight that his life has become so much better.

## SUPPORTING HFA

Thanks to the HFA office staff who have been working from home, we have kept a lot of our work going, as you will see from this publication. A great concern is that we have experienced a sudden decline in donation income, possibly partly due to the bushfires and perhaps now because of the difficult time experienced by some of our donors due to the downturn caused by COVID-19. We will need to review our plans significantly going forward to ensure we target the most pressing activities with the funds we have available. Our donation income supports some of our care and services as well as our advocacy and it is critical that we don't slow down our work in this area. If you can help us in any way, please do.

**You can donate online at  
[www.haemophilia.org.au/donate](http://www.haemophilia.org.au/donate)  
or call 03 9885 7800. #**