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From the President

I focused on new therapies, starting school and the national conference in *National Haemophilia* in December. Each of these are seriously big things!

UPCOMING NATIONAL CONFERENCE

You will hear more about the upcoming conference in this issue. We hope you can come to Melbourne for the Conference. We are supported by a great team to develop the program – with multidisciplinary health professionals and community representatives coming together to select topics of interest to people across all ages. There will be some financial assistance available, so please watch out for details on the HFA website or contact us for further information.

STARTING SCHOOL

By now, many of our younger families with a child with a bleeding disorder who started school this year may well be feeling more settled and getting into a routine.

It takes time for everyone in the family to adapt to changes like starting school or going to a new school or university. It can also be challenging for the kindergarten or school if they have not come across another student with a bleed disorder. But we know families know how to provide the right balance of information about their child so everyone can get on with the job of settling in.

Treatment with longer acting clotting factor or other types of products have made a great difference to the child from a bleed point of view, and for planning and organising for the whole family. We hear so many

stories about the ways some of the new therapies now available make such a difference, with fewer bleeds, or no bleeds at all, and better quality of life for everyone in the family.

PARLIAMENT HOUSE CANBERRA

HFA representatives were in Canberra in February 2023 to promote awareness of new and emerging therapies at an education event for Federal Members of Parliament under the banner of the Parliamentary Friends of Children and Adolescent Health.

We were delighted this had been suggested by Dr Mike Freeland, Federal Member for Macarthur in New South Wales in the current Albanese government who is one of the Co-chairs of this Group with Dr David Gillespie, Member for Lyne and member of The Nationals in the House of Representatives and Dr Monique Ryan, an Independent Member of Parliament representing Kooyong, Victoria in the House of Representatives.

Our thanks to Dr Liane Khoo, Director of the Haemophilia Treatment Centre at the Royal Prince Alfred Hospital in Sydney, who gave a presentation on current and emerging haemophilia therapies.



Dr Liane Khoo presenting on new therapies





Dan Credazzi speaking about his experiences as a parent

A special thank you to Dan Credazzi, HFA Vice President and President of HFNSW who attended the event and spoke about his role at HFA and HFNSW and also as a parent of a young man with haemophilia.

Dan told how he and his wife Dao had the opportunity to attend an HFNSW family camp when Jay was just one month old. They had been devastated for their son, that he had haemophilia, but this changed at the camp as they watched the children playing, doing rock climbing and the older kids supporting them, and the parents sharing their experiences about how they coped. Dan said we left the camp saying, “we can do this”.

Jay generously shared his experience of severe haemophilia – the thousands of infusions into his veins during his life, and how this has recently changed since he has used a new treatment, that is so silent in his life that he sometimes feels he must remind himself that he has haemophilia. Jay has started university this year, and haemophilia will not define him or the way he lives.