



ACTIVATED

Newsletter of Haemophilia Foundation Australian Capital Territory

From the President

As another year draws to a close it is worth reflecting on some of the highs and lows of the year and bidding farewell to two wonderful servants of the bleeding disorders community.

On the positive side, the year saw HFACT host a number of events for the community, which was a welcome return from the quiet COVID years. This included the very successful coastal camp held in Batemans Bay, a breakfast, trivia night and BBQ. HFACT continues to be sustainable financially and maintains good relationships with both ACT Health, our key funding partner, and the HTC at the Canberra Hospital.

The passing of Simon McMenamin was without doubt one of the lowlights of the year. Simon was a valued member of the community and an inspiring individual all round. Also sadly leaving us was Petronella Wensing, the mother of Fred Wensing, who many of you know was HFACT President for many years prior to me taking up the position. Fred's mother was previously an active member of the community and much-loved mother, grandmother and great grandmother to the Wensing tribe.

This year saw the departure of Sharon Caris as Executive Director of Haemophilia Foundation Australia (HFA). Sharon has been a wonderful servant to the community both in the ACT and across Australia. She has provided advice and counsel when needed and has been a steady hand guiding HFA for more than 20 years. She will be sorely missed but I look forward to continuing the productive relationship between HFACT and HFA over the coming period with her successor, Natashia Coco.

Also departing is HFACT's Counsellor, Kathryn Body. Kathryn is retiring after six years in the role. She has been a wonderful counsellor and will also be sorely missed. HFACT has commenced the process to find a replacement, although that may be easier said than done. We give Kathryn our best wishes in retirement.

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There is a renewed push to ensure people with a bleeding disorder who are using products such as factor replacement or Hemlibra are recording their usage in MyABDR. This is important as it provides clinicians with a valuable view of product usage as part of patient reviews, enables individuals to monitor their own usage, and also provides valuable data to the National Blood Authority to optimise supply of the product. I encourage all of you that are using products to utilise MyABDR appropriately.

In this newsletter there is information on the PROBE study, which aims to help measure the impact of haemophilia in Australia. Further details are provided, but in a nutshell the study is seeking survey responses by 31 January 2024. Importantly, you don't need to have a bleeding disorder to complete the survey.

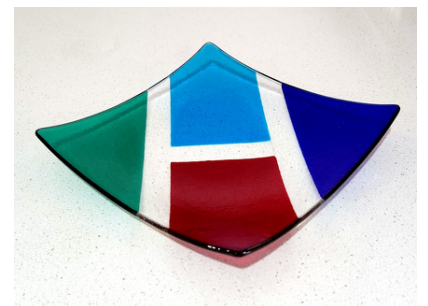
Finally, I'd like to wish you all a merry holiday season and hope you get to have a relaxing break, recharge and prepare for 2024. See you in the new year!

Claude Damiani
President

AGM report

HFACT's 2023 AGM was held on 21 October to coincide with the Community Coast Camp at Batehaven. Around 15 people, including HFACT members and several guests, attended in person. The president and treasurer presented their respective annual and financial reports, which were accepted by those present. These documents are available on the HFACT website.

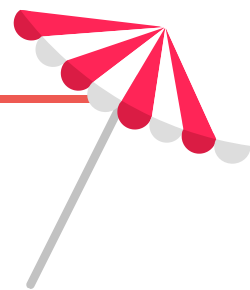
Elections were held for the 2023-24 HFACT committee. Details of the incoming committee are on the HFACT website. **The position of secretary was not filled and the committee would be happy to hear from any member who would like to volunteer for the role.**



One of HFACT's guests at the camp was Ms Sharon Caris, Executive Director of HFA. Attending the camp was one of her last official duties after 23 years in the role. As a thank you from HFACT and in recognition of her years of service, Sharon was presented with a certificate of appreciation and a custom glass platter.



Coastal Camp tidbits



On Friday 20 October, some 42 people started to gather at the NRMA Batemans Bay Resort for the 2023 HFACT Community Camp, to be held over the following two days. As well as HFACT members, we were joined by our haemophilia nurse, Jayne Treagust, and her husband Steven (aka Shrek), Sharon Caris from Haemophilia Foundation Australia (HFA), and of course our counsellor, Kathryn Body.

The weekend started with a relaxed family meal at a local club where parents were able to take advantage of a supervised play area for children. The following morning, the program began in earnest with formal conference sessions for the adults and supervised fun activities for the children. The sessions were informal and informative. It was great to see people at camp who had never been before and great that one young boy had the opportunity to meet not only other children like himself but adults that have the same condition.

Highlights of the camp this year were undoubtedly the kite making and flying exercise (some people are so creative!) – followed closely by the visit from the ice cream van!

As Sharon Caris was retiring from her role as Executive Officer of HFA, HFACT took the opportunity to thank her for her service and friendship with HFACT and presented her with a certificate and a specially made glass platter.

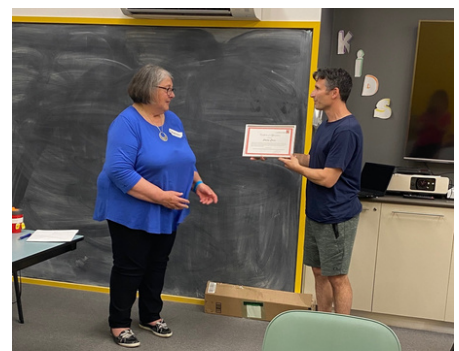
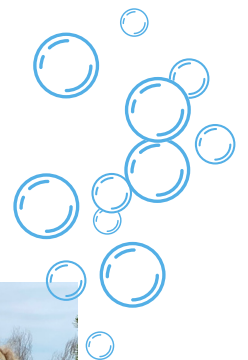
Following Sunday breakfast, a number of families took advantage of the opportunity to visit the Aquatic Pavilion at Batemans Bay for a fun morning in the water before returning to Canberra.

Camp would not have been possible without the planning and organising done by the HFACT Committee and Counsellor, the presence of Katherine, Lisa, Cass and Chelsea who provided childcare on Saturday, and the help of all families at mealtimes.

We hope those that attended the camp had a wonderful weekend and will be back again next time – and we'd love to see some new faces and families joining the fun next year too!



Some photos from camp...





HFA Conference highlights

The **21st Australian Conference on haemophilia, VWD & rare bleeding disorders** was held in Melbourne in August. Over 210 delegates attended – from people with bleeding disorders and their families and carers, to health professionals, policy makers and industry. More than 50 speakers shared their perspectives on topics under the umbrella theme **Working together – improving outcomes**. Discussions traversed gene therapy, women with bleeding disorders, mild haemophilia, VWD, rare bleeding disorders, family planning, pregnancy and newborns, making career choices, getting older, pain and musculoskeletal issues.

Several members of the HFACT community attended the conference, a couple of whom have kindly shared some of their notes below, for the benefit of those who were unable to attend in person. Most of the presentations are now available online at: www.haemophilia.org.au/Presentations23.

Thank you to our sponsors



Thoughts from Jayne Treagust (Haemophilia Nurse)

This year's conference seemed to have many sessions on Australia's experience with new and emerging treatments, gene therapy, genetics and inheritance, and women's and girls' bleeding disorders.

There was a great deal of interest in the gene therapy sessions. Gene therapy is where a functional copy of FVIII or FIX gene is placed into a viral vector (typically an adeno-associated virus) and delivered intravenously where it targets the liver cells. It enters the liver cells, travels to the nucleus where it becomes functional, and instructs the cell to produce FVIII or FIX proteins, which are then secreted into the circulation, providing more effective blood clotting. There are still many limitations identified for current gene therapy, more with Haemophilia A than Haemophilia B. Let's see what the future holds.

I spoke at the HFACT education evening in September, about some of the problems that women with bleeding disorders have.

Mild haemophilia was also a topic of discussion. Dr Heather Tapp, a paediatric haematologist from the Women's and Children's hospital in Adelaide presented a particularly interesting session on the challenges faced by those with factor levels >5-40%. It was fascinating to hear how physiological changes such as infection, inflammation, pregnancy and even age can influence factor levels.

Dr Tapp's talk also explored the fact that these people had less engagement with their HTC, less experience in recognising and treating bleeds and realising that mild haemophilia may not always be mild. I do worry that people who are now having prophylactic Hemlibra will also have these issues in the future. For this reason, it is important that we continue to speak about bleeds, what to look for and how to treat, focusing on why we need to treat bleeds – preventing future damage and disabilities.

I would also like to thank HFACT for supporting me to attend this conference by paying for one night's accommodation at the hotel where the conference was held. It was greatly appreciated. I came away from the conference feeling very motivated and inspired.

wave a very merry Christmas and a safe and happy New Year.

Thoughts from Martha Soria on Plenary 2: Gene Therapy

Dr Glenn Pierce (Vice President Medical, World Federation of Haemophilia) told us that gene therapy may be a cure, i.e. 'once and done'. He also noted that gene therapy administered via a viral vector can never be repeated because once the virus is introduced, the immune system creates an immune response to the virus, and any other of the same family.

Dr Pierce has been researching for the last 25 years and noted that it seems Haemophilia B (FIX) is finished but type A isn't there yet because FVIII is a very unique molecule and very different to FIX. For Haemophilia A there is no therapeutic index yet for the high levels of toxicity to the liver. Further, for Haemophilia A, FVIII is not stable (in contrast to Haemophilia B, where FIX remains stable).

Before opting for gene therapy, it is necessary to consider all available therapies to decide which maximises the individual's quality of life. Dr Pierce shared the WFH Shared Decision-Making Tool, which includes the following steps:

- *Seeking information*
- *Decision making*
- *Treatment initiation*
- *Short term considerations*
- *Long-term considerations*

There are two products already approved in the United States and Europe. At a per-patient cost of US\$3.5 million at present, gene therapy is cost effective and in the long term, even cost saving.

There are many eligibility criteria for participating in gene therapy. A healthy liver is a must. At present women and children are not eligible – the former because they did not participate in trials and the latter due to ethical restrictions. The goal is to eliminate 'severe' and 'moderate' haemophilia at least; and at best, all haemophilia.

Dr Pierce concluded by noting that all involved in this new technology need to consider the risks seriously and that he will keep looking for a cure, not therapies – we already have lots of them!

New HFA education resource: Haemophilia booklet

New haemophilia booklet

The new HFA **Haemophilia** booklet is now available. Much has changed with new haemophilia treatments and the 2023 edition has been revised completely.

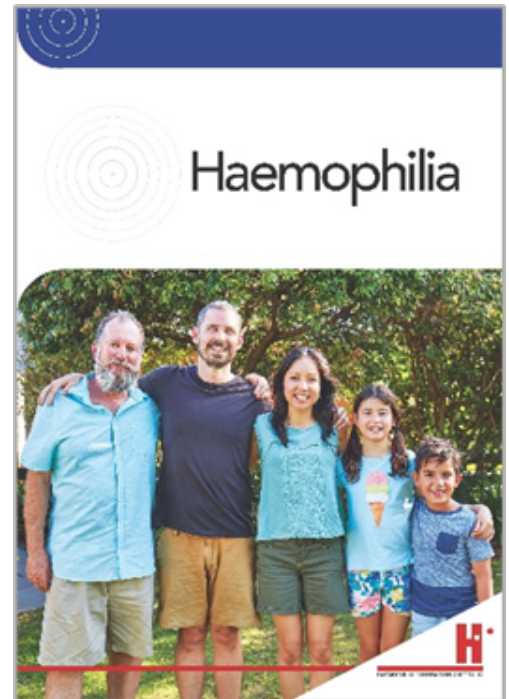
It is a great introductory resource about haemophilia that is very useful for new families and educating others – for example, extended family, schools, employers and health professionals who are new to haemophilia. It covers:

- what causes haemophilia
- diagrams of genetic inheritance and how bleeding occurs in haemophilia
- diagnosis
- treatment (including new treatments)
- carrying the gene alteration
- family planning and pregnancy
- tips on living well.

Thank you to all of the community members and health professional experts who contributed to its development.

Accessing Haemophilia 2023

- download it from the HFA website – <https://tinyurl.com/HFA-haemophilia>
- ask HFA to post you a free print copy – hfaust@haemophilia.org.au



Important message: MyABDR

There has been a recent update to the MyABDR app and the National Bleeding Authority (NBA) has asked if you can delete the current app that you have and download it again. This will hopefully stop any of the issues that you may have been experiencing with the app.

Unfortunately, we have a poor uptake of people using the MyABDR app in Canberra. It is a valuable tool and by using this app you are helping the NBA to forecast and plan Australia's clotting factor supply. We are very privileged in Australia as not only do we have access to clotting products, but they are free!

The medical staff at the Canberra Hospital would like to encourage all people who are receiving factor and/or Hemlibra to start using the MyABDR app. It is a record of product administration and bleeds and can be a valuable tool to other centres if, when travelling, you have a bleed that needs attention. Remember, your privacy is protected as only ABDR authorised people have access to see this information.

Please continue to use, or begin using, the app. We want to ensure that your ability to access free clotting products continues. If you are having any issues with the app, call **1300 025 663** or email **support@blood.gov.au**

- treatment (including new treatments)
- carrying the gene alteration
- family planning and pregnancy
- tips on living well.

Thank you to all of the community members and health professional experts who contributed to its development.

Jayne Treagust

Haemophilia Nurse



PROBE study

PROBE Australia Study



Have you done the 2023 PROBE Australia survey yet?

Don't wait! Please complete the survey **by 31 January 2024**.

You can contribute to the Australian evidence on the different experiences of living with haemophilia – the impact of new treatments, being younger or older, a woman, having mild haemophilia. HFA uses PROBE survey data in advocacy and planning for the future.

WHO CAN COMPLETE THE SURVEY?

Adult men and women (**18 years+**) who live in **Australia** and:

- **have haemophilia or carry the gene**

OR

- **do NOT have a bleeding disorder** (comparison group)



HOW TO DO THE SURVEY

The questionnaire is available:

Web version at myprobe.org

Or download the **myPROBE app** from Apple Store or Google Play (Android)

Or ask **your local Foundation** or **HFA** for a print survey pack

FOR MORE INFORMATION

Visit www.haemophilia.org.au/probe-study.

Or contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au T: 1800 807 173



Farewell to Kathryn

Kathryn Body, HFACT Counsellor since 2016, is currently on long service leave and will then be resigning for personal reasons due to other commitments.

The HFACT Committee is sad to see Kathryn go. We thank her for her dedicated service and the enthusiasm and energy she has brought to the role. Kathryn's departure will be a huge loss and it will be hard to replace her unique qualities and experience. Kathryn helped many families of the Canberra region affected by haemophilia and other related inherited bleeding disorders.

HFACT will hold a farewell event for Kathryn on Saturday 3 February 2024 (see below).

Recruitment for a suitable person to fill the counsellor position is underway. Our counselling service will be temporarily unavailable until the position is filled. If you need support related to haemophilia or another inherited bleeding disorder, please contact the Canberra Hospital Haemophilia Treatment Centre in the first instance.

A message from the Canberra Hospital haemophilia team follows:

Kathryn – you have been a big support to not only the haemophilia patients but also to the staff who help care for the haemophilia patients at the Canberra Hospital. You have always been willing to 'go the extra mile' to ensure the patients receive the support and treatment they need. You have been an excellent patient advocate.

Your skills will be greatly missed but we wish you every happiness in your future endeavours. You will be hard to replace. Thanking you for everything you have contributed to the haemophilia community.

Dr Michael Pidcock, Dr Nalini Pati, Jayne Treagust and all the other people you have worked with.





Merry Christmas!

HFACT wishes you all a
safe and happy festive
season.

Looking forward to seeing
you in 2024!



DATES FOR THE DIARY

Contact HTC if you need product over the Christmas period	ASAP
Farewell gathering	3 Feb
Bleeding disorders clinic	23 May



To improve the wellbeing of the haemophilia community through mutual support, networking, advocacy and striving for optimal health care.

Haemophilia contacts

Canberra Hospital

Main telephone: 5124 0000
Website:
<https://www.health.act.gov.au/hospitals-and-health-centres/canberra-hospital>

Haemophilia Treatment Centre

Mon-Fri 9am - 5pm
On duty nurse: 0481 013 323
Email: haemophilia@act.gov.au
More details at:
www.hfact.org.au/treatment

Haemophilia Foundation ACT

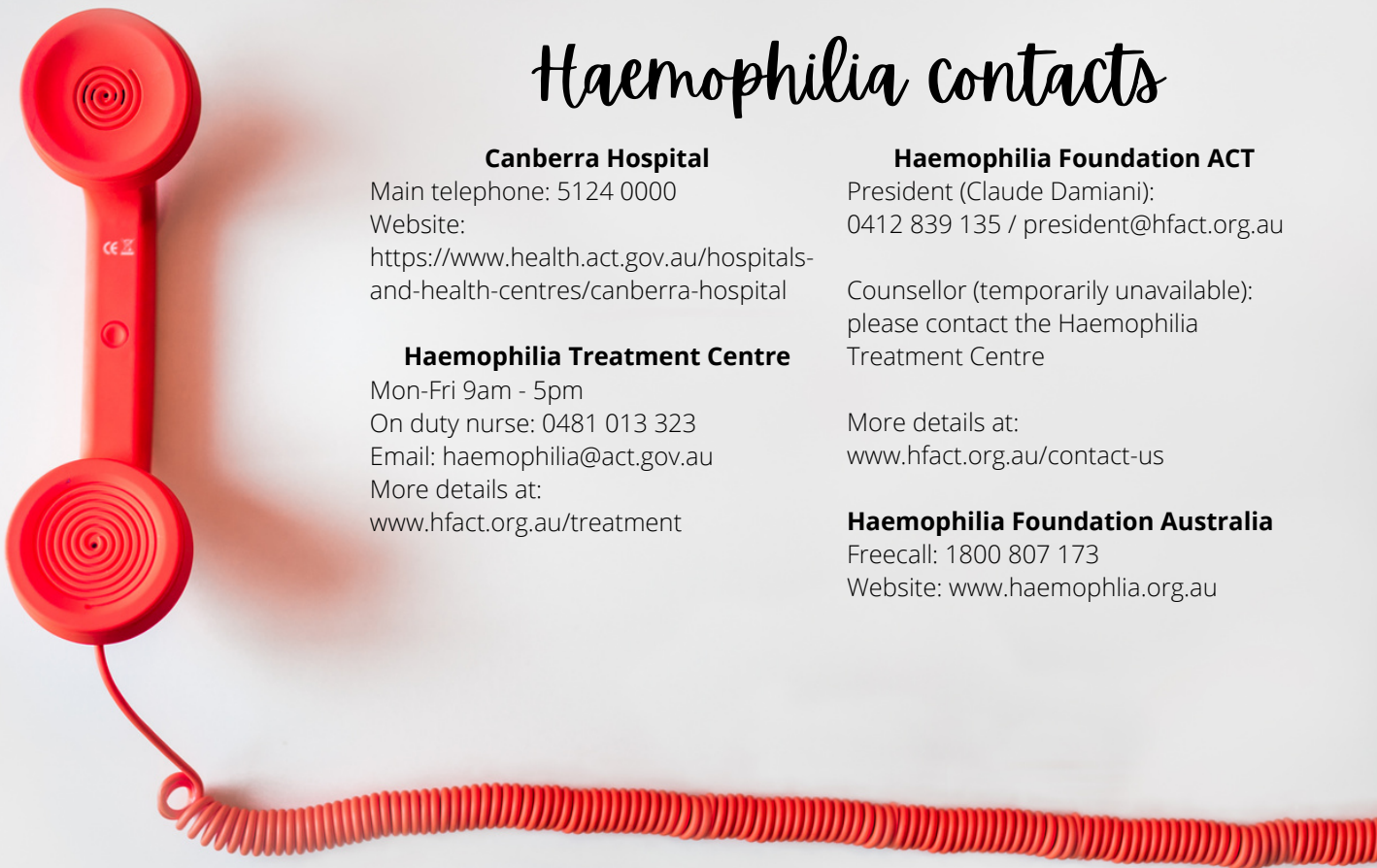
President (Claude Damiani):
0412 839 135 / president@hfact.org.au

Counsellor (temporarily unavailable):
please contact the Haemophilia Treatment Centre

More details at:
www.hfact.org.au/contact-us

Haemophilia Foundation Australia

Freecall: 1800 807 173
Website: www.haemophilia.org.au



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