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Newsletter of Haemophilia Foundation Australian Capital Territory

From the President

It was an odd summer in Canberra - not particularly hot, sometimes wet - although it was a glorious sunny day for our annual summer BBQ held at Nara Park in February. It was great to see some familiar faces and to enjoy the outdoors, fresh air and bacon & egg rolls. This is one of a number of social activities planned for 2023, with the next being a pub trivia night in May (details in this newsletter) followed by a mid-winter dinner in August. Given the success of last year's community camp, we are also looking to hold another camp later this year (further details to come in the next newsletter).

Pre-COVID, HFACT held a meeting with the Haemophilia Treatment Centre (HTC) annually. This meeting provided an opportunity to receive updates from both sides (HFACT and the Canberra Hospital/HTC), seek clarification on matters and raise any concerns or grievances brought to HFACT's attention by the community. I am in the process of arranging the first post-COVID bilateral meeting with the HTC, with the intention of holding these meetings annually going forward. I'll provide a readout of the meeting in the next newsletter (assuming, as I'm expecting, that the meeting takes place).

With World Haemophilia Day just around the corner, I want to take a moment to reflect on just how fortunate we are, living with a bleeding disorder in Australia. I know that from time to time, members of the community get frustrated with our health system, but when you consider how challenging it is for many people in developing parts of the world to get decent care and access to high quality treatments like we have here in Australia, it puts our situation into some perspective.

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President's Report cont.

Those who know me well would be aware that I'm a voracious reader of news, so it was a pleasant surprise to stumble across an article in late February advising that the European Commission had granted conditional marketing authorisation for CSL's new one-time gene therapy, HEMGENIX, for treating severe and moderately severe haemophilia B (congenital Factor IX deficiency) in adults without a history of Factor IX inhibitors. The article states that clinical trials found HEMGENIX reduced the rate of annual bleeds with a single infusion by delivering a functional gene that acts as a blueprint for coagulation Factor IX. The conditional marketing authorisation of HEMGENIX in Europe follows its approval in the US in late 2022. The article also states that the therapy is currently under review by the UK's Medicines and Healthcare products Regulatory Agency and a submission, presumably for approval to market, is being prepared for Australia's Therapeutic Goods Administration. Whilst this is exciting news, it's important to note the likelihood that the therapy, should it be approved for use in Australia, is likely to be extremely expensive. We will watch this space and report on any further developments.

Claude Damiani

President

February BBQ & banter



A wonderful summer's day greeted the HFACT community for its annual summer BBQ. It was great to see the bleeding disorders community out and enjoying the beautiful surrounds of Nara Park. As a bonus we managed to 'snag' the best spot in the park (thanks Len!), with a rotunda adjacent to barbeques. Egg & bacon rolls were followed by sausages and patties (and chips and lollies for the kids). No one left hungry (quite the opposite!). Look forward to the next in summer 2024 - hope to see you there!





World Haemophilia Day 2023

Every year on 17 April, World Haemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel's birthday.

This year the international theme is **“Access for All: Prevention of bleeds as the global standard of care”**. The aim is to improve access to treatment and care with an emphasis on better control and prevention of bleeds for all people with bleeding disorders. This means making home-based treatment available as well as prophylaxis treatment to help people with bleeding disorders to have a better quality of life.

Did you know, WFH estimates that over 65% of people living with haemophilia worldwide have not yet been identified and diagnosed.

The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work to improve access to diagnosis, treatment, care and support for people with bleeding disorders in less well-resourced countries with their GAP and Twinning Programs and the Cornerstone Initiative. HFA is currently connected with the Myanmar Haemophilia Patient Association as a part of the WFH Twinning Program.

Haemophilia Foundation Australia is a WFH member organisation and many Australian volunteers have been involved with WFH programs. HFA has supported many programs over the years and participated in the WFH Twinning Program and various committees that work to achieve the objectives of WFH.

In Australia, our community is fortunate to have access to a range of treatments, care and services. During recent times, some new haemophilia therapies available in Australia have led to fewer or no bleeds and greatly improved the quality of life of those who have been able to use them. We look forward to more novel therapies in the future for everyone.

LIGHT IT UP RED

We have many locations and landmarks all over Australia **Lighting up Red** in support of World Haemophilia Day. In ACT we have the following locations:

Telstra Tower | Carillion | Australian Mint

For updated locations keep an eye on the HFA website (www.haemophilia.org.au/WHD) and HFA social media platforms.

Save the date...

★ JOIN THE FUN ★



PUB TRIVIA NIGHT



JOIN THE FUN ON
**WEDNESDAY
17 MAY**

COME AND RELAX...

TRIVIA SKILLS OPTIONAL!

ARRIVE FROM 6:30PM FOR DINNER, DRINK & CHAT...TRIVIA KICKS OFF @7:30PM
DURHAM HOTEL - GREEN SQUARE, KINGSTON

HFACT WILL COVER ONE MEAL + DRINK PER PERSON

RSVP: CLAUDE 0412839135 BY 10 MAY



COASTAL GETAWAY

MID-OCTOBER 2023

DETAILS COMING SOON



HFA conference 2023

The **21st Australian Conference on haemophilia, VWD & rare bleeding disorders** will be held in person at the Pullman on the Park, **Melbourne, 24-26 August 2023**. After a few years communicating and running events virtually and online it will be wonderful to see everyone come together again and at a different time of year to our previous conferences.

HFA conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

The multidisciplinary program will include presentations from people living with bleeding disorders, experts, as well as health professionals and other specialist speakers. There will be something for everyone:

- new developments in care and treatment
- inhibitors
- new treatments
- gene therapy
- living with a bleeding disorder
- getting older with a bleeding disorder
- women/girls with bleeding disorders
- family planning and genetics
- von Willebrand disease
- rarer bleeding disorders
- managing pain
- bloodborne viruses
- new diagnosis
- youth
- sport and healthy activities
- and...what's on the horizon?

The venue has good access in and around the hotel and on the conference floor, with direct lift access. The hotel is suitable for people who use wheelchairs.

COMMUNITY FUNDING

HFACT will subsidise conference attendance. For details, see **item on conference funding in this edition of ACTivated**. Applications close Friday 2 June (using the form available at: www.hfact.org.au/conference). HFA has also allocated funding to help community members with expenses to attend the Conference.

MORE INFORMATION

Registration link and details: www.haemophilia.org.au/conferences or email hfaust@haemophilia.org.au

Thank you to our sponsors

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HFACT conference funding

Once again, HFACT is pleased to be able to offer grants to subsidise attendance at the **21st Australian Conference on haemophilia, VWD & rare bleeding disorders**.

Conference is a wonderful opportunity to learn about the latest advances in treatment, meet other people in the bleeding disorders community and mix with health professionals in a relaxed atmosphere. It's also fun! If you haven't been before I recommend that you consider attending the August conference in Melbourne.

The funding HFACT has available for conference comes from donations and fundraising and is limited. To help HFACT determine how available funds are used, we ask those interested in applying for funding to complete an **application form**. The form is available on the HFACT website (www.hfact.org.au/conference) and is also attached to the newsletter email. A paper copy has been included with the newsletter mailout (for those who opt for paper copies of the newsletter) and our counsellor, Kathryn, also has paper forms available on request.

Applications for conference funding close on Friday 2 June. This will give us time to assess the applications and make decisions before registrations close.

Jenny Lees

Treasurer

Resources for managing school and childcare information for staff

New childcare, new class, new sports team...how can you manage information to keep your child with a bleeding disorder safe?

As any parent knows, managing information regarding their child's bleeding disorder can be difficult when their care is managed by others. If you would like assistance with information to share with the new childcare, new class or new sports coach/manager, then your HFACT Counsellor and HTC Nurse can assist.



We have designed some forms with both general information and child-specific details that parents can share with those responsible for the care of their child. Both Kathryn Body (Counsellor) and Jayne Treagust (HTC Nurse) are willing to speak to schools and childcare centres to educate staff on managing a child with a bleeding disorder.

If this is something we can assist with, please email counsellor@hfact.org.au and Kathryn will arrange a meeting with you.

Greetings from the HTC

I would like to say an enormously huge thank you to Lauren, who covered the haemophilia and bleeding disorders role for me whilst I was covering the haematology managers role. The feedback that I have received from patients and doctors alike about Lauren has been nothing short of excellent! Thank you, Lauren.

It certainly hasn't taken long to readjust, and I feel like I have never been away. It seems that the surgical teams within the hospital, and privately, have returned to normal as I have been busy organising factor replacement for people who are having surgery and dental work performed.

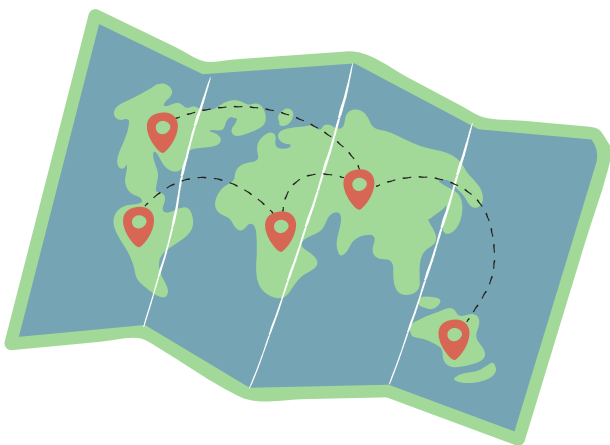
For people who are currently using Hemlibra, Roche (in conjunction with the National Blood Authority) has indicated that if you are planning on travelling overseas for an extended period (>3 months but <12 months), you are able to enrol in a patient support program called HEMLINK. They will cover the costs of the Hemlibra but will not cover or subsidise any additional fees such as dispensing fees that a pharmacy may charge. Roche have set up specific overseas locations from which you can pick up your medication. You will also need to be linked with an overseas haematologist who will be able to write a script that abides by the local laws.

This is the perfect way for a student who is doing an overseas exchange to ensure they still have access to Hemlibra, or for a family undertaking an extended holiday to allay fears of not being able to store a large amount of Hemlibra effectively. If you are planning to leave Australia for this extended period, I do need to know three months in advance as the NBA also has to be informed. Please be confident that Hemlibra formulations are standardised globally.

I look forward to catching up with everyone at the Haemophilia Clinic on 26 May.

Jayne Treagust

Haemophilia Treatment Centre Nurse



DATES FOR THE DIARY

World Haemophilia Day	17/4
Pub Trivia Night	17/5
Bleeding Disorders Clinic	26/5
Conference funding applications due	2/6
Mid-winter dinner	Aug (tbc)
HFA Conference	24-26/8
HFACT Coastal Getaway	Oct (tbc)



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

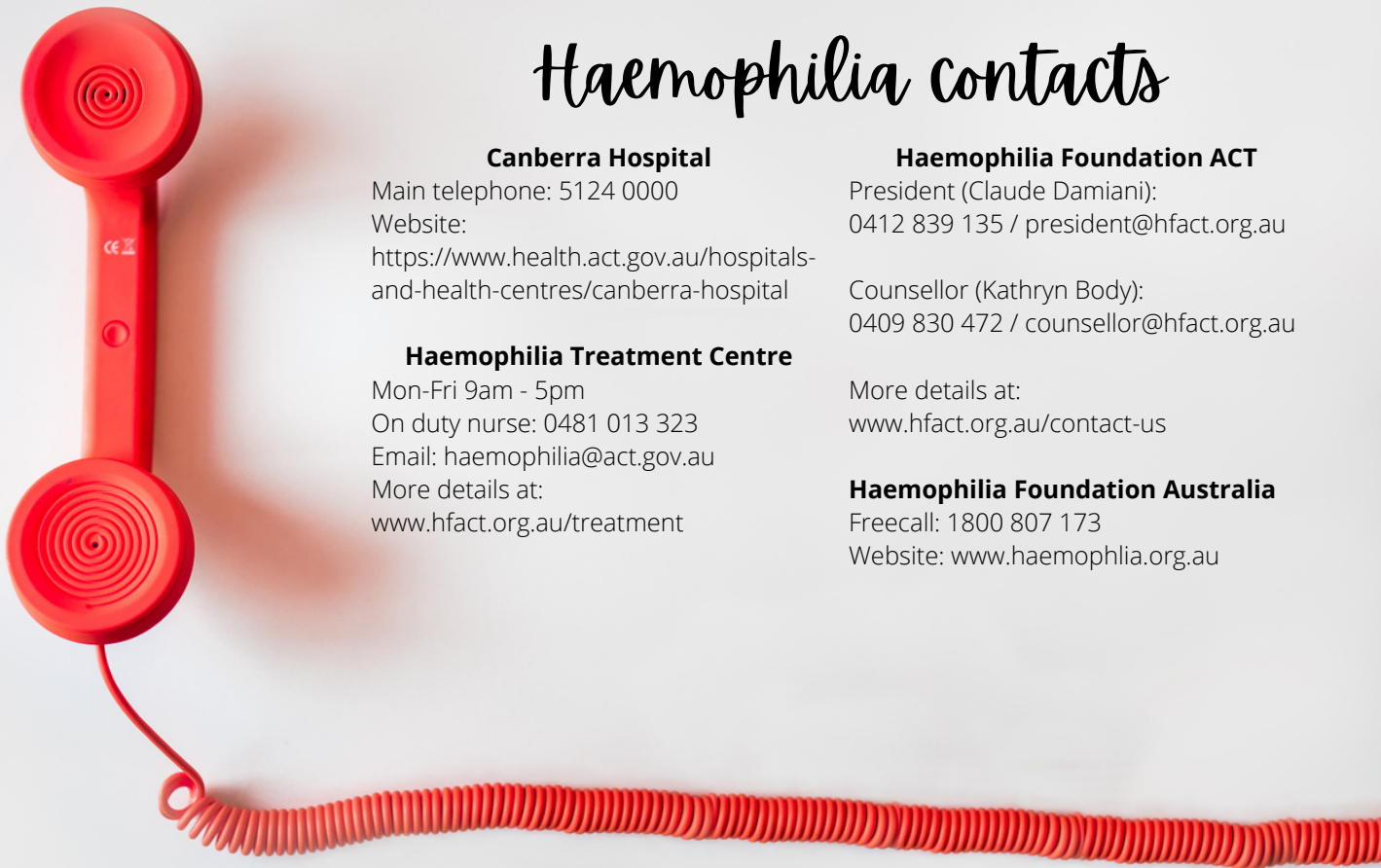
Haemophilia Foundation ACT

President (Claude Damiani):
0412 839 135 / president@hfact.org.au
Counsellor (Kathryn Body):
0409 830 472 / counsellor@hfact.org.au

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

Haemophilia Foundation Australia

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Website: www.haemophilia.org.au



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