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ACTIVATED

Newsletter of Haemophilia Foundation Australian Capital Territory

From the President

Welcome to 2024!

I'm excited about what the year brings. There are a number of events planned for the year, including a celebration for HFACT's 40th anniversary, a trivia night, a kids get-together, and a staycation. These will be great opportunities to bring the bleeding disorders community together, enjoy each other's company and reflect on just how far HFACT has come since its inception in the 1980s. Details on the first couple of events are in this newsletter - further information on the kids activity and the staycation will follow in the next newsletter.

On the hospital front, HFACT welcomes a new haematologist, Dr Fathima Ayyalil. Fathima is excited to be working with the bleeding disorders community in Canberra and I look forward to engaging with her over the coming year. A short bio for Fathima is provided in this newsletter.

While welcoming Fathima to the community, we say goodbye to Kathryn Body, HFACT's counsellor for the past six years. A wonderful BBQ event to farewell Kathryn was held in February and was well attended, reflecting the high regard the community held for Kathryn. HFACT is currently in the process of hiring a new counsellor.

World Haemophilia Day will be held on 17 April. It's a great opportunity to raise awareness of bleeding disorders, and this year we're fortunate to have four monuments around Canberra "lighting up red" in the evening to mark the event. I look forward to travelling around after sunset on the 17th to take photos of these "red" monuments!

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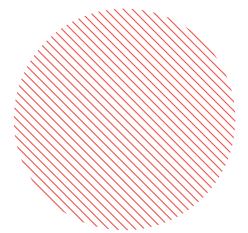


On a personal note, treatment for my four boys with moderate haemophilia is getting easier. Three of the boys are now on Hemlibra and doing remarkably well. Injecting the two older boys subcutaneously on a fortnightly basis is a breeze, although the third boy wants to be injected while he sleeps as he's still afraid of needles. While this may sound a little challenging, in the scheme of things its relatively straightforward. Although this is now our new routine, I do from time to time catch myself reflecting on how the treatment regime for my boys, as well as many others with a bleeding disorder, has improved markedly. I can only hope the improvements continue - indications based on clinical trials of new drugs and gene therapy are positive on this front.

While life seems to be getting busier and busier, I do look forward to seeing you during the year at one of the numerous events we have planned.

Claude Damiani

President

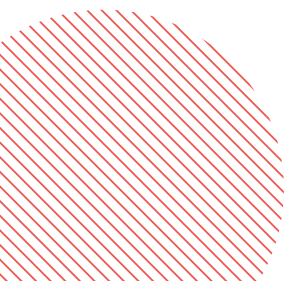


Welcome Dr Fathima Ayyalil

Dr Fathima Ayyalil is a haematologist at the Canberra Hospital and National Capital Private Hospital. She completed her Haematology training at Calvary Mater Newcastle and Canberra Hospital. She has a special interest in the areas of bleeding disorders, haemostasis/thrombosis and platelet disorders.

Dr Ayyalil is a member of the Thrombosis and Haemostasis Society of Australia and New Zealand (THANZ). Her abstract '*A unique regional outreach program to provide targeted quality care to individuals with bleeding disorders*' was selected for a THANZ AHCCDO conference grant in 2017. She attended the Haemophilia Academy Program in 2021.

Dr Ayyalil has a passion for individualised and evidence-based patient care and translational research.



Kathryn's farewell

It is with great sadness that Kathryn Body has departed HFACT after more than six years of wonderful service. Kathryn has been an excellent counsellor. She has demonstrated professionalism and a real skill in dealing with a wide range of stakeholders, including (but certainly not limited to) the HFACT Committee, hospital staff, and individuals and family that make up the bleeding disorders community across the ACT and beyond. We would consistently receive positive feedback on Kathryn's performance and her ability to engage people in a professional yet friendly and authentic manner.

Here we share some photos from the recent farewell BBQ that HFACT organised to farewell Kathryn. It was at this event that HFACT formally thanked Kathryn for her service and wished her well in her future endeavours.

It is important to note that HFACT has commenced the process to fill the position of HFACT Counsellor following Kathryn's departure.





HFACT turns 40!

It may be hard to believe, but HFACT has turned 40! While there's some discussion over whether that was in November 2023 or early 2024, the key thing is we've been supporting each other for four decades - and that's something worth celebrating. I've borrowed some words from Fred Wensing covering the early days of the group to provide information to our newer members and for us to reflect on how far we've come.

In late 1983 a group of concerned people in Canberra felt that it would be a good idea to meet from time to time to share our experiences and discuss ways of improving treatment for people with haemophilia. Significant in this push were Stephen Russell and the Williams family, both of whom moved to Queensland in later years. The Wensings hosted the first meeting with about 12 people present. We figured there was enough interest to meet again and so the group started formally in 1984.

It took two years to get to a point where we took the next big step - and that was to become "incorporated". This was seen as a necessary requirement to be able to present ourselves to hospital management and to the ACT Government as an advocacy group and also to potentially qualify for funding.

The first president of our support group was Carol McKenny, and other committee members included Stephen Russell, Patti Luhrs and Fred Wensing. That was in November 1985. At our first committee meeting we also put together a draft constitution.

Not long after we became incorporated, we also started talking to the Haemophilia Foundation Australia about becoming a member. That way we could find out how things were in other places and discuss how things were in the ACT. They also had lots of resource material that we could give to our members.

The early years of our group saw many challenging times. This included the period where the contamination of blood products occurred, having a devastating effect on the haemophilia community Australia-wide. It was a time when treatment was only available on demand, the consequence of which was terrible joint and other serious bleeds. It was a time of early treatment products which were bulky and 'primitive'. All in all, it was a difficult period for HFACT but it was also an inspiring time where foundations were laid, support was given and received, and lasting friendships forged.

We applied to the ACT Health Department for funding in 1986 to enable us to employ a counsellor to help our members handle the difficulties of that time. While the challenges of haemophilia and bleeding disorders have transitioned to other issues, that funding continues to this day.

Our endeavours were also directed at improving the management of haemophilia by the establishment of a Haemophilia Treatment Centre at the hospital in Woden. With the cooperation of Dr Pembrey, that centre was set up at the end of 1986. Important in the arrangements was the acceptance of our haemophilia counsellor as part of the clinical team.

We participated in various fundraising campaigns that HFA instigated as well as some of our own. We sent people to workshops and conferences (including overseas) to learn more about haemophilia and the latest developments. We sent people to family camps in Newcastle and Sydney, and we have held our own family camps. The camps are a great opportunity for families to get together to share their experiences and for children and young adults to have a great time in a safe environment, but also to know they're not alone with their bleeding disorder.

Despite the improvements in treatment over the years, our existence is still centred around the "support-group" ethos. I know we have a committee and constitution and meetings and paperwork to get through but fundamentally it is about sharing the experiences and offering some help or advice when needed. Of course, on a formal level, the committee is here to ensure we have access to the best treatment possible and that we address the issues that inevitably arise with this complex medical condition.

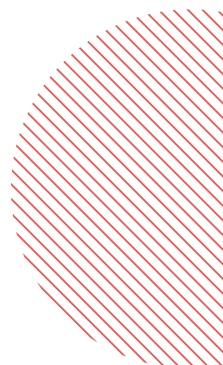
Come and help us to celebrate our 40th birthday (more info in this newsletter!) and talk about where we have been and where we want to go in the future!

Jenny Lees

Treasurer



A trip down memory lane...





New website

Due to a change in software licencing conditions in early 2023 it became necessary for the websites of HFA and its affiliated state/territory foundations, including HFACT, to move to a new web hosting platform.

Since October last year, HFA and the state/territory foundations have been redeveloping their respective websites. The process involved staff or volunteers from each organisation, led and supported by creative partner Heartburst Digital. The HFA website went live mid February, with the others following in the last week of February.

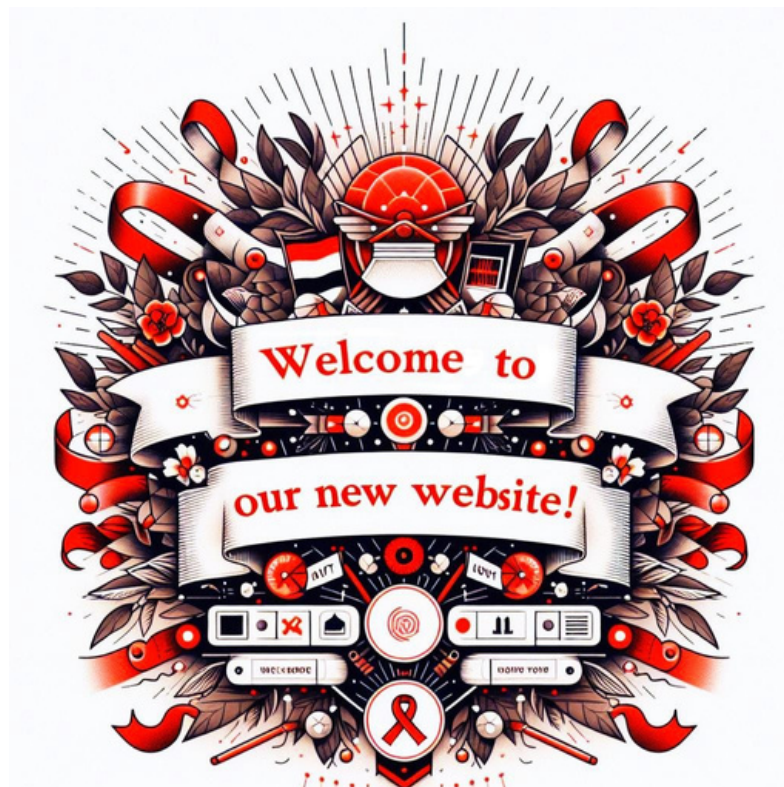
Each state/territory website synchronises shared information about bleeding disorders from HFA, merging that with tailored local news, events and support information. The redevelopment process also gave us the opportunity to refresh the websites for a more modern look, supporting a broader range of devices, including a focus on better accessibility and inclusion.

The websites are chock full of information, resources and personal stories relating to haemophilia, von Willebrand disease and other inherited bleeding disorders.

We urge you to visit HFACT's new website at www.hfact.org.au and take a look.

Ron Lees

Committee Member



Spotlight: PROBE study



Why is PROBE important?

HFA is building evidence about the needs of men and women affected by haemophilia in Australia with the PROBE Australia Study and would really appreciate your help.

WHAT IS THE PROBE STUDY?

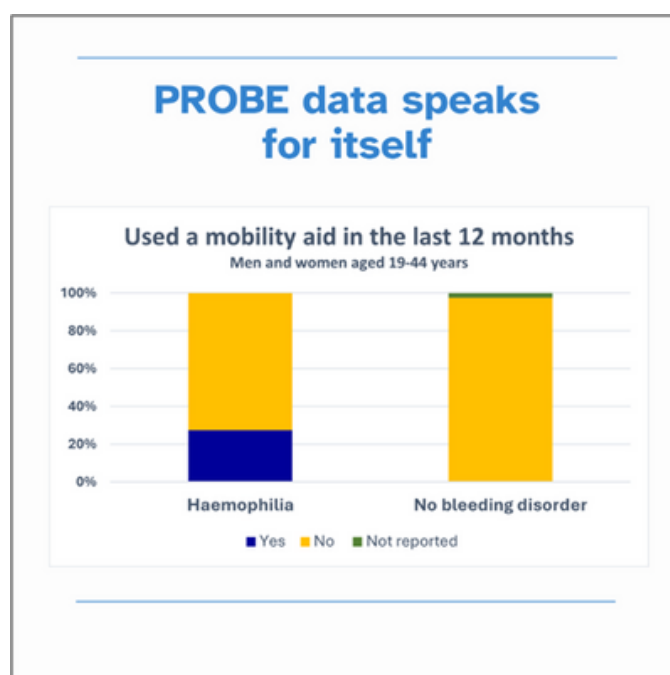
The study is coordinated by HFA and is an internationally recognised and validated questionnaire. It collects data on the impact of haemophilia on the quality of life of both men and women who are affected, either because they have haemophilia or carry the gene. It compares their experience to people who do not have a bleeding disorder.

So far HFA has only had around 150 men and women complete the PROBE survey – they need at least 400 for good data.

WHAT DO WE DO WITH THE DATA?

PROBE data is high quality and credible, and HFA and Foundations use it in many ways. You may have seen some of the data from the 2019 PROBE Australia Study in reports and conference presentations. Some examples of its use include:

- in discussions with and submissions to government, to advocate for people with bleeding disorders about new treatments and services
- in the HFA Getting Older report, to underline the issues for physical function and pain, and for people with mild haemophilia, hepatitis C, and for women
- at the 2023 Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders, in the plenary on mild haemophilia
- international meetings to discuss the issues for people with mild haemophilia
- HFA has had a poster on 2019 PROBE data accepted for publication at the 2024 WFH Congress in Madrid – this is a peer-reviewed publication



HOW CAN YOU HELP?

Please consider completing the current PROBE Australia survey as soon as possible – and remember, you don't need to have a bleeding disorder to contribute!

If you don't have a bleeding disorder, you can be a health professional, someone interested in haemophilia, or any adult Australian. The comparison group is a slice of the general Australian community.

PROBE is voluntary and anonymous, so it's up to you – but we would really value your support.

WHO CAN COMPLETE THE SURVEY?

Adult (18 yrs+) men and women living in Australia, who:

- have haemophilia or carry the gene
- OR
- do NOT have a bleeding disorder (comparison group)



HOW TO DO THE SURVEY

It's very easy! There are three options:

- go to **myprobe.org** for the web version
- download the **myprobe app** from the Apple Store or Google Play (Android)
- ask HFA or your local Foundation for a **print survey pack**

If you've already done the survey, perhaps you can spread the word to family and friends and encourage them to complete it too.

FOR MORE INFORMATION

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

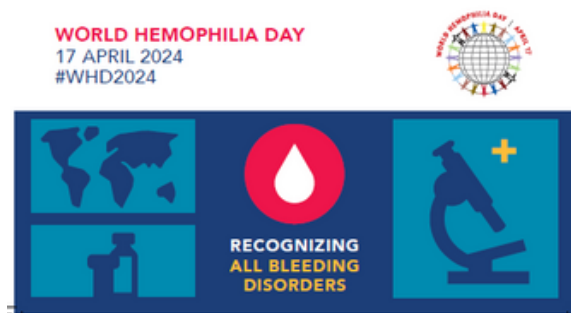
Or contact Suzanne at HFA:

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



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. 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.

In 2024 the international theme is **Equitable access for all: recognizing all bleeding disorders**. The World Federation of Hemophilia (WFH) vision of **Treatment for All** is for a world where all people with inherited bleeding disorders have access to care, regardless of their type of bleeding disorder, gender, age, or where they live.

WFH estimates that over 75% of people living with haemophilia worldwide have not yet been identified and diagnosed.

The WFH, 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. For more information on their programs visit www.wfh.org

HFA 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 the ACT, we have **Telstra Tower**, the **Royal Australian Mint**, the **Malcolm Fraser Bridge** and the **Canberra Times Fountain**. Keep an eye out on www.haemophilia.org.au for updated locations and share photos on HFA social media platforms.

HFA SOCIALS

HFA will showcase stories recognising all bleeding disorders on their social media pages.



<https://www.facebook.com/HaemophiliaFoundationAustralia>



<https://www.linkedin.com/company/haemophilia-foundation-australia>



<https://www.instagram.com/haemophiliafoundationaustralia/>

SAVE THE DATE



YOU'RE INVITED TO CELEBRATE

HFACT TURNING 40!

SATURDAY 4 MAY | 6PM

33 MACROBERTSON ST MAWSON
RSVP: BY 28 APRIL TO CLAUDE (0412839135)
PLEASE BRING A MAIN OR DESSERT
DRINKS WILL BE PROVIDED



COME ALONG TO A MID-YEAR

TRIVIA NIGHT

WEDNESDAY 5 JUNE | Durham Hotel
Green Square, Kingston

Arrive 6:30pm for dinner, drink and chat.
HFACT will cover one meal and drink per person. Trivia starts 7:30pm.

RSVP to Claude (0412 839 135) by 29 May

HOPE TO SEE YOU THERE!



CALLING ALL KIDS!

...DO YOU LIKE TO BOUNCE?

Come along to **Flip Out** for an afternoon of fun, flips & food!
Saturday 27 July, 3pm

MORE INFO IN THE NEXT NEWSLETTER!

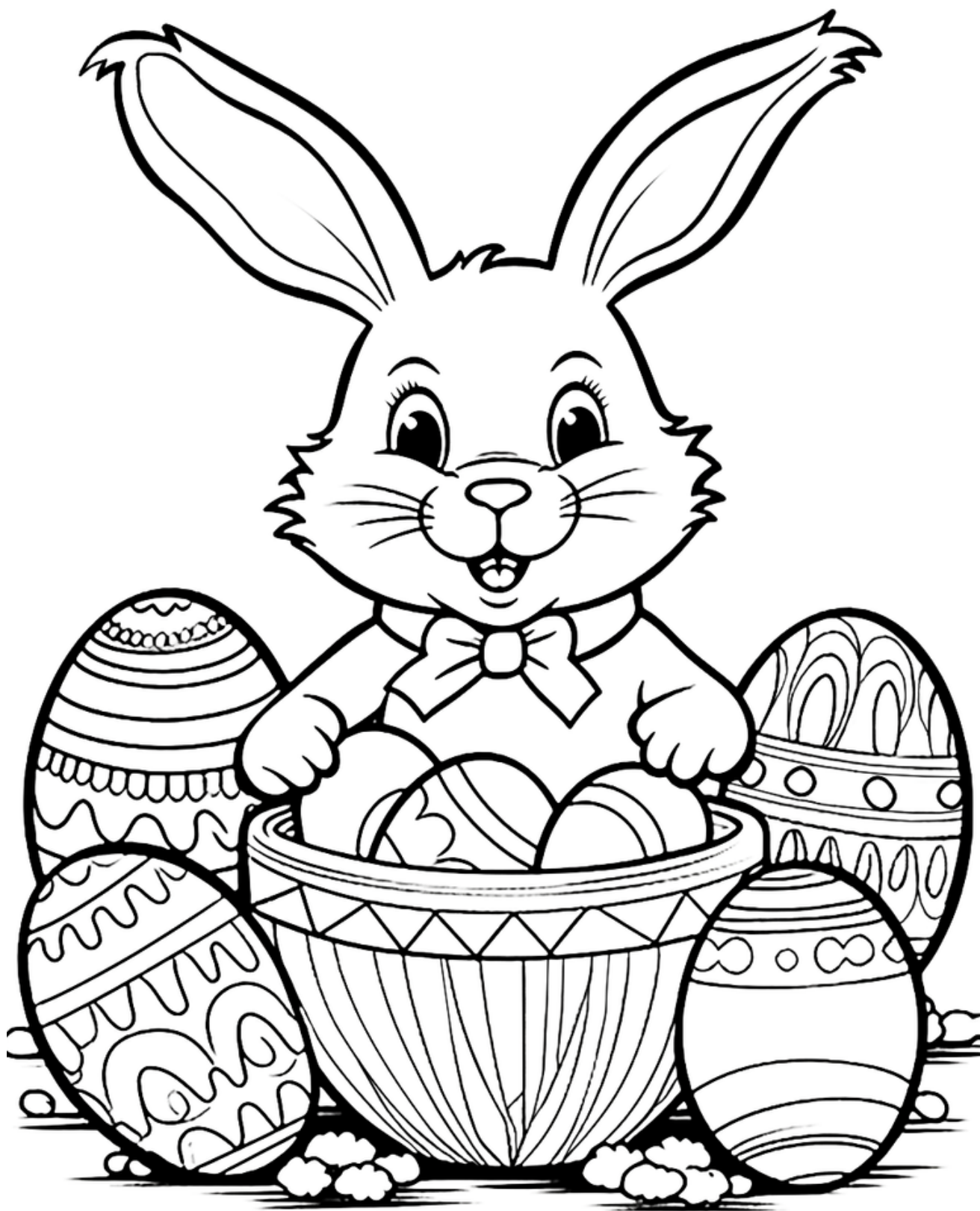


Staycation

Instead of a family camp, this year HFACT will host a day of locally-based fun activities in October (date tba).

More info in the next newsletter!

One for the kids...



DATES FOR THE DIARY

World Haemophilia Day	17 April
HFACT 40th birthday celebration	4 May
Bleeding disorders clinic	24 May
Trivia Night	5 June
Kids afternoon @ Flip Out	27 July
HFACT staycation	Oct (date TBA)



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

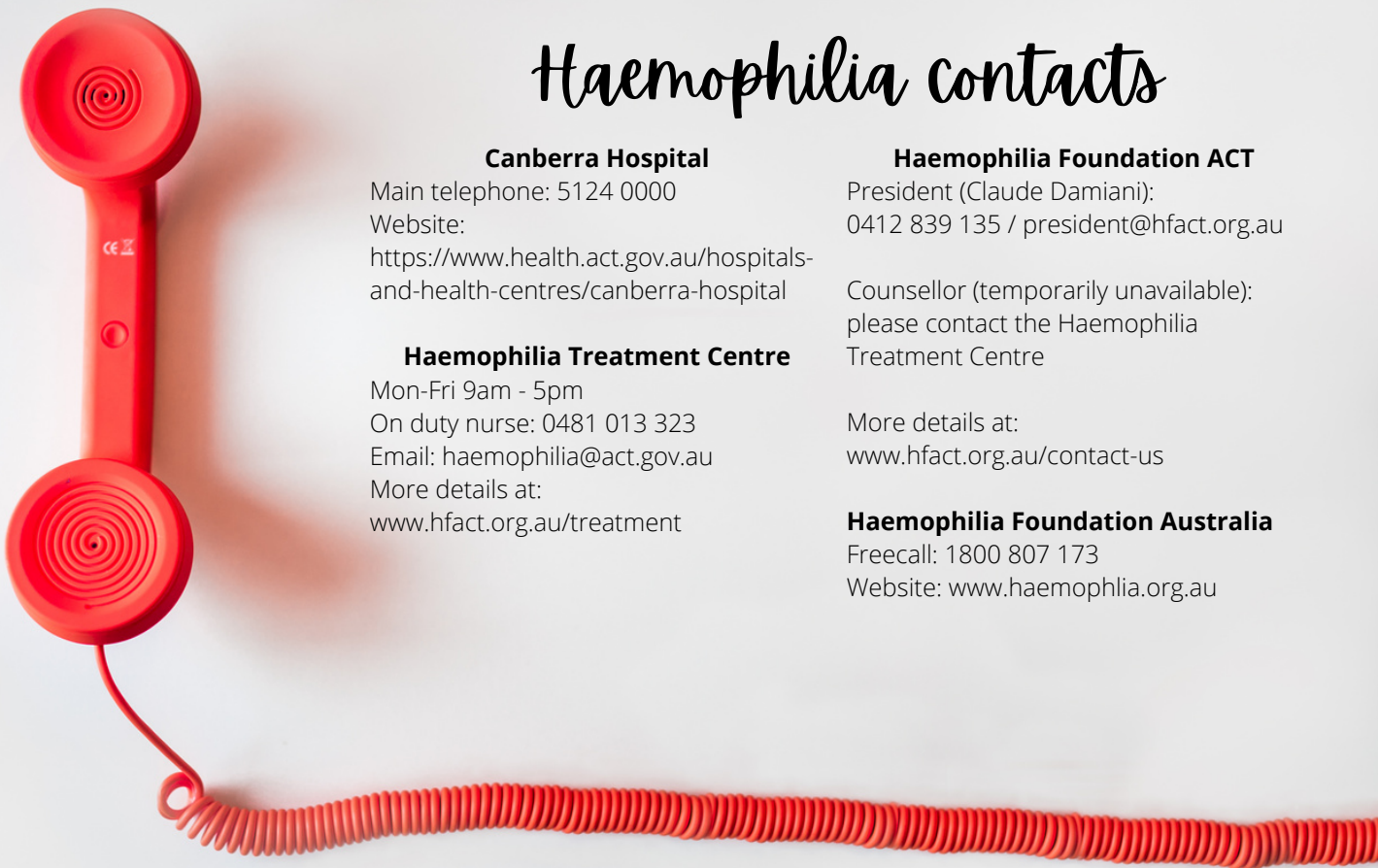
President (Claude Damiani):
0412 839 135 / president@hfact.org.au

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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