

PATRON  
Dr Richard Pembrey AM,  
MB BS, MD, FRACP, FRCPAMarch 2021  
Newsletter  
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## President's Report

After the challenges of 2020 and COVID-19, including adjusting to working from home, physical distancing and the curtailing of interstate and international travel, along with the general uncertainty, 2021 has to date been a very welcome reprieve. Suppressing COVID-19 in the ACT and across Australia (albeit with an outbreak here or there) has enabled HFACT to recommence social activities and return to (close to) normal functioning, albeit with videoconferencing replacing face-to-face Committee meetings.

By this stage, a sizeable portion of the ACT's bleeding disorder community has transitioned to Hemlibra, the new and innovative drug product which clinical trials have shown to be very efficacious. Indeed, my son, Emiliano, is one of those that has made the transition and it's been a very positive experience. The smooth transition has been aided by the strong support provided by The Canberra Hospital, including Jayne Treagust, the haemophilia treatment nurse.

Of course, despite the huge advancement in treatment afforded by Hemlibra, things continue to move apace with a range of other drugs under trial, providing hope to those not on Hemlibra, or indeed those that are, that even more effective and longer lasting treatments will one day in the not too distant future, be available to the community.

Looking forward, we have a range of social activities planned for the year. It would be great to get a strong turnout for these events to maintain a vibrant community and to provide support and share knowledge amongst ourselves. The next event is a Men's Business trivia night, scheduled

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for Thursday 22 April. Details are provided in this newsletter.

*Claudio Damiani*

President

## Read all about it!

HFACT's first face-to-face event post easing of COVID-19 restrictions: community breakfast BBQ.  
Details inside!



## Women's Wisdom

The HFACT women's group is there to provide support to women living with a bleeding disorder or supporting someone with a bleeding disorder. We aim to provide the opportunity for people to meet with others who may have the same challenges. All are welcome – women with a bleeding disorder, carriers, partners, sisters, daughters, carers, grandmothers. We generally get together around food or drink, sometimes with a guest speaker or theme and sometimes just for a relaxed chat.



We first met on 17<sup>th</sup> April 2008 at the Hyatt for High Tea. Are you in the photo? Do you remember the occasion?

Now that things are getting to a 'COVID normal' state, and while restrictions are not too bad, it is time to start to reconnect and share experiences, coping mechanisms and hints... over nice food and drink.

The Women's Wisdom group will be reconvening on 2.30 pm on Sunday 11th April 2021 for High Tea at the Hyatt Canberra.

HFACT Committee has agreed to cover the cost of High Tea for financial members (cost is \$75 pp for non-members or members who are not financial) \*. This special afternoon tea will provide an excellent opportunity to meet and mix with women in the bleeding disorders community in Canberra and surrounds.

Numbers are limited so please RSVP (details below) as soon as possible but by 2<sup>nd</sup> April 2021 at the latest. As we must pay for the number of places booked, not the number of people who turn up, we ask that you keep us informed of any change of mind or inability to attend.

We will of course be abiding by the ACT COVID 19 rules in place at the time.

### Details

Where: The Tea Lounge - Hyatt Hotel 120  
Commonwealth Ave, Canberra

Date: Sunday 11<sup>th</sup> April

Time: 2.30pm to 4.30 pm (COVID restrictions specify maximum of 2 hours)

RSVP: 2<sup>nd</sup> April 2021 to Jenny (0410 543 086 or [treasurer@hfact.org.au](mailto:treasurer@hfact.org.au)) or Kathryn (0409 830 472 or [counsellor@hfact.org.au](mailto:counsellor@hfact.org.au))

Please notify and dietary requirements – gluten-free / vegetarian / etc

*Not sure about your membership status? Contact Jenny on [treasurer@hfact.org.au](mailto:treasurer@hfact.org.au)*

\* annual membership is just \$20.00 join at [www.hfact.org.au](http://www.hfact.org.au)

*Jenny Lees*

### **Did you know?**

In Australia there are more than 6,200 people diagnosed with haemophilia, von Willebrand disease (VWD) or other related inherited bleeding disorders.

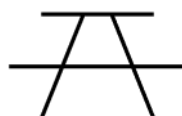
Source: HFA Annual Report 2019-20  
([www.haemophilia.org.au](http://www.haemophilia.org.au))



## HFACT Community Breakfast

The day dawned sunny and clear for HFACT's first face-to-face get together in more than a year! And what better way to catch up with each other than a bacon and egg breakfast personally cooked by our President, Claudio. If fruit was more your thing, there was a ton of fruit salad and juice, very much appreciated by the younger attendees. The turn-out was good, with the younger crew playing Finska, kicking a soccer ball and exploring the lovely surrounds of Nara Park. A big thanks to Claudio for his organisation, and the weather gods for coming to the party. We look forward to more face to face social contact (COVID permitting) in 2021!

*Rebecca Minty*



## Personal experiences of Hemlibra

This is an edited version of comments shared by Sarah McGuire, a parent of two boys who have transitioned to Hemlibra.

“We feel like it’s a life changer. We live a really busy crazy life, so this has fitted in perfectly. We went from 2nd daily injections worried about veins, to a subcutaneous injection every 2 weeks.

The boys love it, treatment has controlled their lives until now, and I have always been very cautious with when I treat them before Hemlibra came along. Now it’s different, I actually look forward to the Monday I get to give their injections as I feel relieved, that it’s here again. In the beginning it was strange, and I felt like I was forgetting, missing something. To have my full faith in this product and that it would do the job was hard, how could a product like this come into our lives and change our lives into almost normal?

We went camping for a week and it was super strange not to take product with us or to have to treat, I let my son Tate go away with another family with no treatment or worry.

It is a perfect age for my boys to get onto Hemlibra, with sports, living a crazy busy teenage life. This product allows



them to be like normal teenagers, it has changed our life. I still do worry, and that won’t change, but I have found that they have tested it to its full limits and seems to be doing its job. My son Tate had a sore ankle and I had to treat it like I would for a child without haemophilia: rest ice compression etc, and it worked.

I am so excited by this product and so excited for all those parents with young children that they won’t have to go through all the crazy, scary times and worries we had over the years. As I look back on all those years of treatments it makes me value how wonderful this new treatment has been and look forward to the future ahead to hopefully a cure.

The boys still can’t play football, and I am still very cautious and will always worry but I am so grateful this product has come into our life.”

*Sarah McGuire*



### Men’s Business Trivia



When: Tuesday 20 April  
Where: Durham Hotel in Kingston. 52 Jardine St Kingston.  
Time: 7.30pm start, so arrive at 7pm for a starter drink to lubricate the brain and get the neurons and synapses working effectively.

A HFACT table has been arranged for the night. HFACT will fund the cost of a meal and a drink for each attendee.

Please RSVP to me by 10 April on 0412 839 135 or by email: [president@hfact.org.au](mailto:president@hfact.org.au).

For those not familiar with Men's Business, it's a casual get-together for male members of the HFACT community (those with a bleeding disorder, carers, family and friends). It provides an opportunity for members to meet and enjoy each other's company and share their experiences.

## HFACT Grants – now open!

HFACT are offering grants of up to \$500 to support people affected by a bleeding disorder and inspire them to achieve their goals or try new things.

It is open to members of all ages (not just persons with bleeding disorders, it could also be carers, siblings, children etc).

HFACT's aim in offering these grants is to assist in improving the quality of life for members.

Some examples of things that a grant could be used to contribute to are:

- enrolling in art classes
- swimming lessons to help with physical fitness
- purchase of a laptop to assist with studies
- purchase of orthotics or special footwear
- addition of ramps to assist with access

### Who can apply?

Any financial member\* of HFACT who NOT has received financial assistance from HFACT in the period from July 2019 to present. (Funding for 2019 HFA Conference does not preclude you from applying for a grant.)

\* Membership covers family members residing at the same address.

This grant is not restricted to adults, children may also apply – with parental permission.

### How to apply

An application form and grant guidelines are available on the website ([www.hfact.org.au](http://www.hfact.org.au)) and have been included with paper versions of the newsletter.

Applications close on 30 April 2021.

We would like you to outline in words, drawing, or a video how you would use a grant to support your needs, work towards a goal, or try something new.

### Criteria

Applicants must be current financial members of HFACT as at 30 April 2021.

Applicants may not have received financial assistance from HFACT in the period 1 July 2019 to 30 April 2021 except for funding to attend HFA Conference in 2019

Successful applicants must demonstrate the funds were spent as outlined in their application (receipts etc).

**Applications close: 5.00pm 30 April 2021**

Send applications to: [treasurer@hfact.org.au](mailto:treasurer@hfact.org.au) or

HFACT

PO Box 331

Mawson ACT 2607

## Haemophilia Treatment Centre Update

Hello again,

It has been a very busy time here at the Haemophilia Treatment Centre with the implementation of the changeover to Hemlibra. So far 13 people have made the change and at this stage there doesn't seem to be anyone having any adverse effects. The changeover has run very smoothly and, as I expected, everyone has been very skilled at maintaining aseptic technique (keeping your hands and equipment clean); although there have been a few hesitations at pricking oneself with a needle, everyone has done remarkably well!!

The feedback that I have received has been positive, particularly only having to prick yourself once a fortnight. I would like to remind everyone that Hemlibra is not used for an active bleed and factor VIII MUST be given for this. Also, if you are having any type of surgery, please notify the HTC as you will probably need factor cover. Another reason to contact the HTC is if you miss a dose and advice will be given.

The COVID vaccine is finally here. It is very safe for a person with Haemophilia to have the vaccine. It is an intramuscular injection so please put pressure on the site for 10 minutes after administration to help curtail any bleeding and bruising. I still don't see the world opening up for at least another year but travelling in and exploring your own country is awesome; it will give us a chance to appreciate what is in our own backyard!

The next Haemophilia Clinic will be on May 14. I will begin to make the appointments for everyone shortly.

Stay safe and be well.

*Jayne Treagust*

Advance Practice Nurse - Haemophilia Treatment Centre

## Dates for the diary

April 2	RSVP for Women's Wisdom
April 11	Women's Wisdom at the Hyatt
April 22	Men's Business Trivia Night
April 30	HFACT Grant Application due
May 14	Haemophilia Clinic at TCH

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## Haemophilia Contact Details

### Canberra Hospital

**Main telephone:** 5124 0000

**Website:** <https://health.act.gov.au/hospitals-and-health-centres/canberra-hospital>

### Haemophilia Treatment Centre:

Mon to Fri 9am - 5pm

**On duty nurse:** 0481 013 323

**Via email:** [haemophilia@act.gov.au](mailto:haemophilia@act.gov.au)

**More details at:** [www.hfact.org.au/treatment](http://www.hfact.org.au/treatment)

### Haemophilia Foundation ACT

**President:** 0412 839 135 [president@hfact.org.au](mailto:president@hfact.org.au) **Counsellor:** 0409 830 472 [counsellor@hfact.org.au](mailto:counsellor@hfact.org.au) **More details at:** [www.hfact.org.au/contact-us](http://www.hfact.org.au/contact-us)

Haemophilia Foundation Australian Capital Territory  
PO Box 331, MAWSON ACT 2607

### Haemophilia Foundation Australia

**Free call:** 1800 807 173

**Website:** [www.haemophilia.org.au](http://www.haemophilia.org.au)

### Our Mission

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

The newsletter of Haemophilia Foundation ACT is supported by ACT Health Directorate

