



PATRON

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Newsletter
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President's Report

It is really unfortunate that just as we appeared to put COVID19 in our rear view mirror it has sprung right back up again. While at the time of writing, Canberra has yet to record a locally transmitted case, developments impacting people with a bleeding disorder provide a very real reminder of how precarious the situation is. Restrictions around the number of visitors to hospitals for example, wearing of masks, checking into venues, being hypervigilant, is just part of my routine again.

While it's difficult to predict the impact of COVID going forward, I am aware that if risk persists it could impact on the biannual treatment clinic at the hospital, as it did in 2020. While clinic is normally held around November each year, I will continue to liaise with the Canberra Hospital to receive any updates closer to the date.

COVID has also required HFACT to delay a couple of planned events. The first was to be a mid-winter dinner which has now shifted to being a Spring dinner to be held on 9 October (COVID situation dependant of course) at my residence – keep the date free. The second was a getaway outside of Canberra, which has been postponed for obvious reasons; we will re-evaluate later in the year to identify opportunities to proceed with this getaway if prudent.

In the meantime, stay safe and look forward to seeing you later in the year.

Claudio Damiani

President

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SAVE THE DATE!

(COVID permitting)

9th October – Spring Dinner and AGM

Come along for a relaxed, fun, kid-friendly get together at the Damiani house. More details to come.

Haemophilia Treatment Centre Update

With COVID going crazy in NSW, the idea of going on an interstate holiday, is just a thought. But one day it will happen again; and it is important to manage your haemophilia prophylaxis, whether at home or on holiday. For those on Hemlibra now, remember the days when you had to ensure that you had a fridge? The fridge wasn't for the food but for your factor. It had to be kept cold and you needed enough supply for your prophylaxis, plus some. This hasn't really changed. You will still need to ensure that you have enough Hemlibra to cover you for the time you are away, and that you have a fridge to keep it in. You will also need to take a dose of factor with you; just in case you have an injury that requires treatment. The nearest treatment centre may be a few hours away!

The latest information from the Haemophilia Foundation regarding the COVID vaccination states that having haemophilia should not impact you receiving either of the vaccinations. You will not need to have extra factor if you are on prophylaxis and you won't need any factor prior to the vaccination if you don't usually have prophylaxis. You have to stay and be observed for 15 minutes after the injection so please apply pressure to the injection site for at least 10 minutes of that time.

I would also like to take this opportunity to remind everyone who is now on Hemlibra to notify me once they have used the second to last dose. This will facilitate the ordering of Hemlibra and allow for it to be delivered in a timely, non-urgent, fashion.

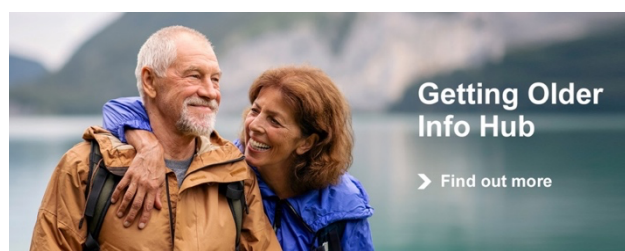
And the last piece of information that I would like to share with you is the importance of moving, for both adults and children with haemophilia. Why not try some new activities such as yoga, tai chi or dance. Any weight bearing exercises are good for the bones and it is important to maintain strong,

healthy bones without putting too much pressure on your joints. Have fun and let me know how you go 😊

One more thing to note, my working hours are now 8:00 -16:30.

Jayne Treagust

Advance Practice Nurse - Haemophilia Treatment Centre



Getting Older Info Hub – what's new?

New content is added to the HFA Getting Older Info Hub regularly.

Check it out at www.haemophilia.org.au/getting-older

WHAT'S NEW?

- HEALTH AND WELLBEING section – lots of great info on getting older and exercise
- WORK AND FINANCES section – concession cards for older people
- CONNECT TO OTHERS section – videos of personal stories

Any feedback or ideas on more topics?

Contact Suzanne at HFA on socallaghan@haemophilia.org.au

or phone 1800 807 173.

Membership Renewal

It is membership renewal time again. Haemophilia Foundation ACT membership fees for 2021-22 are now due.

The membership fee has remained unchanged and is just \$20 per annum. Donations are always welcome and are tax deductible.

Membership fees can be paid either:

Via direct bank deposit to:

Westpac Bank
BSB Number: 032-778
Account Number: 440919
Account Name: Haemophilia Foundation ACT
Incorporated

Please include your name in the reference or payee field. Or via cheque to:

HFACT Inc
PO Box 331
Mawson ACT 2607

Membership renewal time is a good opportunity to review whether any of your contact details have changed. If so you can inform us either by using the change of details page on our website (www.hfact.org.au/update) or by completing a membership form, also available on the website (www.hfact.org.au/join), or from Kathryn Body, our counsellor. A copy of the membership application / renewal form has been included with this newsletter. Please note that HFACT does not have access to hospital records, so informing the hospital does not update HFACT.

In cases of genuine financial hardship, the committee is prepared to waive or reduce the membership fee. Requests will be handled with discretion and should be directed in the first instance to the Treasurer.

I encourage you all to complete the membership form as that will enable us to:

- Update our records
- Make sure you get communications in the appropriate format
- Tailor our activities to our membership
- Provide evidence to ACT Health on the size of our community to justify ongoing receipt of the grant that covers Kathryn's services

It will also save HFACT the cost and effort involved in mailing out renewal invoices.

Access to the services of our counsellor is not dependent on being a member as Kathryn is there for anyone with an inherited bleeding disorder in the ACT and region. However, being a financial member entitles you to other benefits, listed on our website, and in having a say in the running of the organisation. You also support HFACT financially in the work that we do.

HFACT Grants

The HFACT grants round announced in the March edition of ACTivated was a great success and resulted in the awarding of 4 grants of \$500. These grants will assist members with health outcomes, fitness and activity and studies. It was great to receive applications from both young and not-so-young members. We hope to bring you stories from grant recipients in future newsletters.

We hope to be able to offer more grants during the current financial year so stay tuned ... and pay your membership fee to be eligible!



Men's Business Trivia

Going into the night, the HFACT trivia team - "the bleeding obvious" - were looking to back up their 2020 victory with a win in 2021.

Well, not to make excuses but we were operating under less than optimal conditions. On arriving to the pub, primed to bring home the win, we discovered we were on an outdoor table. Normally that wouldn't be an issue, but during a very chilly and wet Canberra

night, it was less than ideal. Under those conditions we certainly couldn't bring home the winners medal and settled for mid-table mediocrity. Again, not making excuses.

Notwithstanding the result, we enjoyed the night and each other's company and vowed to come back stronger (that is smarter) in 2022.

Claudio Damiani

HFA Conference

Conference will
take place
VIRTUALLY on
8-9 October
2021



**HFACT will cover the
cost of registration for
financial members.
For more information
contact**

treasurer@hfact.org.au

20TH AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

EMBRACING A CHANGING WORLD

Program will cover

- New and emerging treatments
- Managing complications of bleeding disorders
- Approaches to care in the future
- Von Willebrand disease and rarer bleeding disorders
- Living with a bleeding disorder over a lifetime
- Women and girls
- Getting Older
- Staying fit and well
- Participating in clinical trials

Visit

www.haemophilia.org.au/conferences/2021-conference for more information and to register

You will need a computer with internet connection to participate.

You don't need to attend all sessions; there will be breaks, live sessions and pre-recorded sessions.

Women's Wisdom Report

Women's Wisdom High Tea

Hyatt Hotel Canberra

11 April 2021



A happy and talkative group of women met on the 11th April for high tea at the Hyatt. It was a great spread and lovely to meet new members and reconnect, face to face, with others.

We had hoped that this would be the first get together for a refreshed, post-COVID, group. Unfortunately, COVID Delta has made things difficult again. We will keep monitoring the situation and try for another function as soon as feasible. When the 'Weekend Away' (see President's Report) eventually happens we will include a Women's Wisdom event in the program.

Jenny Lees

From Factor VIII infusion to Hemlibra

A patient's perspective

By Emiliano Damiani, aged 9 years.



Why is Hemlibra better than prophylaxis?

Well, I only have to have one needle every two weeks, it's really quick to set up and I can inject it by myself, and that is really helpful because I don't necessarily need my mum or dad to be there to do it.

The other day I did it at my grandparents house.

It's also helpful because you just need to jab it in, whereas with factor I had to get it in the vein - actually my mum or dad had to do it because I have never done it.

It also hurts less, so overall its great!



HFACT exercise video project

HFACT is looking to develop a series of videos demonstrating low impact exercises that support joint health and overall fitness that can be completed at home with minimal equipment. This program would allow members to continue exercise regimes that would benefit their overall health when periods of social distancing are required. HFACT will be working with a physiotherapist, and if you are interested in being part of this project please contact: secretary@hfact.org.au.

Dates for the diary

July onwards	Membership dues
8-9 October	HFA Conference (online)
9 October	Spring Dinner and AGM
26 November	Haemophilia Clinic, The Canberra Hospital

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 8am – 4:30pm

On duty nurse: 0481 013 323

Via email: haemophilia@act.gov.au

More details at: www.hfact.org.au/treatment

Haemophilia Foundation ACT

President: 0412 839 135 president@hfact.org.au

Counsellor: 0409 830 472 counsellor@hfact.org.au

More details at: 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

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



Our Mission

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

This newsletter is printed on 100% recycled paper, carbon neutral if possible. **Contact us at newsletter@hfact.org.au if you would prefer to save paper and postage by receiving the electronic version via email.**