



PATRON

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Newsletter

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## President's Report

### An open letter of thanks to ACT Health and the ACT Health Minister

2020 is without any doubt one of the toughest years in living memory. The impact of COVID-19 on the Australian economy and way of life has been profound. Panic buying, protests, anxiety, home schooling, lockdowns, separation from family and friends, unemployment, sickness, death and the myriad other impacts have tested the Australian community and governments. Despite all these challenges I can comfortably say that it has been a relief that we live in Australia, and particularly within the ACT and surrounding region, with governments making tough but sensible decisions to protect the health and wellbeing of its citizens.

The ACT Government has done a marvellous job of supporting HFACT and the local bleeding disorders community. During the early phases of the pandemic, ACT Health extended additional funding to HFACT to support the provision of telehealth and the move to doing business virtually while strong social distancing requirements were implemented. Regular updates and alerts from ACT Health and from the ACT's Chief Medical Officer, were also provided; these provided invaluable information around social distancing rules, travel bans and exemptions, medical advice, local case numbers and hotspots.

Additionally, ACT Health maintained regular contact with me, as president of HFACT, to discuss service provision, risks, impacts of COVID-19 and ways in which ACT Health could better support the community through these unprecedented times. This was really encouraging and symptomatic of a government that really cares

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about valuable community organisations such as HFACT. It is in the context of this that I say a big thank you to the ACT Government and ACT Health on behalf of the bleeding disorders community.

Lastly, I want to extend another thanks to all those in Government, from within the ACT and beyond, that supported the funding of Hemlibra® (also known as emicizumab) through Australia's national blood arrangements. This will be a game changer for many in the community, particularly those most impacted from having a bleeding disorder. Its decisions like these, knowing just how expensive Hemlibra® is, that make you thankful we live in this country.

*Claudio Damiani*

President

## Successful Hemlibra® information night

On 17 November, HFACT in partnership with The Canberra Hospital (TCH) Haemophilia Treatment Centre (HTC) held a successful information night about the new treatment for haemophilia A, known as Hemlibra®.

Hemlibra® is a treatment that can reduce or stop bleeding in people with severe or moderate haemophilia A with and without inhibitors. It is delivered via a subcutaneous injection rather than intravenous infusion which is a huge development in haemophilia treatment. It should make administration of the product much simpler,



including (and in particular) for children where it can be a challenge finding a vein and successfully

infusing. Furthermore, injections would be weekly, fortnightly or monthly, with the majority of patients likely to be recommended for fortnightly injections. Importantly, Hemlibra® is not to be taken in the event of a breakthrough bleed, with regular factor replacement product to be taken in these instances. As such, individuals currently storing and using factor will likely retain a single dose or more only.

The event was well attended by 18 in person including medical professionals, and 5 or so joining via Zoom videoconference. Dr Michael Pidcock and Dr Nalini Padi gave presentations about what Hemlibra® is, how it works, and eligibility criteria. They also discussed the studies on adult and paediatric patients, summarising the results of clinical trials and responding to Q&A

from the audience. It would be accurate to report that the results from clinical trials were stellar, with annualised



bleeding rates dropping significantly against control groups used in the trials.

The first patients from ACT and surrounding region will be transitioning to Hemlibra® from mid-December. While details were to be finalised, it became clear that Hemlibra® would be administered through the TCH Pharmacy.

Many of you may have a range of other questions in regards to Hemlibra®, including understanding whether you are eligible or suitable to move onto Hemlibra®. If you have any questions, please talk to the HTC.

HFACT would like to thank Dr Pidcock and Dr Padi for their presentations, and to Jayne Treagust, Anastasia Wilson and Kathryn Body (HFACT Counsellor) for organising the information night.





# Community Breakfast BBQ

13 February 8.30am

Canberra Nara Peace Park, Lennox Gardens, Flynn Drive, Yarralumla

After a year without social events due to the impact of COVID-19, the HFACT committee has decided the time is right to reinvigorate the community and host a community breakfast bbq on 13 February 2021.

Given the middle of February is likely to be one of the hottest parts of the calendar year, the bbq will commence at 8.30am with egg and bacon rolls provided. Also provided will be some basic juices and other non-alcoholic drinks, as well as fruit salad. A range of games will be available for kids to partake in.

Please rsvp to [president@hfact.org.au](mailto:president@hfact.org.au) or 0412839135 on or before 8 February 2021.

Hope to see you there!

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## Haemophilia Treatment Centre Update

I hope that everyone who attended the information evening on Hemlibra® found it to be highly informative and worthwhile. I was so disappointed when I found out that I was not

able to attend due to COVID isolation but would like to say a big thank you to Kathryn Body who helped with the final arrangements, Anastasia Wilson who stepped in for me and the HFACT for funding the refreshments.

Unfortunately, I was also unable to attend the haemophilia clinic for the same reasons but hope

that the information sheet that I asked the doctors to pass on to everyone changing to Hemlibra® helped.

Hemlibra® is probably one of the biggest breakthroughs for the haemophilia A community ever. I believe it will even rival gene therapy! Changing from an intravenous infusion every few days to a subcutaneous injection once a fortnight is life changing. I hope that the transition from intravenous infusions to subcutaneous injections will be uneventful but if anyone is having any issues please contact me.

My Christmas wish for you is that both you, your families and friends stay safe and I look forward to catching up with everyone at the next haemophilia clinic.

*Jayne Treagust*

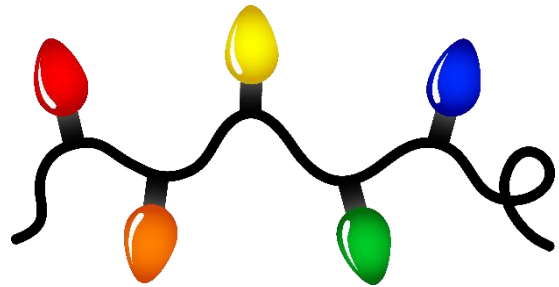
Advance Practice Nurse - Haemophilia Treatment Centre



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## **HFACT “Zooms through” 2020 AGM**

Who would have thought a year ago that HFACT would have a ‘virtual’ 2020 AGM? In what is now unremarkable practice, HFACT held the 2020 AGM via Zoom videoconference. One of the great benefits was that we could have HFA Executive Director Sharon Caris join us from lockdown in Melbourne to provide an update from HFA.



Some highlights included the way our community and HFA have adapted to working in a virtual space due to lockdowns and travel restrictions. HFA continue with their projects such as Women with Bleeding Disorders and personal stories. The Getting Older Project report was finalised and published. HFA have been involved in advocating for better treatment options for our community, so that individuals can choose from a number of options based on what is right for them. This includes new products and gene therapy. Members are able to access information about research and trials on the HFA website and through their HTC.

We also appreciate the attendance at the AGM of Richard Pembrey, HFACT’s patron.

The office bearers for 2021 were elected as follows:

- President: Claudio Damiani
- Vice President: Rebecca Minty
- Secretary: Shauna Adams
- Treasurer: Jenny Lees
- Committee Member: Ron Lees

General committee member positions remain open throughout the year. Any member of the community is always welcome to come along to a meeting to see what it’s about, and of course become a general committee member if you wish! Just get in touch with [president@hfact.org.au](mailto:president@hfact.org.au) if you’d like to know more.

## World AIDS Day 2020



1 December was World AIDS Day globally.

The theme for World AIDS Day in 2020 was **Now more than ever.**

For the bleeding disorders community this is a profoundly meaningful message.

1 December is a day when we are mindful of the members of our community living with HIV and those with HIV who have passed away.

In the mid-1980s the bleeding disorders community in Australia and internationally was devastated when many people with bleeding disorders acquired HIV through their plasma-derived clotting factor treatment products. HFA's recent *Getting Older* report documented the ongoing impact of this epidemic on our community: the trauma and health challenges for those who were diagnosed with HIV and now live with the consequences, and the grief and sadness experienced by those who lost loved ones and friends to HIV. Often forgotten is the emotional impact on the health professionals at the Haemophilia Treatment Centres too, who had cared for their patients with HIV over their lifetime and knew them so well.

The *Getting Older* report recognised the very positive contributions people with bleeding disorders and HIV have made to our community: the inspiring optimism and generosity of individuals with HIV, in spite of all their

experiences, speaking out and providing leadership and a way forward into the future.

Some of the people with HIV who participated in the *Getting Older* consultation also highlighted other issues that need addressing, including discrimination by health professionals in the wider health sector, based on an unfounded fear of transmission. This can result in barriers to testing and treatment and access to services.

*'There needs to be a concerned education campaign for health professionals to educate them about the low risks of HIV infection when the patient is well suppressed.'*

### TAKING ACTION

On World AIDS Day we were encouraged to educate ourselves and others about HIV.

In Australia HIV infection is now usually well-managed with treatment. However, the *Getting Older* report reminded us how important it is to acknowledge the experiences of our community members with HIV and the impact these experiences have had on them. We also need to recognise the impact on those who love them and care for them: their partners, family, friends and carers.

Hearing their stories and learning about the impact of HIV on them in the past and now is an important part of acknowledgement in our community. Foundations are also conscious of making sure there is always a supportive environment at community events. Wearing a red ribbon on World AIDS Day can help to raise awareness and reduce discrimination by demonstrating solidarity with people with HIV.

World AIDS Day challenges us to take action– and by this action to ensure that people living with HIV can participate fully in the life of the community, feeling supported and free from judgement, stigma and discrimination.

*Taken from National Haemophilia, the journal of Haemophilia Foundation Australia (forthcoming)*



## New website focusing on ACT Women’s health



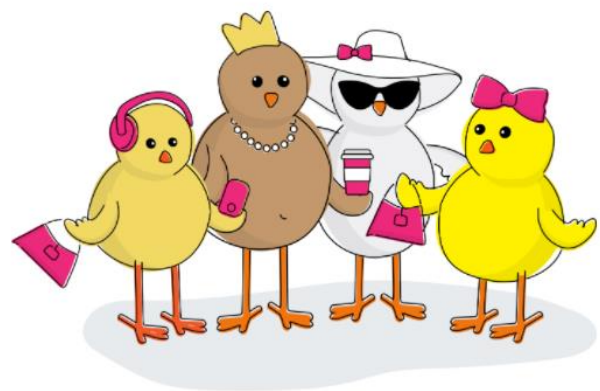
Diabetes NSW & ACT with support from ACT Health have released a new website called Capital Chicks Canberra. Described as “an opportunity to turn women’s health around, one step at a time”, it is online at [capitalchickscanberra.com.au](http://capitalchickscanberra.com.au).

Sometimes, all you need is the right information and a little bit of motivation to get started towards your health and wellbeing goals. The Capital Chicks CANberra has been designed to do just that. Get online access to healthy living tips, resources, events, recipes, workouts on your phone anytime, anywhere. Designed for all women, we pride

ourselves on practicality.

Whether you want to connect with other like-minded women, get fit, lose weight, prevent disease such as gestational diabetes and type 2 diabetes or just live healthier and happier - our online community and dedicated experts has you covered in a supportive and non-judgmental online environment.

Capital Chicks CANberra is free for any woman living in the ACT over the age of 18 years. For more information about registration: [www.capitalchickscanberra.com.au](http://www.capitalchickscanberra.com.au)



By: Emiliano

# Word Search!

Topic: Haemophilia

t	r	e	a	t	m	e	n	t	w	k	w	f
c	e	p	i	d	s	r	e	t	c	a	f	p
i	n	h	i	b	i	t	o	r	q	c	u	s
b	c	k	t	y	w	i	l	z	t	p	d	h
t	a	a	p	i	b	l	o	o	d	o	g	r
f	w	h	i	y	z	x	r	a	n	t	i	g
d	s	t	i	i	p	k	w	q	a	c	f	e
m	z	x	x	e	i	l	a	z	e	t	a	m
z	d	h	i	l	k	h	c	e	l	p	w	f
s	r	e	k	p	u	r	p	m	t	a	c	a
e	g	i	r	r	b	k	q	o	e	s	t	n
s	p	l	t	u	c	s	l	s	m	p	e	y
i	s	e	m	p	s	c	e	t	s	e	w	s
u	p	g	l	k	p	n	k	p	d	s	a	a
r	l	t	q	x	e	m	n	l	f	q	x	h
b	l	o	o	g	j	n	e	y	a	e	b	s

[editor's note: Thanks to Emiliano Damiani for this wordsearch.

To get a prize, please email a photo of completed wordsearch to: newsletter@hfact.org.au]

words to find

- Bruise
- needle
- Hurt
- Haemophilia
- treatment
- hemlibra
- clot
- inhibitor
- Factor
- blood
- rice
- Genes



## 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)

## Date for the diary

February 13 HFACT Breakfast BBQ

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### Our Mission

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

### Acknowledgement

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

