

# Contact



**Newsletter of Haemophilia Foundation WA Inc.**

**August 2020**



**HAEMOPHILIA FOUNDATION WA INC.**

City West Lotteries House, 2 Delhi Street, West Perth WA 6005  
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## Your Committee

Gavin Finkelstein (President)	0415 978 031
Cheryl Ellis (Vice President)	0402 033 652
Robert Butler (Treasurer)	9381 3386
Shane Meotti (Secretary)	

Susie Couper  
Dale Spencer  
Paul Keogh  
Michelle Dinsdale

Profiles of committee members can be found on the website, [www.hfwa.org](http://www.hfwa.org) 'Your Committee'.

**HFWA Office Coordinator**  
**Haemophilia Foundation WA Office**  
**Phone: (08) 9420 7294**  
**Email: [office@hfwa.org](mailto:office@hfwa.org)**

## Year of the Nurse and Midwife 2020

### PERTH CHILDREN'S HOSPITAL CONTACT DETAILS

Clinic H, Level 1 (Haematology/Oncology Outpatients: **Ph: 6456 0170**  
Medical Staff: **Dr Tina Carter Ph: 6456 0170**  
Nursing Staff: **Natalie Gamble-Williams and Stacey Hutchison**  
**(Monday—Thursday 8:00 am—4:30 pm) Ph: 6456 0170 or 0466 318 286**  
After Hours **(EMERGENCIES ONLY) Ph: 0410 717 816**  
Social Worker: **Helena Reynolds (Monday to Thursday, 8:00 am - 4:30 pm, adults and paediatrics, contact for appointment) Ph: 6152 6527**  
ABDR Data Manager and Clinical Trial Coordinator: **Marina Goruppi**



### FIONA STANLEY HOSPITAL CONTACT DETAILS

Clerk Front Desk: **08 6152 6542**  
Medical Staff: **Dr Stephanie P'ng and Dr Dominic Pepperell**  
Nursing Staff: **Sandra Lochore, Lara Olson**  
Social Worker: **Helena Reynolds (Monday to Thursday, 8:00 am - 4:30 pm, adults and paediatrics, contact for appointment) Ph: 6152 652**  
ABDR Data Manager and Clinical Trial Coordinator: **Marina Goruppi**



Entrance to the Cancer Centre is on the outside of the building  
Haemophilia and Haemostasis Centre  
Level 1 Cancer Centre  
Fiona Stanley Hospital  
102-118 Murdoch Drive  
Murdoch WA 6150

Postal Address (address all correspondence as Private and Confidential);  
Haemophilia and Haemostasis Centre  
Level 1 Cancer Centre  
Fiona Stanley Hospital  
Locked Bag 100, Palmyra DC WA 6961

Opinions expressed in Contact do not necessarily reflect those of the Foundation. All information is published in good faith but no responsibility can be accepted for inaccuracies that may result from events beyond our control. HFWA reserves the right to edit articles as it sees necessary. Material supplied on the internet is for information purposes only and is not to be used for diagnosis or treatment.

## President's Report

Hi Folks

I hope everyone has come out the other side of the COVID-19 situation with little or no impact on your lives. We are very fortunate to live in the isolated state of Western Australia. We still have to be cautious, but it is time for HFWA to recommence our community activities. Our first peer group activities were a Men's and Women's Breakfast at The Hamptons Restaurant at City Beach, a great venue to reconnect and chat about the happenings of the last six months.

Our big community reboot event is at Holey Moley in Cannington at the Carousel Shopping Centre on Sunday 20 September (see page 9 for further details).

The latest NBA Tender has been announced with the addition of EHL's (Extended Half Life) products for both Factor VIII and IX patients (see page 6 for further detail) and contact your treatment centre for any further information as these products will be of benefit to a number of patients. There are also ongoing discussions for the introduction of another product but details haven't been finalised and a bit of advocacy is being undertaken by HFA to help this process along.

The HFWA AGM is on Thursday 8 October at 7.30 pm at City West Lotteries House and we would appreciate you making an effort to attend. If you are looking to get more involved we are always looking for new blood (pun intended) on the committee. We will not over burden you with responsibilities but we would dearly welcome new committee members - give it a thought please.

Bleeding Disorder Awareness Week (BDAW) is the week of 11 to 17 October and see what you can do to celebrate BDAW and raise awareness of bleeding disorders at the same time.

Your committee and I look forward to catching up with you over the next few months to reconnect.

All the best!  
Gavin Finkelstein (President)

## Introducing Jenny Hough

I was previously on the City West Lotteries House reception for five years. I have had a good relationship with Gavin and my predecessor Mel and I have big shoes to fill to keep the HFWA office running up to Mel's standards and I have a lot to learn!

I am a mum of two adult children and one four year old grandchild and of course I spoil her as only a grandparent can. My interests range from renovating to gardening and of course I love to travel, and hopefully that will happen in 2021.

I look forward to catching up with you all at one of our events. Aren't we the lucky ones to be living in WA!



## Year of the Nurse & Midwife 2020

As 2020 is year of the nurse and Midwife we thought we would update our members on how we as HFWA are educating nurses and midwives on bleeding disorders and exposing them to who we are and what we can provide to them as a community.

It is also an opportunity to recognise and say thank you to these extraordinarily people who we rely on in often in difficult times.

Of course we have all had experience with how nurses help us and our families whilst we are patients or carers, but in the past three years HFWA has been speaking with Curtin Midwifery students about bleeding disorders and how they may come across these in their profession.  
(Cheryl Ellis)

As a mother of a child with haemophilia and also with myself having mild haemophilia and von Willebrands, I am able to educate the students on family planning, delivery, post-partum care and signs to look for in a newborn that may indicate a bleeding disorder is present.

Having delivered many public speaking events educating people from all areas about bleeding disorders, it gives me a great deal of reassurance knowing that I am playing my part about teaching the reality of the disorders and busting all of the myths and reducing peoples fear about interacting with a person with a bleeding disorder.

I have always said I will talk about haemophilia all day if you can find me someone who wants to listen. As they say (and happens to be my old school motto 😊) Knowledge is Power!!!  
(Sharri Brodie)

I have joined Sharri and Cheryl in helping to deliver these talks. As a member of HFWA I am incredibly proud of the connections we build and community work we do to help improve the lives of people with inherited bleeding disorders.

To be invited back is great vote of confidence in us and a clear indication in the value of hearing lived experience. We as mothers as well as patients have an opportunity for our voices to be heard. The questions asked are insightful and targeted at providing better care for mothers and their families.

The hope is that we provide these students with useful and memorable information as well as few laughs in our non-medical tell it like it is presentation. (Susie Couper)

*Article written by Cheryl Ellis (Vice President), Susie Couper (Committee Member) and Sharri Brodie (Member)*

## HFA GETTING OLDER REPORT



The **HFA Getting Older with a bleeding disorder needs assessment report** was published in May 2020.

The report describes the needs of older people with bleeding disorders and the needs of their partners, family and carers. It includes proposed solutions and recommendations for an HFA national strategy.

Many members of the community, health professionals and other experts contributed to the needs assessment through interviews, community forums, the HFA Getting Older Community Survey and the PROBE Australia Study. Our thanks to all involved for their valuable input.

There are two versions:

- The full report - with all the details of findings and recommendations
- A community report - a short summary of the findings and suggested solutions

These are available online on the HFA website [www.haemophilia.org.au](http://www.haemophilia.org.au) and in print. If you would like a print copy of either report, contact HFA on [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or phone 1800 807 173.



And check out the new **Getting Older Info Hub** on the HFA website - [www.haemophilia.org.au/getting-older](http://www.haemophilia.org.au/getting-older). Your go-to zone to find online information on getting older with a bleeding disorder!



## **New NBA EHL Treatment Tender Announced**

The National Blood Authority (NBA) has announced the outcome of its recent tender process for extended half life clotting factor products today. You will see the relevant document on the NBA website - <https://www.blood.gov.au/plasma-and-recombinant-product-procurement>

This means that there is funded access to extended half life factor VIII for all people with haemophilia A and an extended half life factor IX for all people with haemophilia B where they and their treating doctor at their Haemophilia Treatment Centre consider it for their treatment. Due to COVID-19 and some other local reasons there may be some delays to access; however, those who have been waiting for this development should speak with their doctor at their Haemophilia Treatment Centre.

This announcement does not include a decision about government funding for Hemlibra (emicizumab) which is registered in Australia for the treatment of people with severe and moderate haemophilia A with and without inhibitors. Hemlibra is not on the National Product List.

HFA will continue to advocate for Hemlibra to be funded as well as the products on this list for our community.

## **HFWA membership**

HFWA membership fell due on 30 June 2020 and the HFWA Membership period runs from 1 July 2020 to 30 June 2021. Please click the following link or enter it into your browser to access the membership form <https://www.hfwa.org/get-involved/memberships>.

HFWA is committed to the promotion of Haemophilia and related bleeding disorders on a state, national and international level and being a member entitles you to:

- Membership to Haemophilia Foundation Australia
- Receive the quarterly newsletter
- Access to peer support activities
- Access to library resources
- Subsidised Medic Alert emblem
- Shoe subsidies

The cost of membership is \$25.00 and payment can be made by EFT or over the phone on 9420 7294.

## **Entertainment Books**

Entertainment Books are now available in digital format only and can be purchased via the the following link.

They will now expire on the anniversary of when you purchase and remember that for every purchase you make, HFWA will receive a donation.

<https://www.entertainmentbook.com.au/orderbooks/847b23>

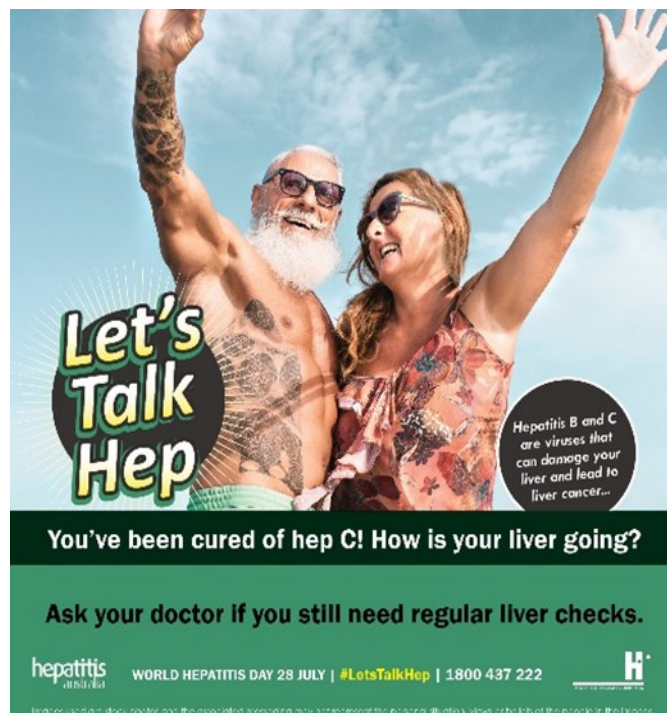
## World Hepatitis Day 2020

We mark World Hepatitis Day globally on 28 July. In 2020 we asked our community to help with the worldwide goal of Hepatitis elimination by 2030 by starting a conversation - talking to friends, family or a doctor.

New revolutionary Hepatitis C treatments are widely available in Australia. They have very high cure rates. Treatment is simple - tablets not injections, few if any side effects.

### WHAT ARE THE ISSUES FOR THE BLEEDING DISORDERS COMMUNITY?

**Many Australians with bleeding disorders and Hep C have now had treatment and been cured.** See their stories on the World Hepatitis Day page on the HFA website - <https://tinyurl.com/BD-WHepD2020>.



**Have you been cured of Hep C? How is your liver going?** Ask your Hepatitis specialist or GP if you need follow-up for your liver health. For example, if you have cirrhosis and have successful treatment, you will still need ongoing care of your liver.

**Some people with bleeding disorders or who carry the gene may not realise they have Hep C.** You could be at risk if you ever had a blood product before 1993. Is this you or someone you know? Have you ever been tested for Hep C? If not, now is the time to talk to your doctor about a Hepatitis test - and have treatment to be cured, if you do have Hep C!

**Thousands of Australians are now living free of Hep C, but many have not yet had treatment.** Treatment is simple and nearly all are cured – start the conversation.

**There is a small number of people with bleeding disorders and Hep C whose treatment has not yet been successful.** Close liaison between their Hepatitis specialists and their Haemophilia Treatment Centre is very important for their care. Research into new and improved Hep C treatments continues.

### FOR MORE INFORMATION

Visit

- [www.world.hepatitisday.org.au](http://www.world.hepatitisday.org.au)
- The HFA World Hepatitis Day page - <https://tinyurl.com/BD-WHepD2020>

## myWAPPS app

Since Paul returned home from the recent 2019 Haemophilia Conference, he has been talking about this new app to track our son Blaize's factor medicine levels. We all agreed to trial this new app, being the first in WA. It is very successful in Canada.

What got Paul's attention was the detail of tracking in real time, the level of factor present in Blaize's system at any given time. The app is also compatible with Android and Apple products including smart watches, so you can see personally what percentage your factor levels are in your body.

This was definitely of interest for me, because Blaize is a very active 10 year old who likes to test his limits. We often have to remind him that it isn't injection day, and that activity or sport he wants to partake in, is probably not advised and will be at a risk if he continues. He is also asking to skip an injection day. Blaize has been performing his own intravenous injections for a few years now, bringing his treatment into his own care and we believe this will assist him to understand when bleeds occur due to certain reduced factor levels.

This app is connected to the Haemophilia Treatment Centre (HTC), where the individual pharmacokinetic (PK) study was done (which is the half life study of your own factor medicine). The PK levels were sent from the HTC to the myWAPPS, and our treatment regime was set using the WAPPS-Haemo clinical calculator. We were sent an email to create login details and uploaded the app to my phone and we began using the app.

The most enjoyable feature of the myWAPPS app is the estimator function, that allows us to forecast his factor levels. For example, when Blaize doesn't want to do his injection; I bring out the app and I show him the current levels of factor in his system, and if he has sport at lunch time I can show him how low his levels will be, and how risky activity might be. But if he has the injection, he will be covered all day! Being able to show him the colours in a graph and in percentage, green is safe, yellow is edging on risky and red needs attention; it is a very easy way to understand where his body is at.

For myself, the reminder feature is very helpful. We do our injections before school, which everyone knows can be a hectic time! The app sends a reminder notification for your infusion day, and also can be set to let you know when the factor levels drop into the red zone.

It is a very easy app to use and I think very important for boys taking the treatment into their own care. It has been very helpful for me, and helped Blaize understand how the medicine is working within his body.

*Article by Lena Smith as told to by Paul Keogh (Committee Member)*



# RE-BOOT DAY - HOLEY MOLEY

**SUNDAY 20 SEPTEMBER**

We are having a **Re-boot Day** that adults and kids can be involved in and have a bit of fun. This is a wonderful excuse to get out there and mix with other members and their families – a vital part of your wellbeing.

Included on the day will be one round of 9 hole mini golf and one game of Strike 10 pin bowling. Closed in shoes essential. Snacks and light refreshments will be provided.

**Where:** Holey Moley Golf Club  
Westfield Carousel Shopping Centre,  
Shop MM204, 1382 Albany Highway, Cannington  
**When:** Sunday 20 September 2020  
**Time:** 10:30am

**RSVP: ASAP - Contact Jenny in the office by email or phone**

<https://www.holeymoley.com.au/locations/carousel#Mini-Golf>

We are sending a huge **THANK YOU** to **CommBank** because HFWA has been very fortunate in obtaining a grant that is going to directly benefit our members.

A cheque was presented to our President Gavin Finkelstein by Steve Benson and Robin Dique and we will share more of this generous grant in our October Contact newsletter. Let's make this a day to remember how lucky we are to be in WA!



## Women's Breakfast

An enjoyable time was had by both the ladies and men's groups at Hampton's City Beach on Sunday 23 August. Perth brought on a beautiful sunny day and we could clearly see Rottnest!

This was my first breakfast and I enjoyed meeting all the lovely ladies.

We welcomed our newest HFWA member Mel Gould. You will all know Mel from being such a large part of HFWA being in the Office Coordinator role on and off for many years. Mel will be lending her expertise in helping with the setup of the Bunnings Sausage Sizzle on the 17 October. See page 12 for details - welcome Mel!

## Men's Breakfast

I was going through my (very large unread) inbox and noticed an invite for the quarterly HFWA mens breakfast. Going straight to the date to see if I was actually available I noticed the change of location to Hamptons City Beach and instantly I was intrigued.

We were blessed with awesome near-spring weather. Pulling into the carpark and seeing the Hamptons sign on the building against the backdrop of the always beautiful Indian Ocean, I instantly knew today was going to be a good day.

The restaurant's presentation was amazing, it was bright, busy and had the cleanest bathrooms I've seen in a restaurant for a long time. Being a free a la carte meal you instantly disregard the prices (which I thought were quite fair) and go straight for the biggest thing on the menu - the big breakie and a strong coffee!!

Anyway back to the actual topic of the Men's Breakfast. We had the permanent older gentlemen come along (they know who they are) and this time around a good turnout of young and older new faces I hadn't met before; from memory we ended up with about 16 blokes attend. The conversation flowed, food was great and the location was prime. 10 out of 10, would attend again.

*Article written by Dale Spencer (Committee Member)*



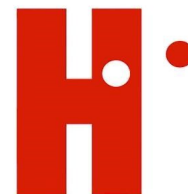
## Bombardier Blood

The powerful movie **BOMBARDIER BLOOD** will be available to buy or rent on Google Play. HFA had brought the rights to premiere the movie in Australia but unfortunately had to cancel due to COVID-19.

Even more exciting, Chris Bombardier is going to join the HFA community for a live chat on **Friday, 4 September** to talk about the experience and answer questions!

More details to follow, but in the meantime buy or rent the movie, watch it and note your questions and feedback. Parents, great movie for kids and teens!!

## Notice of Annual General Meeting



### HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA INC.

Notice is hereby given that the Annual General Meeting of Haemophilia Foundation WA Inc. will be held on Thursday 8 October 2020. Details as follows:

**DATE:** THURSDAY 8 October 2020  
**TIME:** 7:30 pm start  
**VENUE:** City West Lotteries House, 2 Delhi Street, West Perth  
**RSVP:** By midday Monday 5 October 2020

To ensure COVID-Safe practices, refreshments will not be served at this year's AGM

## Agenda

- |                        |  |
|------------------------|--|
| 1. Opening and Welcome | 7. Office Coordinator's Report                     |
| 2. Apologies           | 8. Appointment of Auditor                          |
| 3. Minutes of 2019 AGM | 9. Life Memberships                                |
| 4. Business Arising    | 10. Election of Management Committee—<br>2020/2021 |
| 5. President's Report  | 11. General Business                               |
| 6. Treasurer's Report  | 12. Close  |

**Following the AGM there will be a screening of Bombadier Blood**

## Nomination for HFWA Committee

The continued viability and functioning of the HFWA relies on a strong Management Committee. The present committee has a number of long-serving members and it is critical that we have fresh faces and ideas to steer the Foundation into the future. Contact the office or Gavin if you would like to know more about the Management Committee or how you can assist.

I wish to nominate for the 2020/2021 Management Committee

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Bunnings Sausage Sizzle

Calling all volunteers and generous donors



**Saturday 17 October 2020**

Yes it is on this year! As long as WA doesn't have any community transmission of COVID-19, we are going ahead!!

Come and join us for a fun time at our annual Bunnings Sausage Sizzle. HFWA has been fundraising at **Bunnings Homebase in Subiaco** as part of Bleeding Disorders Awareness Week for a number of years now.

We would love you to come along for a couple of hours to help on the day (any time between 7.30 am and 4.00 pm).

Plenty of volunteers are needed. Those 500 sausages won't cook themselves so sign up early to get your preferred time - don't miss out!

Everyone always has a great time!

We are also looking for donations of canned soft drinks or bottles of water to sell on the day - lemon squash, Coke (any sort), Fanta, Lemonade or water.

**REMEMBER** we are fundraising for Youth Events!

To let us know how you can help by volunteering or donating drinks please ring the office on 9420 7294, email the office at [office@hfwa.org](mailto:office@hfwa.org) or complete the form below and return it to the office

.....

I .....

☐ Would like to volunteer at the Bunnings Sausage Sizzle between the hours of .....

☐ Would like to donate soft drink or water, quantity .....

My contact details are: .....

.....

## Kids Colouring Corner





HFWA are selling quality shopping bags to support our state programs.

To order your bags and arrange collection  
email: [office@hfw.org.au](mailto:office@hfw.org.au) or  
call: 9420 7294.



**Jute Large Shopping Bag**  
42cm W x 33cm H



**\$6.50**

**Red Shopping Bag**  
33cm W x 35cm H



**\$3.00**

I would like to order \_\_\_\_\_ Jute large bags

I would like to order \_\_\_\_\_ Red bags

**Total \$** \_\_\_\_\_ (postage can be arranged at extra cost).

Please complete credit card details below or deposit the total with your Surname as your reference to:  
Acct Name: **The Haemophilia Foundation of WA Inc.** BSB: **086 488** Acct No: **03 523 3031**

**PLEASE NOTE THAT CREDIT CARD DETAILS WILL NOT BE RETAINED AFTER PROCESSING**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

Card Type:

☐ Visa ☐ MasterCard ☐ AMEX ☐ Diners

Card Number:

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Expiry Date:

		/		
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CVV:

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Name on Card:


# HFWA NAIL POLISH GIFT PACKS

In Stock Now

Three bottle gift packs available.  
Looking for that personalised gift with a real message for family  
and friends? Look no further!

## Gift packs

Gift packs contain Helen's Melons (red) and two colours of your choice.



**\$40.00  
Per Pack**

## Assorted colours

Helen's Melons, Emerald Green, Rose Gold, Silver and White.



**\$20.00  
Each**

I would like to order \_\_\_\_\_ gift packs with the following colours:

I would like to order \_\_\_\_\_ bottles of the following colours:

**Total \$** \_\_\_\_\_ (postage can be arranged at extra cost)

Deposit the total with your surname and 'Polish' as your reference to:

Acct Name: **The Haemophilia Foundation of WA Inc.**

BSB: **086 488**

Acct No: **03 523 3031**

Phone the office: 08 94207294 to pay by credit card

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

**HURRY STOCK IS LIMITED!**

2020

WHAT'S  
ON?



**Sunday 20 September 2020 - Holey Moley**

**Thursday 8 October 2020 - HFWA AGM**

**Saturday 17 October 2020 - Bunnings Sausage Sizzle**

**Save the date**

**October      11 - 17 October 2020**  
**Bleeding Disorders Awareness Week**

**November    Men's and Women's Breakfasts - TBA**

**December    Sunday 6 Dec - Christmas Party**  
**Outback Splash Bullsbrook**  
**11.00am - 3.00pm**