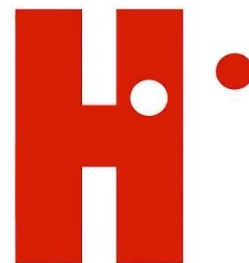


Contact



Newsletter of Haemophilia Foundation WA Inc.

August 2021



HEP CAN'T WAIT!

HAEMOPHILIA FOUNDATION WA INC.

City West Lotteries House, 2 Delhi Street, West Perth WA 6005
P: 08 9420 7294 E: office@hfwa.org W: www.hfwa.org

**HFWA is grateful to Fuji Film Australia for their ongoing support in printing the
Contact Newsletter**

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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
Belinda Broughton

Profiles of committee members can be found on the website, www.hfwa.org 'Your Committee'

HFWA Office Coordinator - Jenny Hough
Haemophilia Foundation WA Office
Phone: (08) 9420 7294
Email: office@hfwa.org



Cover Picture

World Hepatitis Day 2021

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**
(Mon - Thurs 8:30 am - 4:30 pm) Ph: 6456 0170 or 0466 318 286
After Hours: **(EMERGENCIES ONLY) Ph: 0410 717 816**
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** and **Lara Olson**
Social Worker: **Helena Reynolds** (Mon and Thurs 9:00 am - 1:00 pm, contact for appointment)
Ph: 6152 6527
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

2021

Hi everyone

I hope everyone is well and into the vaccination cycle for Covid-19. If you have any concerns please contact your treating doctor to help you make the best decision for you. I have had my second AstraZenica vaccination without any side effects, not even a bruise at the injection site.

HFWA had a Sundowner at the Windsor Hotel last Sunday 22 August. Perth put on a lovely spring day and it was an enjoyable event for those who attended. It was an opportunity to catch up in nice surroundings and have a good chat over a drink and nibbles. We hope to have a river cruise early next year, so please watch this space for the details and don't miss out on the opportunity.

I would imagine everyone is turning their attention to the 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders on 8 and 9 October. HFWA is offering to cover the cost of registration to those that apply (see page 11 for more details). It is a pity that we cannot attend in person, but such is the times and doing it virtually is the next best thing to update yourself on what is happening in the bleeding disorders world, new treatments or just to engage with our community.

The HFWA AGM is on Thursday 23 September (see page 8 for details) and it would be great to see as many of you there as possible. Please note the venue has changed from previous years.

Keep well and get vaccinated

Regards

Gavin Finkelstein

Haemophilia Foundation of WA Membership

HFWA membership fell due on 1 July 2021 and the HFWA Membership period runs from 1 July 2021 to 30 June 2022. 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 very minimal cost of membership remains at \$25.00 per family and payment can be made by EFT, pay securely by credit card via the Square Payment link [here](#), or over the phone on 9420 7294.

Your Health Matters

World Hepatitis Day 2021

World Hepatitis Day is marked globally on 28 July. In 2021 we joined the global community in the message of **Hep can't wait!**, reminding us that we need to be proactive and act on viral hepatitis.

Hepatitis C has had a profound effect on our community. In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of bloodborne viruses from plasma-derived clotting factor products in Australia is now considered to be extremely low. But many people in our community live on with the consequences of those early infections.

WHAT ARE THE KEY ISSUES IN 2021?

Revolutionary new hep C treatments are now available in Australia. They are easy to take – tablets not injections - with very high cure rates and few side effects.

Who is at risk?

If you had a blood product or a plasma-derived clotting factor concentrate before 1993, you could be at risk for hepatitis C.

Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured – but some might not even know they have hep C. This could be the case for some women and men with mild bleeding disorders who may have had very few treatments in their lifetime and never thought of themselves as at risk for hep C. If this is you, don't wait to be tested – find out if you have hep C. Treatment is simple and hep C can be cured.

You have been cured – has your liver recovered?

If you don't know the answer to that question, don't wait to find out. Take the time to **contact your hepatitis specialist and check your liver test results.**

It's very important to check that you don't need ongoing follow-up with a liver specialist. For example, if you have cirrhosis or extensive scarring and have successful treatment, you will still need ongoing care of your liver.

Sadly, some people with bleeding disorders and hep C have very advanced liver disease caused by long term infection. Close liaison between hepatitis or liver specialists and Haemophilia Treatment Centres is very important for care and treatment. Research is continuing into new and improved hep C treatments and management of advanced liver disease.

PERSONAL STORIES

We thank Gavin Finkelstein, HFA President, and Mary Jane for sharing their personal stories about living with hep C, treatment and being cured. Read their stories on the HFA website.

FOR MORE INFORMATION

Visit www.world.hepatitisday.org.au

The HFA World Hepatitis Day page – www.haemophilia.org.au/world-hep-day



YOU CAN'T WAIT

Many Australians with bleeding disorders and hep C have had treatment and been cured – but some may not even know they have hep C.

You could be at risk for hepatitis C if you had a blood product before 1993.

**Don't wait! Know your status.
Get tested for hep C.**

**You've been cured of hep C!
Has your liver recovered?**

Don't wait to find out.

Call your hepatitis specialist to check your liver test results.

Know if you need ongoing follow-up for your liver health.

It's important to check that you don't need ongoing follow-up with a liver specialist. For example, if you have cirrhosis or extensive scarring and have successful treatment, you will still need ongoing care of your liver.



Find out more
www.haemophilia.org.au/world-hep-day



Bleeding Disorders Awareness Week



BDAW 10 - 16 October 2021

Bleeding Disorders
AWARENESS WEEK

10-16 OCTOBER 2021

If you have an activity organised and we have a snap shut down due to COVID-19 restrictions, how about doing a virtual event. It's so easy to do and if you don't know how, just ask the kids

Looking for something to do during Bleeding Disorders Awareness Week either face to face or virtual? Host a red-themed event and **Go Red For Bleeding Disorders!** Some great ideas are:

- Host a red-themed morning tea at home or your workplace
- Host a Red Cake Day
 - What about hosting a Red Cake Day during Bleeding Disorders Awareness Week. It's a great way to involve family, friends and workplaces to take part in a campaign to raise funds and awareness
- Dress red for a cocktail night (or make red cocktails or mocktails)
- Host a red themed crafternoon
- Wear red in support of the day
- Organise a red dress day for your school classmates
- What about a red themed pajama party for the kids



For more information or great ideas that will be updated in the coming weeks for face to face or virtual activities, go to haemophilia.org.au/bdaw



Health




The Kids' Bridge is open!

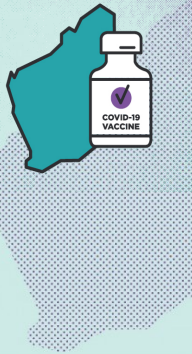
Also known as The Koolangka Bridge, which means children in Noongar, opened on 4 August 2021.

The brightly coloured rainbow bridge spans 3 metres wide x 217 metres long and was funded by The Perth Children's Hospital Foundation. It links Perth Children's Hospital and Queen Elizabeth II Medical Centre to Kings Park, providing hospital patients, staff and visitors much needed respite and distraction from the rigours of medical treatment and some reprieve from the clinical environment.

Such a wonderful project to benefit sick kids and their families. They will be able to access our stunningly beautiful Kings Park and give them some much needed healing power of nature.

A collage of several small images showing diverse people of various ages and ethnicities getting their COVID-19 vaccines. Some are smiling, others are looking at the camera, and some are showing their injection sites.

**Roll up
for WA**
COVID-19 Vaccination

A map of Western Australia in teal, with a white vaccine bottle icon containing a purple 'V' and the words 'COVID-19 VACCINE' placed over it.

To register for a COVID-19 vaccine and book an appointment, visit [Roll up for WA](https://rollupforwa.wa.gov.au)
For more information for West Australian residents see

https://healthywa.wa.gov.au/Articles/A_E/Coronavirus/COVID19-vaccine

Annual General Meeting



HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA INC.

Patron: The Honourable Kim Beazley AC, Governor of Western Australia

All members are advised that the Annual General Meeting of Haemophilia Foundation WA Inc. will take place as follows:

DATE: THURSDAY 23 SEPTEMBER 2021

TIME: 7:30 pm start

VENUE: Telethon Speech & Hearing Centre, 36 Dodd Street, Wembley

RSVP: By midday Monday 20 September 2021

Agenda

- | | |
|------------------------|---|
| 1. Opening and Welcome | 6. Treasurer's Report |
| 2. Apologies | 7. Office Coordinator's Report |
| 3. Minutes of 2020 AGM | 8. Election of Management Committee - 2021/2022 |
| 4. Business Arising | 9. General Business |
| 5. President's Report | 10. Close |

Please join us for light refreshments at the completion of the AGM. For catering purposes, RSVP to Jenny on 9420 7294 or office@hfwaw.org by Monday 20 September 2021.

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 2021/2022 Management Committee

Name: _____

Address: _____

Signature: _____

Bunnings Sausage Sizzle

Calling all volunteers and generous donors

Saturday 16 October 2021

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



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! And what a great fun way to mix with your peers.

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@hfw.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:

.....

Women's Health

The WFH Women & Girls with Bleeding Disorders Summit was a great success!

All the experience shared is of great value to women and girls of all ages and it's a great opportunity for the younger girls to learn how to deal with the ongoing issues that might come along during the course of their lives.



See the list of recorded sessions below or to listen or catch up on all the recordings available go to: <https://na.eventscLOUD.com/website/18115/home-160/>

PLENARY:

- Multi-disciplinary care for WGBDs- what does it look like?
- What are the health outcomes in WGBD
- Signs, symptoms and empowerment: Susie Couper once again stepped forward and presented in this session. (Empowerment comes from having knowledge and feeling that we affect change. First step building knowledge of your bleeding disorder and then using that knowledge as a vehicle for change)

EDUCATIONAL:

- WGBDs experience
- Stages of life - Aging with a BD
- Reproductive choices for women with bleeding disorders from patients and expert's view and prenatal diagnosis

HOT TOPIC EXCHANGE:

- Importance of OBGYNs in the comprehensive care team

TOOLKIT:

- Girls/PreGirls/Preadolescents – How to talk about periods preparation and prevention
- Actions and ways to address the disparities in care, treatment, and diagnosis. How to use the existing instruments for advocacy: European Principles of care WGBDs, VWD International Guidelines, & VWD Global Call to action, hemophilia guidelines section on women

ASK THE EXPERTS:

- HMB-when to seek treatment? HMB-when to seek treatment?
- Speaking and understanding each others language (HCPs-patients)



Celebrate Women's Health Week, 6-10 September

Women's Health Week is a nationwide campaign of events and online activities – all centred on improving women's health and helping you to make healthier choices.

Learn more about the power of good health. After 2020, it's never been more important for women in Australia to put their health first. Join us, along with around 100,000 other women across Australia in this year's Jean Hailes Women's Health Week to power up your health.

For more information go to www.womenshealthweek.com.au/



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

THE 20TH AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD AND RARE BLEEDING DISORDERS WILL TAKE PLACE THIS YEAR FROM 8-9 OCTOBER 2021 VIRTUALLY.

The 20th Australian Conference On Haemophilia, VWD And Rare Bleeding Disorders will take place this year from **8-9 October 2021** virtually.

Registrations are now open - for more information and registration [click here](#)

PROGRAM

- 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

Young people from ages 16-30 are encouraged to attend the conference and participate in the mainstream program. A Youth activity will be organized on Friday.

What do you need to successfully participate?

Computer with sound card, tablet or smartphone and WIFI or data with enough for a 2 day stream.

For all HFWA members only

HFWA is offering to subsidise the registration cost of \$50.00 per person. If you are one of our valued members who would like financial assistance to attend the conference, please send us an email with your registration receipt to office@hfw.org

Our Management Committee will review all applications and if you're successful we will reimburse you. It's that simple and this is something you don't want to miss out on!

So what are you waiting for, there has never been a better offer or way for you to participate!

Telethon Kids Survey

Researchers at the WA Child and Adolescent Health Service and the Telethon Kids Institute are conducting a project to identify the most important questions for research in childhood chronic illness. Participants will be asked to complete a brief online survey to help them rank research priorities.

What they're looking for:

Young people with a chronic condition or disability (14-24)

Parents/caregivers of children & young people (0-24) with a chronic condition or disability

Professionals working with children & young people with chronic conditions or disabilities

Follow the link to participate:

<https://redcap.link/chronicconditions.prioritysetting.stage2>



We are looking for:

- **Young people with a chronic condition or disability (14-24)**
- **Parents/caregivers of children & young people (0-24) with a chronic condition or disability**
- **Professionals working with children & young people with chronic conditions or disabilities**

To take a short survey to rank the most important topics for child & youth chronic conditions research.

For any questions or to participate, please contact

Dr Amy Finlay-Jones

amy.finlay-jones@telethonkids.org.au



Government of Western Australia
Child and Adolescent Health Service



School Holiday and great Father's Day Ideas



Perth Royal Show is planned to go ahead in 2021, so why not grab the family and head on down to our iconic Royal Show.

Important Ticketing Information

All ticket sales for 2021 will be exclusively online with a huge 25% OFF all entry tickets!

For more ticketing info go to:
<https://perthroyalshow.com.au/get-tickets/>

Something for the Seniors - HALF price ticket day!
 ALL Senior's entry tickets for FRIDAY, October 1st will be 50% OFF the original ticket price.

Don't miss the 2021 Perth Royal Show. It's a great day out filled with live entertainment, artisan food and wine, cooking demo's, craft displays plus lots more. And don't forget the Show Bags!

We are definitely living in the 'lucky state', so why not take you and your family to the Show and enjoy great family time with all the festivities.



For more information and to plan your day, go to perthroyalshow.com.au

FATHERS DAY Sunday 5th September

Some fabulous and some silly ideas for you and the kids to make or share with DAD



- Bunnings Gift Card - The ultimate gift card for Dad or for mum because she loves Bunnings too!

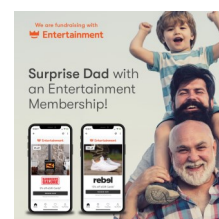
- Of course, there are the standard gifts for the little kids to give dad like socks (\$3.00 from Big W), coffee or beer mug, stubbie holder, anything to do with the BBQ (apron or even a new BBQ from all the family)



- Craft Breweries can be a relaxing day for dad and mum and there are plenty of them that cater for families with kids playgrounds. Just to name a few see these great venues

- - ◇ Bailey Brewing - Henley Brook
 - ◇ Mash Brewing - Henley Brook
 - ◇ Little Creatures - Fremantle
 - ◇ Dutch Brewing Co - Vic Park

- A great Father's Day Gift for all the family to enjoy and don't forget to check out all the fantastic school holiday deals. There are so many fantastic deals that you can use all year round! And you will support us as well. For details **see page 14**



- For those dads that like a little adventure, why not check out Perth Wake Park - the only cable wake board park in WA is the ultimate day out for all the family and those hard to please teenagers will love it too!

For more things that can be found in and around our great city here are a couple of good websites to visit:

- www.buggybuddys.com.au
- www.westernaustralia.com
- www.destinationperth.com.au

2021

WHAT'S ON?



23 September 2021

HFWA AGM

8 - 9 October 2021

HFA 20th Australian Virtual Conference

10 - 16 October 2021

Bleeding Disorders Awareness Week

HFWA Strategic Planning Day - TBA

Save the Date

16 October 2021

Bunnings Sausage Sizzle - Homebase, Wembley

5 December 2021

Adventure World - HFWA Community Christmas Party

More information following in the coming weeks on the abovementioned events
Please contact Jenny on 9420 7294 or office@hfw.org to RSVP to any of these events

Fundraising

The perfect time to start fundraising!

Fundraise with Entertainment and your supporters can enjoy a host of incredible benefits, **plus 20%** of each Membership sale goes directly to your cause!



New promotion commencing August 4!

Buy an Entertainment Membership today and get a **BONUS \$40 eGift card** when you buy a Multi City or a \$20 Gift eCard when you buy a Single City!*

- PLUS,
- ONE extra month **FREE***
 - Chance to **WIN** incredible prizes!*

Promotions runs from 3pm 4th August - 11.59pm 1st September 2021 AEST



The savvy way to win!

When your supporters buy a Membership they automatically go into the draw to **win** the prizes below.



Win a 3-night Quantum of the Seas Cruise

Win a 3 night Royal Caribbean cruise for 2 people. Sail in a balcony cabin onboard Quantum of the Seas. Valued at AUD \$1,559.



Win 3 nights at a TFE hotel!

2 x 3 night certificates to give away, includes Adina Apartment Hotels, Vibe Hotels, Travelodge Hotels and Rendezvous Hotels.

Win a \$200 dining voucher!
The chance to win a weekly \$200 dining voucher for your favourite Entertainment venue.



Laithwaites Wines

You'll receive \$50 off sitewide with free delivery when you order 12 or more bottles*



Entertainment Books Digital Membership

For every purchase **Haemophilia Foundation WA** receives **20%** of the purchase.

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

Surprise dad with an Entertainment™ Membership this Fathers Day and help support us at the same time!

Plus, buy a Membership today and you'll get 1 extra month FREE and a \$20 gift card to either Woolworths, Big W or Freedom with each Membership purchased! That's 13 months of incredible offers + 20% of your Membership purchase goes directly to HFWA.

Support us today:

<https://www.entbook.com.au/847b23>

 **Entertainment**



Scheme ID
C10338968



This October will mark one whole year of Containers for Change! In celebration, Containers for Change are holding their first ever Change Maker Awards to recognise the incredible individuals and organisations who are making a difference through Containers for Change.

Go to [Change Maker Awards | Containers for Change](#)

You can help your HFWA community by using the scheme ID above to donate.

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

To order your bags and arrange collection
email: office@hfwa.org.au or
call: 9420 7294.

Jute Large Shopping Bag
42cm W x 33cm H



Red Shopping Bag
33cm W x 35cm H



Email your order for the shopping bags and / or nail polish directly to the HFWA office at office@hfwa.org with your name, address and phone number or phone 9420 7294 and we will advise when your order can be collected - or we will dispatch your order promptly by mail (postage can be arranged at extra cost)

For fast and secure payment, follow the secure Square credit card payment link below or simply scan the QR code to go straight to the Square checkout

<https://checkout.square.site/merchant/06461WB19EDA8/checkout/R74ZARTGOWNVOO6YVONMBHMX>

or deposit the total of your order with your Surname as your reference to:

Acct Name: **The Haemophilia Foundation of WA Inc.** BSB: **086 488** Acct No: **03 523 3031**

HFWA NAIL POLISH GIFT PACKS

Three bottle gift packs available.
Looking for that personalised gift for a friend or to spoil yourself? Look no further!

Gift Packs \$20

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



Assorted Colours \$10 each

Helen's Melons, Emerald Green (almost gone), White, Top Coat & Rose Gold



For fast and secure payment, please follow the secure Square credit card payment link below or simply scan the QR code to go straight to the Square checkout below for your Nail Polish purchase

<https://checkout.square.site/merchant/06461WB19EDA8/checkout/V55VON3QLYYU3PUWTEB65RA>