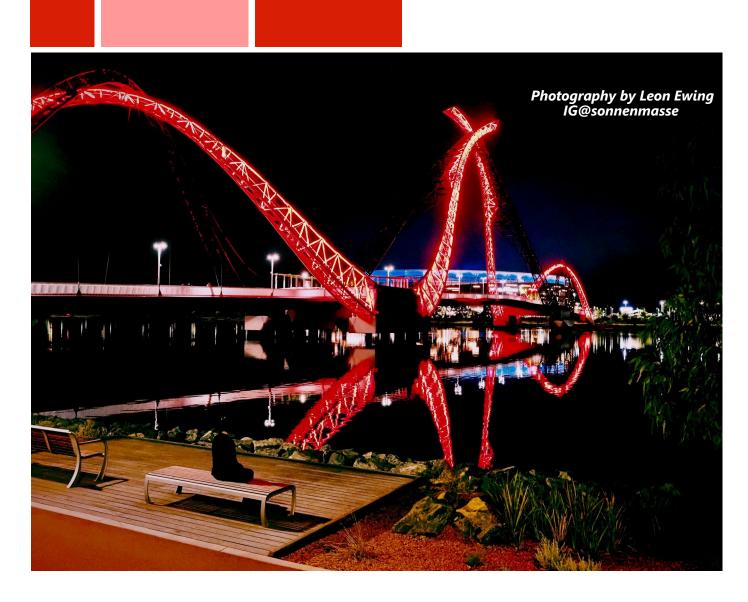
Contact Newsletter of Haemophilia Foundation WA Inc. June 2021





HAEMOPHILIA FOUNDATION WAINC.

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) Cheryl Ellis (Vice President) Robert Butler (Treasurer) Shane Meotti (Secretary) Susie Couper Dale Spencer Paul Keogh Michelle Dinsdale Belinda Broughton Melanie Gould	0415 978 031 0402 033 652 9381 3386			
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				



Cover Picture World Hemophilia 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

(EMERGENCIES ONLY) Ph: 0410 717 816 After Hours:

ABDR Data Manager and Clinical Trial Coordinator: Marina Goruppi

FIONA STANLEY HOSPITAL CONTACT DETAILS

Clerk Front Desk: 08 6152 6542

Dr Stephanie P'ng and Dr Dominic Pepperell Medical Staff:

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 as many of you as possible are getting your COVID-19 vaccinations when you qualify for them. If you have any concerns, see the HFA website or contact the HTC for further information.

I've had my first Astra Zeneca dose and I didn't have any bruising at the injection site and only suffered mild flu like symptoms on the first night. I took two Panadol before going to bed and didn't experience any further reactions and I look forward to receiving my second dose.

Things at HFWA continue on as usual and we were sad to farewell Mel (again). Mel has decided on a sea change and taken the plunge to move down south to the Mount Barker area and we wish her all the best in her new life. Once again we thank her for everything she has done for us over many years in her capacity as Office Coordinator and for her valuable contribution as a committee member.

HFWA is offering to fund a number of members to attend the virtual 20th Australian Conference on Haemophilia and Rare Bleeding Disorders. Registration fee is \$50 for a person with a bleeding disorder, family or carer and Haemophilia Foundation Staff. Please consider attending the national conference in this unique way because the more attendees that participate will ensure a more enjoyable experience for all.

For those of you who have been transitioning to Hemlibra, we hope this has been successful without any issues.

World Hepatitis Day is on 28 July and the theme is '**Hepatitis can't wait'**. This is a timely reminder for everyone that has undertaken treatment to ensure they have follow up tests regularly to monitor their liver health.

Peer group activities are ongoing and we look forward to catching up with you whenever you can possibly join in.

Regards

Gavin Finkelstein



World Hepatitis
Alliance

Haemophilia Foundation of WA Membership

HFWA membership falls 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 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. See pages 8 - 9 for application / renewal form and EFT payment details.

World Hemophilia Day - 17 April 2021

On a beautiful autumn night in Perth, some of our famous landmarks were 'Lit up Red' In honour of World Hemophilia Day.

LIGHT IT UP RED!

We would like to thank Main Roads Department, City of Perth and Curtin University for their very generous effort in 'Light it up Red" locations in and around Perth.



Photography by Leon Ewing IG@sonnenmasse"

Locations 'Lit Up Red'

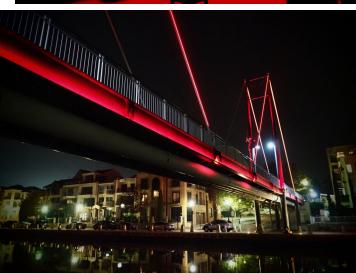
The Bell Tower
Trafalgar Bridge
Curtin Uni Stadium
Matagarup Bridge
Mount Street Bridge
Sky Ribbon Bridge
Northbridge Tunnel

A huge thank you to Leon Ewing for the fabulous photos on the front cover and on this page. Gratitude also goes out to our members who sent through their photos (see page 5).

A comment from one of our members

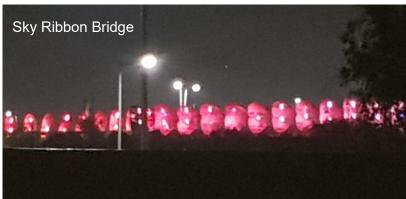
'Lovely effort. We drove around last night to see a couple of landmarks. Very nice indeed.'





World Hemophilia Day 2021 (Cont'd)









port and exercise or girls and young women with bleeding disorders

HFA has released a new fact sheet Sport and exercise for girls and young women with bleeding disorders

This was developed out of a survey of young women and their parents and answers their questions, such as:

- How can I best participate?
- What types of sport or exercise should I do?
- How can I manage my periods?
- What about injuries?
- What should I tell my coach or club?

Accessing the fact sheet

- Read it online or download it from Factored In https://tinyurl.com/FI-sport-girls
- Ask your HTC for a copy
- Contact HFA to send you copies E: hfaust@haemophilia.org.au or

T: 1800 807 173

What kind of sport or exercise do you enjoy?

If you are a young woman or girl with a bleeding disorder, like everyone, you are encouraged to exercise and be active. It's vital to healthy living!

Give it a try!

There is something for everybody and it's a matter of finding something that suits you, that you enjoy and that can get you moving.

> "There is no one size fits all. I keep active and try new things to find what works for me. Having the freedom to take these challenges on has helped me into adulthood and developed my confidence in all areas of life"

What to try?

Looking for ideas? Young Australian women with bleeding disorders gave us some examples of what they do





Health Updates - COVID-19



An important update from HFA below:

Our community has been asking us many questions about the vaccine and how it impacts on people with bleeding disorders.

I would like to draw your attention to the updated version of the HFA COVID-19 vaccine FAQs on the HFA website.

We would like to reassure you that the Australian Haemophilia Centre Directors' Organisation confirmed with us on the 4 June 2021 that there is **no change to the advice they gave us in February 2021.**

The **only change to our FAQs is about where you can get a vaccine**. The Australian Government has now made detailed information about this available on the HealthDirect website and we have linked you through to the relevant page.

CLICK HERE FOR THE UPDATED FAQS

The FAQs are also available on the website as a PDF for downloading and printing, if you wish to show them to your GP or other vaccine provider.

As always, if you have any questions about the vaccine in relation to your bleeding disorder, speak to your Haemophilia Treatment Centre or your treating haematologist.

And keep an eye on the HFA website for further updates - www.haemophilia.org.au



All West Australians over 30 are now eligible for COVID-19 vaccinations

Check your eligibility here https://covid-vaccine.healthdirect.gov.au/eligibility

For more information for West Australian residents see

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







Thank you for rolling up for WA.

Take a selfie or photo to share with your friends and family!

#Rollup4WA

















We're all in this together.

Haemophilia Foundation of WA Membership

APPLICATION FOR 2021/22 MEMBERSHIP							
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First Name							
Last Name							
Address							
Telephone							
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Grandparents				Parent of Child			
Nurse			<u> </u>	Doctor			
	Other Special Interest Please return this membership form via email or to the address below:						
Individual Extended family	Family members r	(includes imm	ediate	family members) - Membership \$25.0 bown membership. stances - Please contact the HFWA o			
I would like to n	nake a dona	tion of:					
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Cheque e	nclosed						



APPLICATION FOR 2021/2022 MEMBERSHIP Family History

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WFH Women & Girls with Bleeding Disorders Global Summit

Registration is now open for the 2021 WGBD Global Summit!

Registration is free as the WFH would like to encourage as much participation as possible in this event and make it accessible for everyone.

The registration link is: https://na.eventscloud.com/wgbd2021

One of the huge benefits of registering for this event is the exhaustive access to resources 6 months post summit.



This event is a perfect opportunity to advance knowledge, to inspire action for adequate care and treatment for WGBDs, and to build connection.

Please, feel free to share the social posts below:

Facebook/LinkedIn/Instagram

The conversation on care and treatment for women and girls with bleeding disorders (WGBD) continues with the 2nd WFH Global Summit on WGBD! Join us July 8-10 to discuss the realities of WGBDs worldwide, and exchange on care, treatment, advocacy, and empowerment. Registration is now open, learn more here: http://ow.ly/lqlp50EKbYb

Twitter

The conversation for women and girls with <u>#bleedingdisorders</u> (WGBD) continues with the 2nd WFH Global Summit on <u>#WGBD</u>! Join us July 8-10 to discuss the realities of WGBDs worldwide and to engage and exchange on care, treatment, advocacy, and empowerment: http://ow.ly/1yhe50EKbXT

Events of Interest

July 21 School Holidays - Educational and Fun!

There are so many things that you can do with the kids over the school holidays. Free events and all sorts of fabulous things can be found at many places around Perth and the suburbs.

Just to name a few of our wonderful play areas: Kings Park, Whiteman Park, Hyde Park, Yagan Square Playscape, Whale Playground Scarborough, Yokine Reserve, Hillary's Area.

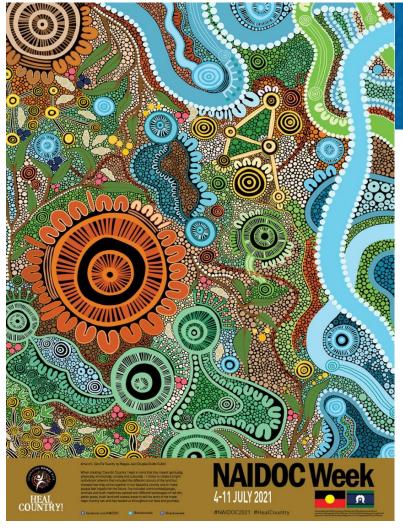
Why not check out your local Shopping Centre for school holiday activities and don't forget your local Bunnings store. They have kids DIY workshops, but sorry mum and dad, someone must stay with them.





Perth Zoo, Scitech and the Aquarium are always a great day out and there is no shortage of entertainment and laughter at '**The Little Hoo-Haa!**' This improvised and interactive comedy will have you laughing along with the kids https://www.ticketswa.com/event/little-hoo-haa

Whatever your budget, stay connected and join in the community activities. It is good for your well being and that of your kids.





The theme 'Heal Country" is the new theme chosen to reflect the important issues and events for NAIDOC Week in 2021.

<u>Country is more than a place</u> and inherent to Aboriginal identity. It sustains lives in every aspect – spiritually, physically, emotionally, socially, and culturally.

NAIDOC Week celebrations are held across Australia to celebrate the history, culture and achievements of Aboriginal and Torres Strait Islander peoples. NAIDOC is celebrated not only in Aboriginal communities, but by Australians from all walks of life. Local community celebrations during NAIDOC Week are encouraged and often organised by communities, government agencies, local councils, schools and workplaces.

Source: NAIDOC Week - Creative Spirits, retrieved from https://www.creativespirits.info/aboriginalculture/history/naidoc-week

Peer Support Events

Let's have a Sundawner!



Women's Event
Sunday 29 August 2021
2.30pm
RSVP by 12 August 2021
To: office@hfwa.org

Men's Event
Sunday 22 August 2021
2.30 pm
RSVP by 5 August 2021
To: office@hfwa.org

THE WINDSOR HOTEL in THE GARDEN BAR

Peer Support Events are free to all financial members

RSVPs are essential for these events to office@hfwa.org and no later than the dates specified



Fundraising

Entertainment Books - Digital Membership



Relax and make the most of savings at your fingertips wherever you go!

Hurry, competition ends Wednesday 30 June 2021

Enjoy the benefits of a Membership that gives you access across Australia & New Zealand.

Don't miss the School Holiday Savings available!

Entertainment

Purchase a Single City Membership and go into the draw for a chance to WIN a 5 night Port Douglas holiday package for two, thanks to Discover Queensland#

- Return economy class flights from Sydney, Melbourne, Brisbane, Perth or Auckland to Cairns
- ✓ 5 nights accommodation at Silkari Lagoons Port Douglas
- √ 5 day compact rental car hire
- ✓ Green Island full day tour including lunch



BUY
SINGLE CITY
MEMBERSHIP

\$699

\$11999

SAVE
\$50

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

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



Scheme ID **C10338968**

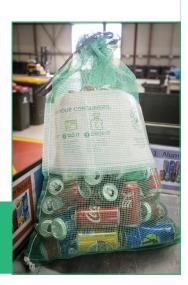
One of the most common questions asked is, what can I recycle through Containers for Change?

Here's a simple three-step process to work out if a container is in or not:

- 1. Look for the 10c refund mark on the container.
- 2. Ask yourself if the drink is consumed on the go. If yes, then it most likely can be recycled through Containers for Change.
- 3. Still unsure? Use the eligibility checker at containersforchange.com.au

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

Now you know what's in and out, it's time to head to your local refund point!



2021

WHAT'S ON?



8 - 10 July 2021

Women and Girls with Inherited Bleeding Disorders Global Summit
Virtual Event

22 August 2021 - Men's Peer Support Sundowner 29 August 2021 - Women's Peer Support Sundowner

8 - 9 October 2021

HFA 20th Australian Virtual Conference

10 - 16 October 2021

Bleeding Disorders Awareness Week

Save the Date

HFWA Strategic Planning Day - TBA

HFWA AGM - 9 September 2021

Community River Cruise - TBA

16 October 2021

Bunnings Sausage Sizzle - Homebase, Wembley

5 December 2021

Adventure World - HFWA Christmas Party

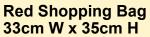
HFWA are selling quality shopping bags to support our state programs.

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







I would like to order I would like to order	Jute large bags @ \$6.50 ea Red bags @ \$3.00 each	ch		
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Acct Name: The Haemophilia	Foundation of WA Inc.	BSB: 086 488	Acct No:	03 523 3031

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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 and Sil-



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 for Nail Polish purchase



- https://checkout.square.site/merchant/06461WB19EDA8/checkout/V55VON3QLYYYU3PUWTEB65RA
- 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

I would like to order _____ Gift Packs with the following colours:

I would like to order _____ Bottles of the following colours:

Name:
Address:

LIMITED STOCK AVAILABLE!