

# Contact



Newsletter of Haemophilia Foundation WA Inc.

April 2021

## ADAPTING TO CHANGE

Sustaining care in a new world



**HAEMOPHILIA FOUNDATION WA INC.**

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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  
Melanie Gould

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

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



## Cover Picture World Hemophilia Day 2021 Adapting to Change

### 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 8:00 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, Lara Olson**  
Social Worker: **Helena Reynolds** (Mon - 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

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## President's Report

# 2021

Hi Everyone

I hope this message reaches those of you who are considering when to have their COVID vaccination.

Haemophilia Foundation Australia has information on its website titled Covid-19 Vaccines - FAQ's on the following link [COVID-19 vaccine FAQs - Haemophilia Foundation Australia](#)

If you have any further questions, please don't hesitate to ask your clinician at your next appointment at the Haemophilia Treatment Centre (HTC).

For those of you who didn't attend the HFA Community Camp - Haemolympics, you missed a great fun filled and enjoyable weekend. A big thank you goes out to our Haemolympics coordinator Sharri who was ably assisted by Roma, Mel, Jenny and Lena. A thank you must also be given to the members of the committee for their efforts and even though it was a rather hot weekend, the pool helped cool us off and a great time was had by all who came along.

World Hemophilia Day is on Saturday 17 April (see page 7 for the list of Perth landmarks to be lit up red). The HFA Conference being held on 8 - 9 October is going to be virtual this year enabling more people to attend. We have decided to go virtual this time due to uncertainty with travel and the possibility of snap lockdowns. This will make it much easier to participate and get benefit from the sessions.

Please seriously consider attending HFWA's Strategic Planning Day set down for 15 May at City West Lotteries House, in order to have your say on the future direction of your foundation.

Looking forward to catching up with you at upcoming Foundation activities.

Regards  
Gavin



## HRH Prince Philip - The Duke of Edinburgh : 1921 - 2021



HRH Prince Philip has died and has left a world in mourning. Whether or not you are a royalist, I am sure that we can all agree that the royals have played a very large part in the lives of every Australian and Prince Philip was a truly remarkable man.

Barack Obama summed up the integrity of Prince Philip when he said "At the

Queen's side or trailing the customary two steps behind, Prince Philip showed the world what it meant to be a supportive husband to a powerful woman ... Through his extraordinary example, he proved that true partnership has room for both ambition and selflessness - all in service of something greater." ...



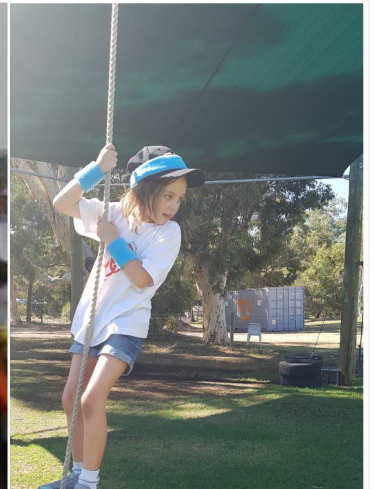
Farewell Prince Philip



## Haemolympics Community Camp



The HFWA annual Community Camp was held at the Swan Valley Adventure Centre and it lived up to all the hype. A lot of fun and games were had by all! From ages 1 - 70 years, there was something for everyone on this jam packed weekend

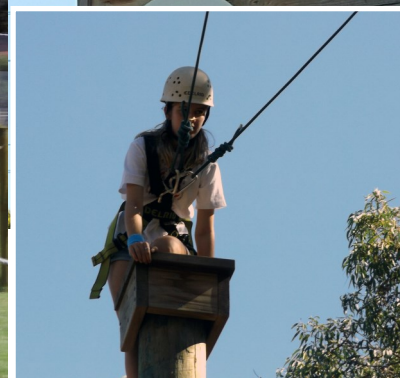
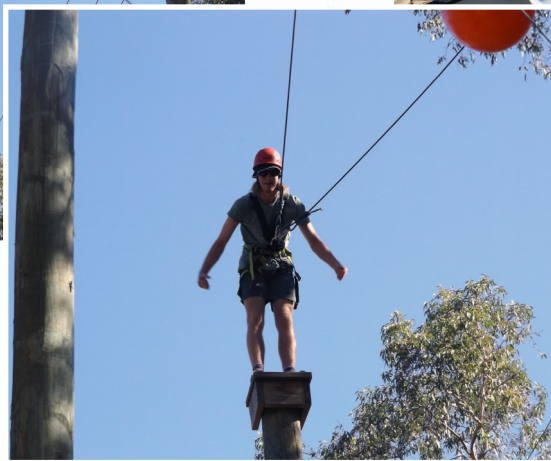




## Haemolympics Community Camp



SWAN VALLEY  
ADVENTURE CENTRE









## WORLD HAEMOPHILIA DAY

# ADAPTING TO CHANGE

Sustaining care  
in a new world



GET INVOLVED



## World Haemophilia Day 2021

Every year on 17 April World Hemophilia Day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Hemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel's birthday.

This year the theme is **Adapting to Change**. Living during a pandemic can pose many challenges, not only for our health, but also for our mental health and wellbeing. In 2021 World Hemophilia Day is a platform across the globe for exploring our community's resilience and how we will overcome this new challenge - as we have overcome other challenges in the past.

The following locations have confirmed that they will be supporting WHD by lighting up Perth **RED** on April 17

- ◆ Sky Ribbon
- ◆ Bell Tower
- ◆ Council House
- ◆ Trafalgar Bridge
- ◆ Matagarup Bridge
- ◆ Mount Street Bridge
- ◆ Northbridge Tunnel
- ◆ Curtin Uni Stadium



Photos of the above locations that have been 'Lit up Red' will be printed in the next issue of the Contact newsletter

### How will you commemorate the day?

- ⇒ Will you wear **RED** ?
- ⇒ Can you spread the word to your family and friends to join in the activities and virtual events that HFA will be running. Follow the link below to head to the HFA website

<https://www.haemophilia.org.au/get-involved/events/world-haemophilia-day-1>

## Health Updates

### AstraZeneca Vaccine

This isn't forever.  
It's just right now.

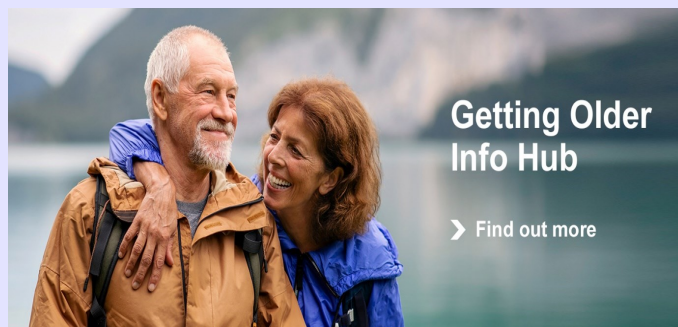
If you or any of your family members have any questions regarding the AstraZeneca Vaccine, we recommend that you get up to date accurate information from the Australian government Health Direct website.

See the link below for information regarding the reported case of thrombosis

<https://www.health.gov.au/news/atagi-statement-covid-19-vaccination-reported-case-of-thrombosis>



### What's new on the Getting Older Info Hub?



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

Check it out at

[www.haemophilia.org.au/getting-older](http://www.haemophilia.org.au/getting-older)

### WHAT'S NEW?

**HEALTH AND WELLBEING** section.  
Lots of great info on getting older and exercise and how to manage joint replacements and other surgery

**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](mailto:socallaghan@haemophilia.org.au)  
or phone 1800 807 173.

### GENE THERAPY

We had an enquiry from one of our members who had heard of a program on SBS regarding Gene Therapy in the UK. Link is below for your information.

BBC Two - Trust Me, I'm a Doctor, Series 8, Episode 2 - Could gene therapy herald a cure for haemophilia?

<https://www.bbc.co.uk/programmes/articles/bRxFbhJBwGt69Q1BTdQ8y8/could-gene-therapy-herald-a-cure-for-haemophilia>

For up to date information from HFA see

<https://www.haemophilia.org.au/about-bleeding-disorders/gene-therapy>







## 20<sup>TH</sup> AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS

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

We have decided to hold the conference virtually this year due to the uncertainty of the pandemic. We are very excited to go down this path. Bringing together the different parts of our community with health professionals and stakeholders has always been stimulating and rewarding.

This year we expect our virtual conference will attract more delegates and create innovative learning and discussion for everyone. We are confident that nothing will be missing, in fact it will be enhanced.

More information and registration details to follow shortly.

## Rare Disease Day - 28 February 2021

On 28 Feb we celebrated Rare Disease Day and the theme for 2021 was

**Rare is many. Rare is strong.  
Rare is proud.**

HFA has showcased a personal story by Belinda. Belinda is a young 20 something with **factor X (10) deficiency** – a very rare bleeding disorder, affecting 1 in a million people

Her interesting story highlights some of the challenges she and some of our younger generation face on a daily basis. Read Belinda's story at

<https://www.factoredin.org.au/stories/rare-and-embracing-independence>



## Women in Leadership



International Women's Day is held annually on 8 March. This year the global theme was **'Women in Leadership: Achieving an Equal Future in a COVID-19 World'**.

COVID-19 impacted women and girls in profound ways, amplifying the inequalities they face every day. It is fundamental that diverse women's voices and experiences are central to national and global recovery plans.

Did you know that the first International Women's Day gathering was held in 1911 and is gaining momentum each year to support all women everywhere.

Women still face significant cultural and socio-economic barriers and a key contributor to a more equal world is increasing women's access to leadership roles. See the full story and much more at

<https://iwda.org.au/take-action/international-womens-day/>



## ANZAC Day 25 April 2021

### ANZAC DAY 2021 100 Years of RAAF



Anzac Day is a solemn day of remembrance, gratitude and national pride.

You can show your respect and remember all our ANZAC men and women in all the usual ways this year i.e. the Dawn Service, ANZAC March etc. If you can't make an event you can still commemorate by joining your neighbours in the wonderful initiative of the driveway dawn service.

### Lest We Forget!



For a list of ANZAC Day events and to find a Service near you, [please click here.](#)

## School Holiday Activities

Perth is alive with activities for the school holidays and the upcoming long weekend.



If the Haemolympics camp didn't wear your kids out, then take a look at what's on offer in and around Perth at

[www.buggybuddies.com.au](http://www.buggybuddies.com.au)



## Ladies Peer Support Event

# HFWA High Tea Invitation

Please join Cheryl for a lovely High Tea  
on a Saturday afternoon with  
good food and great company



- Where:** Waterwall Restaurant at The Pagoda Resort & Spa  
112 Melville Parade, Como
- When:** Saturday 1 May 2021
- Time:** 2.00pm
- Cost** \$25.00 (this event is partially funded by HFWA)
- RSVP:** **ASAP** - no later than midday 29 April 2021  
to Jenny on 9420 7294 / [office@hfw.org](mailto:office@hfw.org)  
or Cheryl on 0402 033 652 / [vice\\_president@hfw.org](mailto:vice_president@hfw.org)

# Men's Peer Support Event

## Men's Breakfast Invitation

**Please come along and join Gavin at  
the first men's breakfast of 2021**

**Where:** Waterwall Restaurant - Buffet  
Pagoda Resort & Spa  
112 Melville Parade, Como

**When:** Sunday 2 May 2021

**Time:** 8.30am

**RSVP:** ASAP - **no later than midday  
29 April 2021**

Jenny on 9420 7294 / [office@hfwa.org](mailto:office@hfwa.org)  
or Gavin on 0415 978 031 /  
[gavfinkelstein@gmail.com](mailto:gavfinkelstein@gmail.com)

The Men's Breakfast is funded by HFWA  
and free to financial members



## Entertainment Books - Digital Membership

Support our fundraiser and SAVE BIG these school holidays.

Your membership is valid for 12 months from when you activate it and you can save at places like **AQWA, SUBWAY, McDONALD'S, SWAN VALLEY CUDDLY ANIMAL FARM, ROTTNEST FAST FERRIES, OUTBACK SPLASH, EVENT CINEMAS** plus loads more.

Heading down south for the Easter school holidays? No worries, the Entertainment Membership has heaps of offers in the South West as well - **ARAVINA ESTATE, WILLS DOMAIN, YALLINGUP MAZE**... the list goes on!



Save big these  
**School Holidays!**

Get your **MEMBERSHIP** and we receive 20% of the purchase!

 Entertainment

 Entertainment

*You only need to use it once or twice and you'll recoup what you spent on the membership. \$69.99 with 20% going back to our fundraising – It's a win win!*



Our new fundraiser Containers of Change is up and running and we are receiving funds from some of our wonderful families and members of the community.

Can you help your HFWA community by contributing to this worthwhile initiative. We are notified each time someone from our awesome community has donated their containers and we are thrilled that you have chosen HFWA as your chosen charity to receive your donation.



### Did you know?

Before Containers for Change, beverage containers made up **44% of all litter** found in parks, streets, waterways and bushland, even though they are made from easily recyclable materials

## Send us Your Pics



We want you to be involved and we would love to see some of your bleeding disorder event pics. World Hemophilia Day, Red Cake Day or any day that you proudly wear your red colours to promote haemophilia awareness.

What are you waiting for, click away!

Any photo published in our newsletter will only be published with the consent of all parties involved and with parent's consent if under 18 years of age.



**2021**

# WHAT'S ON?



**Saturday 1 May 2021 - 2.00pm**

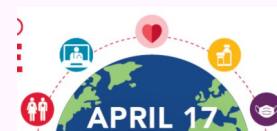
**Ladies High Tea - Waterwall Restaurant, Pagoda Como**

**Sunday 2 May 2021 - 8.30am**

**Men's Breakfast - Waterwall Restaurant, Pagoda Como**

**17 April 2021**

**World Hemophilia Day**



**8 - 9 October 2021**

**HFA 20th Australian Virtual Conference**

**10 - 16 October 2021**

**Bleeding Disorders Awareness Week**

## Save the Date

**15 May 2021 - HFWA Strategic Planning Day**

**2 September 2021 - HFWA AGM**

**16 October 2021**

**Bunnings Sausage Sizzle - Homebase, Wembley**

**5 December 2021**

**Adventure World - HFWA Christmas Party**

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



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

To order your bags and arrange collection  
email: [office@hfwa.org.au](mailto:office@hfwa.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 @ \$6.50 each

I would like to order \_\_\_\_\_ Red bags @ \$3.00 each

**Total Bag order \$** \_\_\_\_\_ (postage can be arranged at extra cost or they can be picked up from the HFWA office on request).

- ☐ 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

<https://checkout.square.site/merchant/06461WB19EDA8/checkout/R74ZARTGOWNV006YVONMBHMX>

- ☐ 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**

Name: .....

Address: .....

Telephone: ..... Email: .....

# HFWA NAIL POLISH GIFT PACKS

**Mothers Day is Sunday 9 May**

Three bottle gift packs available.

Looking for that personalised gift for mum? 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, White, Top Coat, Rose (N/A) Silver Gold and



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: .....

Telephone: ..... Email: .....

**LIMITED STOCK AVAILABLE!**