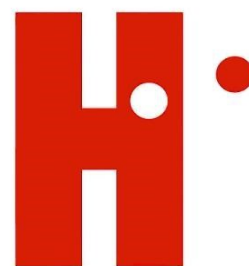


# Contact



**Newsletter of Haemophilia Foundation WA Inc.**

**February 2021**



**HAEMOPHILIA FOUNDATION WA INC.**

City West Lotteries House, 2 Delhi Street, West Perth WA 6005  
P: 08 9420 7294 E: [office@hfwa.org](mailto:office@hfwa.org) W: [www.hfwa.org](http://www.hfwa.org)

**HFWA is grateful to Fuji Xerox 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  
Melanie Gould

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)**

## Cover Picture

## Welcome to 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 8:00 am - 4:30 pm) Ph: 6456 0170 or 0466 318 286

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

Social Worker: **Helena Reynolds** (Mon -Thurs 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** (Mon -Thurs 8:00 am - 4:30 pm, adults and paediatrics, 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

Well the last few weeks show how changeable things can be in the current environment in which we live. Compared to the rest of the world, Perth has been experiencing the most relaxed experience during the current COVID-19 crisis.

It is a timely reminder of how vigilant we need to be even in Perth and the rest of WA. Unfortunately, we had to postpone the Ladies High Tea and the Men's Breakfast due to COVID-19 restrictions but we will advise you when they are to be rescheduled.

For those of you that have severe/moderate Haemophilia A or Inhibitors Hemlibra has been added to the list of treatment products available, please contact the staff at your Haemophilia Treatment Centre to discuss whether or not it is a viable option for your treating regimen.

For any information on the roll out of Hemlibra please go to the NBA website (link below):  
[www.https://www.blood.gov.au/national-supply-arrangements-hemlibra-emicizumab](http://www.https://www.blood.gov.au/national-supply-arrangements-hemlibra-emicizumab)

Or the HFA website (see below):  
[www.https://www.haemophilia.org.au/publications/news/update-on-new-treatment-options](http://www.https://www.haemophilia.org.au/publications/news/update-on-new-treatment-options)

The Community Camp is back on and will take place from Friday 19 to Sunday 21 March and it will be a fun filled and enjoyable weekend for all those who attend (please see pages 8 and 9 for details of a great weekend) .

We are currently in discussions with the Health Department in relation to the terms and conditions of our new contract with them. Thanks to all those who completed the survey it was of great value to us in our discussions with them.

Looking forward to seeing as many of you as possible at the community Camp in March.

Stay safe and well

Gavin Finkelstein  
President

## Health Awareness - Your Health Matters

**Haemophilia and related  
bleeding disorders**



Your health is important! We are living through some unprecedented times and you need to be proactive with your health and wellbeing.

Be aware of your health both mentally and physically!

If you have any concerns or questions about your treatment or treatment products, we recommend that you consult your General Practitioner or contact the Haemophilia Treatment Centre (HTC).



## Christmas Party at Outback Splash

The HFWA annual Christmas party was held at Outback Splash this year and our members and their families had a wonderful time. A very jovial Santa dropped in and handed out joy, merriment and presents to all the children.

Below are some pics of the happy faces (and a not so happy baby) who had a lot of fun on the day!





## Von Willebrand Disease - Susie's Journey

Susie's story below is compelling reading and is testament to how important the Haemophilia community is.



When my family was welcomed into the HFWA community 18 years ago after our diagnoses with VWD, I had no idea of the friendships and knowledge I'd gain. I have the opinion that learning is lifelong and adversity can be reframed as an

opportunity to learn. By being in the committee and putting my hand up to help out, I can share my perspective, learn and effect change. I have had the honour of participating in some truly wonderful and important work.

In the early years I felt most material published and conference sessions available was dedicated to Haemophilia and the experience of boys and men. There was one amazing book on VWD but as it was written by a US author some of the content was irrelevant and downright scary, thinking of their medical system. There were a few brochures but they just didn't seem to cover the reality of what we were experiencing as well as what I was hearing from others at camp and the peer events. Now however, we have a range of relevant publications recently launched by HFA that feature a diversity of experience and women's experiences of living with a bleeding disorder. Through attending conference I was able to share my story and contribute to some of this work. Conferences now have sessions about women and VWD - not just a single one either.

Attending the first international symposium on VWD in Prague was such an honour. My story was part of last year's Bleeding Disorder awareness week campaign. I helped plan and spoke at the recent WFH Global Summit on women and girls with inherited bleeding disorders.

Right now, what I'm most excited about is the creation of guidelines for the diagnosis and management of VWD. This is a first step towards benchmarking international best practice. It involved a bit of secrecy (for confidentiality and protecting against conflict of interest), late night telecons, wading through dense and very technical material but also travelling to the US for the first time in my life. I was impressed each time we convened - the panel members, the panel chairs and the methods team all actively listened to and worked to draw out the opinions and experiences of the patient representatives. The guidelines aren't perfect and show how much work there is still needed to improve VWD care. But they're a start. Next step is creating educational materials, for patients as well medical practitioners and policy makers.

A bit like a treasure trail, each thing I've helped with has opened up more possibilities. I want to be part of continuing to improve the lives of all people with bleeding disorders, in recognition of the years of effort put in by other people in the community. We would not be where we are now without the dedication and involvement of so many others. When I've been asked to do something new I try to focus on how this will help others rather than my own concern of not being good enough or not having anything worthwhile to contribute. HFWA is always looking for new ideas, people who have a little bit of time to spare or a willingness to have a go. If you think you might want to try something new or share some skills with us, please contact anyone in the management committee for a chat or Jenny at office – you never know where it might take you

Susie Couper

## Hemlibra Treatment - a Personal Story



After being asked by the Haemophilia Treatment Centre if I would like to transition over to the subcutaneous treatment Hemlibra product in the new year, I can honestly say I couldn't wait for 2020 to end.

A subcutaneous product (for me) is the next best thing to Gene Therapy. Gone are those cold 4am winter mornings, trying to hit a vein (and keep it going) to get your product in.

I've been having my needles for nearly 32 years now, self-infusing for nearly 22 and I can honestly say those times when you can't get a vein (especially if old faithful fails you) are some of the most stressful moments I've experienced with my condition.

Hemlibra is a tiny insulin-like injection, pretty much pain free and inserted into fatty tissues, preferably either sides of your belly under the belly button, in the front of either thighs or in the outer meaty bit of your shoulders. I myself just do my stomach.

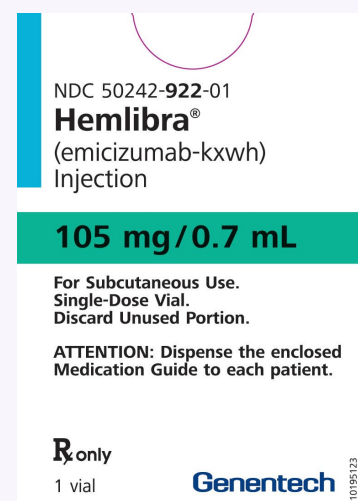
The needle is tiny and you barely feel it penetrate the skin. As the liquid is being injected into fatty tissues and the needle is so small it can be a bit tough the push the plunger and you may get some push back (like when your intravenous needle "came out" of your vein) but don't fret, it's normal and you take it at your own pace and what you're comfortable with.

My maintenance dose based on my weight isn't even a millilitre of liquid. It's simple to draw up, quick and easy to inject and I've been told after long term usage it may have an anti inflammatory effect for some lucky people.

Although I'm still only in the early stages I've spoken to people who have been on Hemlibra since the early trial days and they have nothing but great things to say about how much it's changed their lives.

If you would like to know more about Hemlibra or are interested in possibly getting into it just contact the HTC and I'm sure the lovely ladies in there will be more than happy to answer any of your questions.

Dale Spencer



## Bushfire Emergency Plans

### Do you have a plan?

Western Australia is at the height of its bushfire season and we are witnessing devastating loss in our community of homes, wildlife and bushland. We are grateful that no lives have been lost in the current crisis.



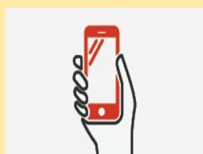
The present situation is dire for so many. If you don't have an emergency plan, we encourage visit the DFES website on the link below.

<https://www.dfes.wa.gov.au/bushfire/prepare/>

To those of you in our HFWA community who may have been affected by these latest fires, we want you to know that you are in our thoughts and we are hoping that everyone remains safe throughout the remainder of this season. The latest bushfires have been contained (the rain was a huge help to the very exhausted fire fighters), but there may be more. While there are arsonists in our midst there will always be a time for you to stay vigilant.

### DOWNLOAD THE APP

You can access your bushfire plan anytime - even without an internet connection.



To those of you who are on the front line, who put themselves in the face of danger in sometimes catastrophic and extreme conditions, THANK YOU! These very brave people may be saving your home while their own is lost to fire.

If these events happen to you, stay alert, be aware and above all else stay safe!



## WORLD HAEMOPHILIA DAY

World Haemophilia Day is held annually on the 17 April. This day is recognised worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders.

With increased awareness comes better diagnosis and care for the millions who remain without treatment.

Whether you are you a patient, family member or caregiver, a corporate partner, a volunteer, or a healthcare provider, we encourage you to help increase awareness of inherited bleeding disorders and help to make access to adequate care possible everywhere in the world.

We will be lighting up Perth **RED** so keep an eye on your inbox to find out what locations and landmarks will be lighting the way to awareness.



We would like to encourage you to make a small step in raising awareness. Will you wear **RED** to commemorate the day? Can you think of an event that you would like to run through your school? Every small step leads to greater education and education is the key to future improvements and accessible treatments for everyone.

We will keep you informed in the coming weeks of how we will be raising awareness and we hope that you are able to participate in any way. Large or small, your participation matters!



# WFH

WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

**HFWA is excited to invite  
you and your family  
to the  
**HFWA**  
**Haemolympics**  
**2021**  
**Family Camp****



**Friday 19 to Sunday 21 March 2021**  
**Swan Valley Adventure Centre, 58 Yule Avenue, Swan Valley**

The camp is open to people with bleeding disorders and their families and will provide an opportunity to meet new people and catch up with old friends. All meals and accommodation are provided and included in the camp costs.

Please complete the registration form overleaf and return to [office@hfw.org](mailto:office@hfw.org) or post to HFWA, City West Lotteries House, 2 Delhi Street, West Perth WA 6005 or online at <https://www.hfw.org/HFWA/media/Resources/2021-Camp-Registration-Form.pdf>

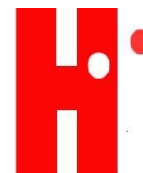
If you have any challenges in meeting these costs an application can be made for assistance by contacting Jenny Hough on 9420 7294 or [office@hfw.org](mailto:office@hfw.org). Travel assistance is also available to country campers.



SWAN VALLEY  
ADVENTURE CENTRE

HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA INC




**HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA INC**

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

**PERSONAL DETAILS**

|                |  |              |                 |
|----------------|--|--------------|-----------------|
| <b>Name</b>    |  |              |                 |
| <b>Address</b> |  |              | <b>Postcode</b> |
| <b>Email</b>   |  | <b>Phone</b> |                 |

**ATTENDEES**

|                        |                         |  |
|------------------------|-------------------------|--|
| <b>No. of Adults</b>   | <b>Names</b>            |  |
| <b>No. of Children</b> | <b>Names &amp; Ages</b> |  |

**MEDICAL INFORMATION**

|                             |  |
|-----------------------------|--|
| <b>Allergies</b>            |  |
| <b>Action required</b>      |  |
| <b>Medical conditions</b>   |  |
| <b>Action required</b>      |  |
| <b>Dietary requirements</b> |  |

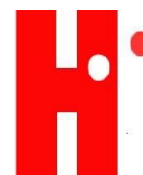
**PAYMENT INFORMATION**

|                              |                             |                      |              |
|------------------------------|-----------------------------|----------------------|--------------|
| <b>Camp Fees Members</b>     | Single \$50                 | Single under 18 \$40 | Family \$200 |
| <b>Camp Fees Non-Members</b> | Single \$80                 | Single under 18 \$40 | Family \$230 |
| <b>Extra Person</b>          | Each additional person \$40 |                      |              |

**See Over for Payment Details**

**HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA INC**

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

**PAYMENT DETAILS**
**Total Amount Payable**      \$ \_\_\_\_\_
**Payment can be made by any of the following methods**

- ☐ Cheque - send to HFWA, 2 Delhi Street, West Perth WA 6005
- ☐ Direct Deposit - National Australia Bank
- |             |                                    |
|-------------|------------------------------------|
| Account     | The Haemophilia Foundation WA Inc. |
| BSB         | 086 488                            |
| Account No. | 0352 33031                         |
| Reference   | Camp (your name)                   |
- ☐ Credit card payment - [Click here for secure checkout powered by Square](#)
- ☐ Or simply scan this QR code to go directly to HFWA 2021 Camp payment via Square.  
(QR Scanners can be downloaded from the Apps Store)



*If you have difficulty covering the cost of the camp, application can be made for assistance.  
Travel assistance is also available to country campers.  
Contact Jenny in the office on 9420 7294.*

| OFFICE USE<br>ONLY | RECEIVED | REC. NO. | CONFIRMED | ENTERED |
|--------------------|----------|----------|-----------|---------|
|                    |          |          |           |         |

City West Lotteries House, 2 Delhi Street, WEST PERTH 6005

Ph: 08 9420 7294 Web: [www.hfwa.org](http://www.hfwa.org) Email: [office@hfwa.org](mailto:office@hfwa.org)

ABN: 42 961 282 521

Donations over \$2 are Tax Deductible Member of Haemophilia Foundation Australia

## Containers for Change Fundraiser

Our new fundraiser Containers of Change is beginning to take shape and we are receiving funds from some of our wonderful families and members of the community. Please help your HFWA community by contributing to this worthwhile initiative and you are helping to save the environment at the same time. Article below from one of our very 'active' HFWA members

Big thanks to my gym Human Garage CrossFit in Forrestfield

### UNOFFICIAL

Hi Folks,

You may have seen in the previous newsletter that HFWA have set up an account for the "Containers for Change" initiative.

I have set up a bin at my gym and folks have been very kind in dropping their recycles in there. 😊

Most of our gym members live local so if they have heaps of cans and bottles, I have also been offering a pickup service.

The "Drop Off" centres are super easy to use and the money is transferred straight away.

I have totalled \$50 already!!!

If you have a group that you think might like to get on board, just do what I did and you will be surprised how enthusiastic people are to help out.

Just need to quote the ID code C10338968

Sharri

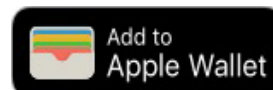


Scheme ID

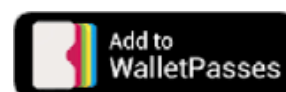
**C10338968**

### Save your scheme ID to your mobile

iPhone users



Android users



If you don't have WalletPasses installed, you will need to download it from the Apps store



## Peer Support Breakfast and Ladies High Tea

Due to the unfortunate timing and the uncertainty which we were facing with the COVID-19 lockdown in Perth, the HFWA Management Committee felt compelled to postpone our breakfast and High Tea events that were planned for 7 February. Your health is our main concern! We wish to extend our thanks to those of you who had RSVP'd and want to reassure that we will be holding the next Men's and Ladies events on **Sunday 2 May 2021**. Please keep an eye on your inbox to find out more details in the coming weeks.

### Men's Breakfast

**Where:** Waterwall Restaurant  
Pagoda Resort & Spa

**When:** Sunday 7 February

**Time:** 8.30am

**POSTPONED**

**Men's Breakfast and Ladies High Tea postponed due to lockdown uncertainty and to keep our attendees safe and well!**

7 February  
Time: 2.00pm

This Ladies Breakfast is partially funded by HFWA to financial members

## Supporting your HFWA Foundation Do You have a Story? Let's Hear From You!

We are all a community and we want to hear from you.

If you have a story that is relevant to the bleeding disorder community and you would like to share - please call or email the HFWA office so that we can publish it in our Contact newsletter and share it with your wider community.

Please don't hesitate! You are important and your experiences or the experiences of a family member might change someone else's life, or answer some of those niggling questions that someone else in your community may hesitate to ask.

All stories can remain anonymous, but your impact on the bleeding disorder's community may be priceless. Go ahead, what's stopping you!

A big **THANK YOU** to Susie and Dale whose stories are published in this edition of Contact. Susie and Dale's stories are compelling reading and are a testament to how important the Haemophilia community is.

WHAT'S  
YOUR  
STORY!

## How's Family Christmas Lights Fundraiser



From all at HFWA we would like to express a huge thank you to the Hows family for generously choosing to support our bleeding community and fundraise for us this year at their annual Christmas lights display. There is a huge amount of time and effort put into establishing the display and also to run the operation. Their efforts and the generosity of the community raised an amazing \$562.00.

**Thank You Hows Family!!**

## Supporting your HFWA Foundation Let's Hear From You!



If you have a fundraising idea that may benefit your Haemophilia Foundation WA community, we would love to hear from you. All ideas and suggestions are very welcome because **you matter**. To grow our community, we need your input. We are here to help if you would like some assistance in setting your idea in motion.

We are continually striving to find new fundraising ventures to improve the services we can provide to you as very valued members and your families.

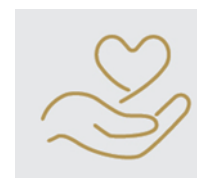
We are also very grateful for the continued support and dedication of our volunteers and their families who 'show up' without hesitation. Along with our dedicated Management Committee, our members who donate their very precious time are at the backbone of our community and help to keep our events going.

All of our Management Committee are volunteers. It takes time out of their already busy lives, it takes patience to deal with some of the issues that sometimes arise and it takes that dedication that is only matched by their ongoing passion to help deliver you a better community.

## Entertainment Books - Digital Membership

You can help support Haemophilia Foundation WA by purchasing the digital Entertainment Books. They are still available and can be purchased via the following link.

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



20% of your Membership purchase goes directly to HFWA so while you are enjoying the benefits of some great products and services at reduced costs, you will also be helping your HFWA community.



New goods and services are updated continually so there is never a shortage of venues or events to choose from.

2021

# WHAT'S ON?



**Sunday 7 Feb 2021 - 8.30am**  
Men's Breakfast - Waterwall, La Como  
**Events Postponed**  
**Sunday 7 Feb 2021 - 2.00pm**  
Ladies High Tea - The Lobby Lounge at The Crown, Burswood

**Friday 19 March - Sunday 21 March 2021**  
Community Camp - Swan Valley Adventure Centre

**17 April 2021**  
World Haemophilia Day

**10 - 16 October 2021**  
Bleeding Disorders Awareness Week

## Save the Date

**Sunday 2 May 2021**  
Ladies and Men's Breakfasts - Venues and Times TBA

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

**2 September 2021** - HFWA AGM

**16 October 2021**  
Bunnings Sausage Sizzle - Homebase, Wembley

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@hfw.org.au](mailto:office@hfw.org.au) or  
call: 9420 7294.



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



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



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:

















Expiry Date:





Name on Card:

# HFWA NAIL POLISH GIFT PACKS

**Remember Valentine's Day is everyday!**

Three bottle gift packs available.

Looking for that personalised gift with a real message for family and friends? 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 Gold and Silver (N/A)



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)

Please 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!**