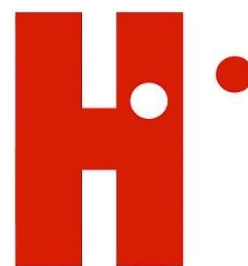


# Contact



**Newsletter of Haemophilia Foundation WA Inc.**

**November 2021**



## **Probus Club Murdoch taking part in Bleeding Disorders Awareness Week**

### **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 Film Australia for their ongoing support in printing  
the Contact Newsletter**

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## Your 2021/2022 Committee

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

Shane Meotti  
Susie Couper  
Dale Spencer  
Michelle Dinsdale  
Evyn Webster

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

**Bleeding Disorders Awareness Week**  
featuring Probus Club Murdoch - see President's Report and page 7

## 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 Folks

This is our last Contact Newsletter for 2021 with another unique year greatly impacted by COVID. In many ways we have learnt a lot from it.

The 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders was held virtually for the first time and it was a resounding success, with a number of international speakers and locals participating in this unique conference. Sessions are now available online to view what you may have missed during the conference. They will be available for virtual conference attendees for another 6 months.

Bleeding Disorders Awareness Week was in the week following the National Conference. During BDAW, we held our annual Bunnings Sausage Sizzle which went well, with lots of questions asked by people whilst waiting for their food to be meticulously prepared by our volunteers.

I did a presentation at a local Probus Club (see page 6) where past President of HFWA Syd Tippet and his wife Jan are involved. They were all dressed in red for the day which was great to see (see cover photo).

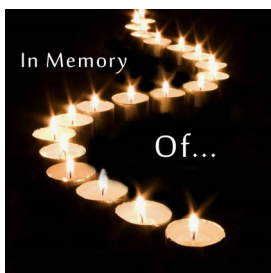
Our Annual Christmas Function is at Adventure World on 5 December (see page 10 for details). We hope to see as many of you there as possible.

The Committee is in the midst of a Strategic Plan review to map an effective future road map for HFWA (see page 8).

On behalf of the HFWA committee I wish everyone a happy Christmas and a safe and healthy 2022.

Gavin

## VALE Russell Woolf



A long time supporter and friend of Haemophilia Foundation Australia Russell Woolf passed away recently. Russell's passing has been deeply felt by the people of Perth who knew him through his extensive media career.

HFWA extends its' sincere condolences to his family, friends and the Jewish community.

## HFWA Office Holiday Closure

HFWA will be closed for the Christmas period from Thursday 23 December 2021 and will reopen from Monday 10 January 2022.



## **A Personal Story - Gavin Finkelstein**

*Reprinted with permission from National Haemophilia, No 215, September 2021.*

### **Finally cured of hep C**

#### **Gavin's story**



*Gavin Finkelstein is President of Haemophilia Foundation Australia (HFA) and Haemophilia Foundation Western Australia (HFWA). He has severe haemophilia A. He talked to HFA about living with hepatitis C, treatment and being cured. Our thanks to Gavin for sharing his personal story.*

For Gavin, growing up with severe haemophilia had meant living with joint bleeds. His generation became adults before the arrival of prophylaxis treatment to prevent bleeds and Gavin had relied on plasma-derived clotting factor concentrates to manage his bleeding episodes whenever they occurred. The regular bleeds resulted in arthritis and other joint and muscle damage.

*'As they say, pain was my constant companion, but not my friend.'*

What he didn't realise at the time was that another unfriendly traveller had also hitched a ride on his treatment products – hepatitis C virus, which had infected blood products like clotting factor concentrates through blood donations. By 1993 Australia had introduced new safety measures to prevent transmission of hepatitis C in blood products, but in the years before then Gavin had already been exposed to hepatitis C through his treatments many times.

Some years earlier Gavin had been told he had non-A non-B hepatitis – the name for hepatitis C before there was a test - but little was known about it at that stage. When his diagnosis with hepatitis C was confirmed in 1993, it had a very different impact on him.

*'At first I freaked out,' he said. 'After living through the HIV epidemic, I thought I was going to die. I was very worried about transmission and passing it on to others. I broke off my relationship and was fearful about going into other relationships. It had a very negative effect on my motivation and my career.'*

### **EARLY TREATMENTS**

*Early hepatitis C treatment with interferon injections and ribavirin tablets was prolonged and arduous, with difficult side-effects.*

## A Personal Story - Gavin Finkelstein (cont'd)

### TREATMENT AND CURE

*'I had 72 weeks of treatment in 2001-2, which was horrific. I was working the whole time, but it turned my mind to mush. I was forgetful, I was grumpy, I had no energy. It affected my home life as well as my work. Then I relapsed 6 weeks after the treatment finished, which was pretty demoralising.'*

With the ongoing impact of hepatitis C symptoms – fatigue, brain fog, lack of energy and motivation – and his increasing arthritis and joint problems with haemophilia, Gavin took early retirement from his job in the public service but continued his volunteer roles with HFWA and HFA.

In 2009 he tried the pegylated interferon and ribavirin treatment again, but his treatment was stopped after 6 weeks when tests showed it wasn't working.

In 2016 the new direct acting antiviral (DAA) treatments for hepatitis C became available in Australia. They were described as 'revolutionary' – and in Gavin's opinion, lived up to their promise.

*'I had one of the new treatments, Harvoni, and it was a doddle. One tablet a day for 12 weeks and minimal side-effects. And I was cured – it was fantastic. It was the best thing I ever did. Now I feel fine and my liver test results are good too.'*

Checking liver test results to make sure his liver had recovered was an important step. This testing took place as a standard requirement when Gavin joined a clinical trial for a new haemophilia treatment, but he encouraged others to ask about testing if they didn't know what their liver test results were after being cured.

'Don't wait' was the message he had for others considering treatment for hepatitis C.

*'Don't even think about it. Go for it – get it done. These new treatments have such positive results and there is hardly any impact on your life to undergo the course of treatment. There are several different treatments, so your doctor will be able to find one that suits your individual health and lifestyle.'*

*'If you are worried about having hep C treatment, ask your haemophilia team or your hepatitis clinic to put you in touch with someone who has had the new therapies so they can have a chat with you about what it's like. These days you don't need to think about the implications for your work or home life because it's so easy to take and there are hardly any side-effects. And when you are cured it puts you in good stead to deal with the rest of your life with haemophilia.'*



## Bleeding Disorders Awareness Week

### BDAW 10 - 16 October 2021

From cover page - The Probus Club of Murdoch

Gavin Finkelstein was pleased to represent HFWA and the bleeding disorder community at a presentation to The Probus Club of Murdoch during Bleeding Disorders Awareness Week. He was warmly welcomed by all of the lovely members and as shown in the cover photo on the front page, their members dressed in 'something red' to mark BDAW. Don't they look fabulous!



Thank you to Probus Club for your hospitality and being an integral part of BDAW in raising awareness!

## Christmas for the Whole Family



### Great Christmas Ideas Perth has to Offer in 2021

From Christmas markets, to Christmas carols, where to have Christmas lunch, gift ideas and even Santa photos in [Perth](#). This is a fabulous website that will have you covered for anything that you can think of.

Christmas markets in Perth are a great way get out and enjoy the gorgeous [Perth weather](#) and the magic of the season. Spend time with friends, hunt for gifts, and see what local vendors have been working on all year. Perth has you covered with day and night Christmas markets and they are all family friendly.

<https://christmasinaustralia.com.au/christmas-markets-perth/>

### Christmas Carols in Perth

It's wonderful to grab the family with a picnic blanket and head out to sing along to some Christmas Carols. Follow the link to find out where all the best Christmas carols are in Perth

<https://christmasinaustralia.com.au/christmas-carols-perth/>

### Christmas Festival In Stadium Park

[Christmas Festival In Stadium Park](#) runs across the first three Sundays in December, head on down to Stadium Park for free [Christmas movies](#), a licensed area to have a drink and enjoy the Stadium's Christmas lights, and markets galore – what better way to sleigh this festive season? Have a feast in food truck heaven, enjoy live music as you watch the sunset over the city skyline, keep the kids amused with roving entertainers, and you might even get the chance to grab an 'elfie' with a very special man in red!

### Theatre Tickets

Another idea for Christmas and everyday. Why not purchase theatre tickets for your loved ones. Visit [The Regal Theatre](#) or [Crown Theatre](#) for some wonderful entertainment coming to Perth. They will never disappoint with their wide range of comedy, musicals, concerts, plays and of course there's always something special for the kids coming along.

Check out this 10% discount deal available now for Little Shop of Horrors at the [The Regal Theatre](#) playing from 24 - 27 November 2021.



10% OFF WITH CODE  
**EN6108**  
★TICKETEK Book Now

## Your Health Matters

### Mental Health Awareness

Whether we have a very happy and content family life, as we approach Christmas there be more anxiety created around this festive period.

If you are feeling overwhelmed and don't know where to turn to or who to turn to, please reach out to someone. you are never alone and there are online chatrooms and orphans Christmases all over Perth. See some ideas below

#### Host an Orphan Christmas

Plan an "orphan Christmas" for those who have no one to spend the holiday with, or join a group of people in similar circumstances. If you feel anxious about reaching out, consider that other people who are alone on Christmas may feel isolated, lonely, and nervous to call on you, too.

#### Celebrate Online from a Distance

Do you have online friends? Do you have long-distance relatives? Host an online Christmas by setting up a Skype or Zoom chatroom or create a Facebook group. People can drop in and out as they please, and you don't have to cook, clean, or even get off the sofa.

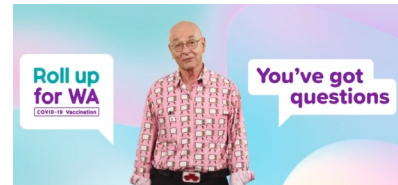
As an added bonus, you'll have a chance to practice your social skills as you welcome new people to the group and catch up with old friends. You'll also be keeping your vulnerable loved ones safe as you socialize virtually.

Remember, if you need support, please reach out. A few links that may be of assistance below

<https://wa.lifeline.org.au>  
<https://connectgroups.org.au/directory/categories/mental-health>  
<https://www.beyondblue.org.au>  
<https://www.actbelongcommit.org.au>  
<https://helpingminds.org.au/christmas/>



### COVID-19 - You've Got Questions Dr Karl has answers



While it's normal for people to have questions about COVID-19 vaccines, it's important we have access to accurate and factual information from trusted medical experts.

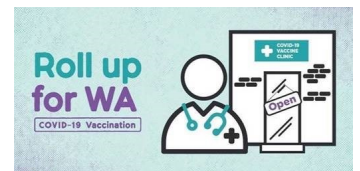
You may be familiar with Dr Karl, a knowledgeable and trusted voice of the Australian medical community, well known for his science hour on the ABC's triple j radio station.

Dr Karl and the WA Government have teamed up to produce a series of educational videos, which answer common questions and dispel myths about COVID-19 vaccines. Everything from dispelling myths on pregnancy and fertility to questions on long term data and possible side effects is answered in the series which launched last week.

The 'You've Got Questions' series is now available [here](#).

### Booster vaccines coming to state-run clinics

Western Australians will be among the first in the country to 'roll up' for a COVID-19 booster vaccine.



From 1 November, fully vaccinated people aged 18 and over, who received their second dose at least six months ago, are able to receive a [booster vaccine from a state-run clinic](#) with no appointment.

Go to <https://www.wa.gov.au/government/covid-19-coronavirus> for more information

## **HFWA Updates**

### **Strategic Planning Day 2 October 2021**

Your Management Committee has been actively involved in Strategic Planning to work out our best way forward in navigating how we can be of more help and assistance to all of our valuable members and their families.

Through our membership with Volunteering WA we sourced the help of two volunteers Paul Leighton and Ashley Cooper from BHP. On 2 October 2021 we held 'Phase 1' with Paul and Ashley. They were outstanding facilitators and we are looking forward to hearing their ideas and suggestions of what we should achieve in Phase 2 and the outcomes we could expect.

Watch this space!

If any members of our community would be interested in helping us pave the way forward please get in touch. We would value any feedback



### **Annual General Meeting 23 September 2021**

Our AGM was held in a different venue this year and it was great to see some of our members come along. Evyn Webster joined our new Management Committee (again). Evyn has been on the Management Committee in the past and we are very grateful to have him back on board. Welcome Evyn!

Very interesting discussions followed the AGM. One of the lively chats was about some of the obstacles associated with haemophilia and other bleeding disorders of school age children.

If you've ever wondered if it's worthwhile coming along to Peer Support activities and other HFWA events, I hear time and again from our community members how valuable the events are. Shared experiences and knowledge with others in similar situations can prepare or help in so many ways through everyone's own journey.

### **Introducing Evyn Webster**

Hello fellow travellers

I'm a widower, father and grandfather and my family was involved in the very early days of starting a haemophilia foundation in the late '60s. Since that time I've been involved with the current HFWA on and off over a number of years and have recently joined the committee again.

When I'm not managing severe haemophilia A, I'm a social worker with a long history working in medical, defence, education, child development and family settings and for the past 20 years I have focused extensively on parenting and father hood.

Why is this of any interest to you, possibly because I've lived through those days of little or non-existent treatment and worked to be a good husband and involved father to my two sons while managing the rollercoaster journey of a bleeding disorder.

I see the extraordinary differences now with our access to excellent products that are funded and provided to us free of charge. However, if we don't continue to be actively engaged in managing our own wellness then those things that many people take for granted and are very expensive to sustain may well slip from our grasp. I have lived through the early days, 'have several tee shirts to show it' and don't want to return. We live in a new world which means creating opportunities in new ways. I thought perhaps that my 40 years of listening to thousands of human beings wrestling with the different elements of their life might be useful in helping our community to be the best they can be.

I hope to see you on the highway.  
Best wishes, Evyn



## International Volunteer Day



### Bunnings Sausage Sizzle

The HFWA Bunnings Sausage Sizzle was held on 16 October 2021 and once again it was a great success. We cooked approx 500 sausages and raised some much needed funds for youth activities.

Thanks to all of our wonderful volunteers who helped out on the day - without whose help we wouldn't have been able to have such a fantastic outcome.

We are also very grateful for all the support of our members who came along to support us on the day and buy a snag or two. Thanks also goes to our wonderful supporters who gave donations and their valuable time.

We all had a lot of fun too!



### International Volunteer Day 5 December 2021

There are so many different communities that are reliant on volunteers. From the disability sector to animal rescue and even the major hospitals. Without volunteers so many worthwhile causes would not be able to operate or run effectively, including HFWA.

One of our HFWA volunteers Beryl Kerr has been an integral part of the office administration for several years and has been a huge help to myself and to my predecessors.

### Thank you Beryl!

Did you know that all of your HFWA Management Committee are volunteers? The time and effort they are all willing to put in time and time again is outstanding and the capacity and level of commitment they display at all times is beyond reproach to our members and the entire bleeding disorder community.

The HFWA community is very fortunate to have them working tirelessly for the foundation



## HFWA Christmas Party Invitation



### You're invited to our HFWA Christmas Party

Where: [Adventure World](#)  
351 Progress Drive, Bibra Lakes  
When: Sunday 5 December - 10.30am  
RSVP's: ASAP - No later than 18 November 2021

Please bring along your picnic lunch, blankets or chairs and food can also be purchased at the kiosk (no BBQ's are available)

Soft drinks and water will be provided and Santa will appear between 12.00pm - 1.00pm

HFWA will supply presents for immediate family members aged 12 and under, to the value of \$10-\$15 (see form next page, for return to HFWA for Santa) or simply email me with the info at [office@hfwa.org](mailto:office@hfwa.org)

If other family members who come along and wish to provide a gift for their children, please bring it wrapped and labelled



See next page for attendance form and preferred gift.





# HFWA Christmas Party Invitation



## Attendance and gift form



I/We will be attending the Community Christmas Party at Adventure World

Names of attendees:	Phone:	Email:
Number of people attending:		

I give permission for photographs of my family taken at the community Christmas party to be published in the HFWA newsletter. Yes/No (please circle).

[illegible]

## Survey - Telethon Kids Institute Survey

# How can health care services best support the needs of families of children with chronic conditions?

We want to hear from parents of children (1-18 yrs old) who have special health care needs, chronic health conditions and/or disabilities. These children may see many specialists and services, both in hospital and in the community.

This research study involves completing an anonymous online survey. It should only take about 20 minutes to complete.

Your views and experiences will help us understand how the health care system can meet your needs and provide the best care for your child.

Approval to conduct this research has been provided by the University of Western Australia, in accordance with its ethics review and approval procedures.



**If you would like to find out more, please contact:**

**Dr Rachel Skoss:**

**E |** [Rachel.Skoss@telethonkids.org.au](mailto:Rachel.Skoss@telethonkids.org.au)

**OR**

**Associate Professor Jenny Downs:**

**E |** [Jenny.Downs@telethonkids.org.au](mailto:Jenny.Downs@telethonkids.org.au)

**To take part in this survey, scan the QR code below or visit:**

**<https://redcap.link/ww2kli5e>**





2021

# WHAT'S ON?



**Strategic Planning Day - Phase 2 - TBA**



**5 December 2021**

**Adventure World**

**HFWA Community Christmas Party**

**23 December 2021 - 10 January 2022**

**HFWA Christmas Closure**

## Save the Date

**Men's Peer Support Breakfast - TBA**

**Women's Peer Support Breakfast - TBA**

**River Cruise - TBA**

**17 April 2022**

**World Haemophilia Day**

## Fundraising

### Entertainment

Purchase your Membership from Haemophilia Foundation  
Western Australia Inc.  
TODAY and support Youth Group Activities!

### Digital Membership

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

One of the best things about the Entertainment Membership, apart from supporting Haemophilia Foundation WA, is that you will receive a **BONUS \$40 or \$20 WISH eGift Card** when you purchase your Membership! Wish eGift cards can be used and Woolworths, Dan Murphy's, Big W, BWS and Cellarmasters!

This is a **limited time offer, so order yours today!**  
Thanks again for your continued support!  
To orders yours today, go to

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

### Get back out and about and SAVE!

Support us, buy an Entertainment Membership today & get a **BONUS \$40 or \$20 eGift Card!**



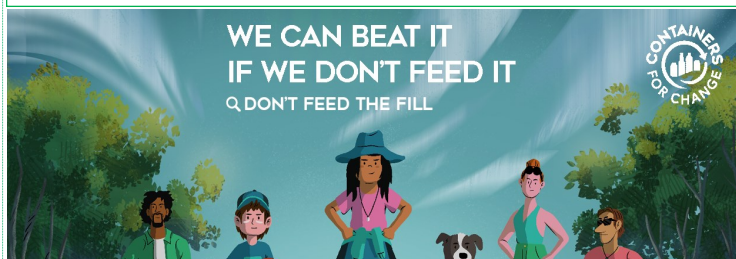
AND go into the draw to **WIN a year's worth of groceries valued at \$10,000!**

### The savvy way to give!

Buy today and **20% of the purchase** goes directly to our fundraising cause.

### The savvy way to save!

Buy today and start saving with your new Membership



When you return your containers to Containers for Change, you're not just keeping them out of landfill and saving the planet - you're also having a direct, visible impact on your local community. And you're helping out your Haemophilia Foundation at the same time when you use the Scheme ID above to donate. A big thank you to our members of the community that have donated.

Scheme ID  
**C10338968**

### One whole year of change!

That's right! On the 1st October Containers for Change celebrated 365 days of being part of Western Australian life! And in their first year they've saved a massive **765 MILLION containers from landfill**.

**There's been a lot of change in just one year, and it's been made possible because of YOU, our West Aussie container savers!**

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



**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](mailto: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 simply scan the QR code above or go straight to the link [Square checkout Shopping Bags](#)

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 Christmas? 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 simply scan the QR code above or go straight to the Square checkout link below to purchase your [Nail Polish](#)



The  
HFWA Management Committee  
would like to wish all of our  
members and supporters  
a very  
Merry Christmas  
and a safe and  
Happy New Year

