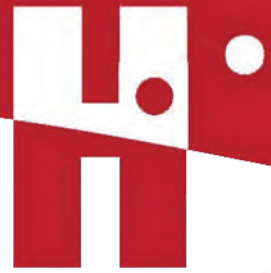


# CONTACT

Newsletter of Haemophilia Foundation WA Inc.

October 2023



... at the HFWA Sausage Sizzle on Saturday 7 October, at Bunnings Subiaco. See page 5 for more details

Stock images sourced from pixabay.com unless otherwise noted . Photos published with permission of individuals. All articles printed with permission of authors.

#### HAEMOPHILIA FOUNDATION WA INC.

City West Lotteries House, 2 Delhi Street, West Perth  
WA 6005

P: 08 9420 7294 E: [office@hfw.org](mailto:office@hfw.org) W: [www.hfw.org](http://www.hfw.org)





## CONTENTS

Contents and Contacts	Page 1
President Report, 21st Conference Report	Page 2
AGM Report, Aged Care services	Page 3
What is Coming Up?	Page 4
Sausage Sizzle Reminder	Page 5
PROBE study information	Page 6
21st Conference report - Vice President	Page 7-8
COAG Clinic dates PCH	Page 8
21st Conference report - Darren Tull	Page 9
21st Conference report - Susie Couper	Page 10-12
HFWA Fundraising	Page 13
Peer Breakfast reports	Page 14
Christmas Party Notice	Page 15

Hard Copy printed by Kwik Kopy Perth

## YOUR COMMITTEE 2022/2023

Gavin Finkelstein (President)	0415 978 031
Cheryl Ellis (Vice President)	0402 033 652
Robert Butler (Treasurer)	9381 3386
Michelle Dinsdale (Secretary)	0407 197 815
Paul Keogh	
Susie Couper	
Evyn Webster	

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

Office Coordinator Ann-Maree Foran

HFWA Office 2 Delhi Street, West Perth

Phone

9420 7294

Email

[office@hfwa.org](mailto:office@hfwa.org)

## 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**

Social Worker: **Sarah Franz** (Three days per week, contact for appointment) Ph: 3456 0413



## 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  
102118 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



## President's Report

## 21st Australian Conference: Sharri Brodie

Hi All

A group of members from HFWA recently attended the '21st Australian conference on Haemophilia, VWD and bleeding disorders' in Melbourne, and it was a great experience as usual. It was most enjoyable to meet face to face after so many years of virtual meetings due to Covid.

There was a wide range of topics covered from gene therapy to a keeping a healthy and realistic perspective on managing a bleeding disorder.

Most notable for me was that gene therapy has made significant advances but will not be available to patients for a number of years due to cost, eligibility due to viral antibodies and strict initial compliance issues. There are a number of new and innovative treatment products in development that will be of great benefit to all patients so we need to ensure that we gain access to these products.

An additional benefit was catching up with people face to face and many conversations continued well into the night over a glass, these conversations are of great value seeing how other states engage and provide services to their communities

Please do what you can to support our Bunnings Sausage Sizzle Bunnings Home Base on Saturday 7th October.

Hope to see as many of you as possible at our Christmas Function at Adventure World on 25 November or at any other activity held by HFWA.

Regards,  
Gavin

I have attended conferences before but not for 12 years. In that time there has been incredible break throughs in treatment and education for all people in our bleeding disorders community.

Gene therapy is certainly the future. For haemophilia B it seems like the doctors and scientist have got that pretty close to being all sorted but still there is still a way to go for haemophilia A. Rest assured, very smart people are working on it every day.

I attended a session on women with bleeding disorders which had several speakers. One was a very dedicated female gynaecologist who shared her experience with patients and preferred treatment for menorrhagia. An interesting parallel to a murder scene was used as perspective. I knew exactly what she meant.

We also heard from a female haematologist. I enjoyed both of these speakers noted their commitment to diagnosing bleeding disorders in women and managing their care. This session we also heard from 2 mothers. A young mum with 2 small children with haemophilia A and our own HFWA legend and mum Cheryl Ellis. Good one Cheryl.

As much as I respect the medical teams and am grateful for their commitment to the bleeding disorders community, its the personal stories I engage with the most.

Another session I attended was about Von Willebrand's. After my son's diagnosis of Haemophilia A, I was also diagnosed with Von Willebrand's type 1 as well as mild haemophilia.

*Sharri Brodie*





## Questions about Aged care services ?

Navigating the different Aged Care services can be confusing.

In the new HFA Getting Older Hub section on **AGED CARE SERVICES AND HOMES**, we walk through types of services and care, special issues for people with bleeding disorders and link you to more information.

Find out more by clicking [here](#) or go to [www.hfa.org.au](http://www.hfa.org.au) and scroll to the getting older hub.



(Below) Attendees at 2023 AGM - Lotteries House



## HFWA AGM 2022/2023:

The HFWA AGM was held on Wednesday 20 September at City West Lotteries House. We had 18 members attend and thank them for their attendance. It was enjoyable to catch up with previous committee members and members of our bleeding disorders community.

We reiterated the need to have an organisation that is able to advocate and represent the needs of the bleeding disorder community in the government and NGO sectors in WA. The need for ongoing funding of the HFWA and improved funding of services to the hospital HTC's (Haemophilia Treatment Centres) is critical. There is a significant disparity between the services provided at The Perth Children's Hospital and those available at Fiona Stanley. This needs to be rectified.

We also need to review the way in which we engage with our community, so any input will be most appreciated.

As per previous years, nominations for the HFWA Management Committee were accepted at the AGM. We are always looking for new committee members to provide fresh insight and direction for your Foundation. Please contact me, Cheryl or Susie if you would like to know more about the how the committee works and what we do.

Once again I thank those who attended, and hopefully we will see increasing numbers and new faces at HFWA activities and at our next AGM.

Gavin Finkelstein,  
President



## WHAT IS COMING UP ?

### **Bleeding Disorders Awareness month 1 – 31 October**

Is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders around Australia.

Spanning the entire duration of October, you can participate in Bleeding Disorders Awareness Month through events, special activities, attending webinars and sharing your story.

### **Bunnings Sausage Sizzle Sunday 7 October**

We look towards our members to volunteer and for donations of drinks.

[Click here](#) for more details

### **Annual Christmas Party Saturday 25 November**

At Adventure World

Save the date!!!! And keep an eye out for your invitation hitting inboxes soon.

Special guests expected.... I wonder who?

### **PROBE Australia Study 2023**

You are invited to complete the questionnaire if you are **an adult (18 years+) who lives in Australia**

Please see the information page in this edition or click on the logo below.





# HFWA

## Bleeding Disorders Awareness Month Annual Bunnings sausage sizzle



Each year we hold a sausage sizzle to raise funds for the HFWA community and to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders around Australia.

**October 7 2023, 8.00 to 4.30 p.m.**

**Bunnings Homebase, Salvado Road Wembley**

Come along and support us by buying a sizzle, a drink or let us know if you can volunteer your time or donate some drinks

[office@hfwa.org](mailto:office@hfwa.org)



## PROBE Australia Study

The 2023 round of the PROBE Australia Study has now commenced!

### WHAT IS PROBE?

What is the impact of haemophilia on Australians? What has changed since new treatments became available? What about people with mild haemophilia and women?

HFA has joined with the international **PROBE (Patient Reported Outcomes Burdens and Experiences)** study team ([www.probestudy.org](http://www.probestudy.org)) in a multi-national and well-respected research study to provide strong and credible data about this for our advocacy. The study compares the answers of people with haemophilia and who carry the gene to other people in their community who do not have a bleeding disorder.

**You may have done the PROBE survey in 2019. This is a new round of the survey.**

The 2023 round will compare results now to 2019, which was before new treatments were widely available in Australia.

### HOW CAN YOU HELP?

You are invited to complete the questionnaire if you are **an adult (18 years+) who lives in Australia** and:

- **have haemophilia or carry the gene**

OR

- **do NOT have a bleeding disorder.**

### HOW TO DO THE SURVEY

The questionnaire is available:

- **Web version** at [myprobe.org](http://myprobe.org)
- Or download the **myPROBE app** from Apple Store or Google Play (Android)
- Or ask **your local Foundation** or **HFA** for a **print survey pack**

Choose **Country-Australia** and **Language-English** and **CONTINUE**. The web and app surveys automatically save answers as you go so you can come back later.

### WHAT HAPPENS TO YOUR DATA?

The survey is voluntary. All responses are anonymous and confidential. They are combined for statistical data and will not identify individuals. You may have seen the 2019 data in the HFA Getting Older report.

### MORE INFORMATION

For more information about the **PROBE Australia study**, visit [www.haemophilia.org.au/research](http://www.haemophilia.org.au/research)

Or contact Suzanne at HFA: E: [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au) T: 1800 807 173





I was fortunate enough to attend the 21<sup>st</sup> Australian Conference on haemophilia, VWD & rare bleeding disorders at the Pullman on the Park, Melbourne, 24-26 August 2023.

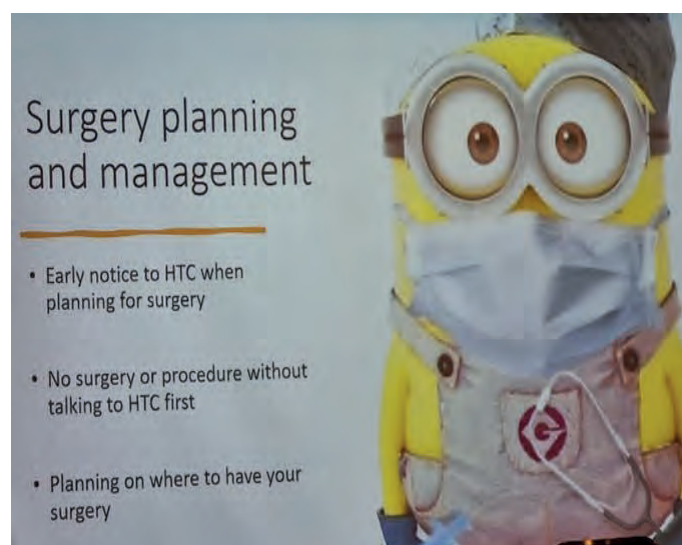
I found most of the plenaries and concurrent session descriptions very interesting and had trouble deciding which concurrent sessions to attend. The sessions & plenaries I attended related to women and girls with bleeding disorders, improving outcomes for people with a mild bleeding disorder, gene therapy, rare bleeding disorders, ageing with a bleeding disorder, and the future of bleeding disorder treatment.

There are some key points I gained from the conference, including the importance of using individual bleeding phenotypes to tailor treatment; this allows clinicians to produce personalised treatment plans for each person with a bleeding disorder, leading to more effective results.

From the Getting Older concurrent session, it was pointed out that hepatitis C treatment is very successful and offered to everyone who have not yet been cured of hep C. The significance of keeping active as we age, both in body and mind was also highlighted, as was the importance of maintaining a healthy weight.

Another point I gained is that it is crucial for us as members of the bleeding disorders community to participate in surveys such as PROBE and the Getting Older Needs Assessment Surveys. The data from these surveys is used to formulate outcomes that

## 21st Australian Conference: Vice President's Report



give clinicians & treatment centre staff, national & state foundations and other decision-makers vital information such as the physical & psychological impacts of living with a bleeding disorder, what treatments & interventions work and how these change over time.

Further points include the importance for girls and women have a bleeding disorder to utilise their treatment centre for education & care, the importance of recording your bleeds & treatments, and keeping in touch with your treatment centre before any planned surgery, and to find out about the new treatment products and trials available. Some of these treatments are life-changing; the future looks

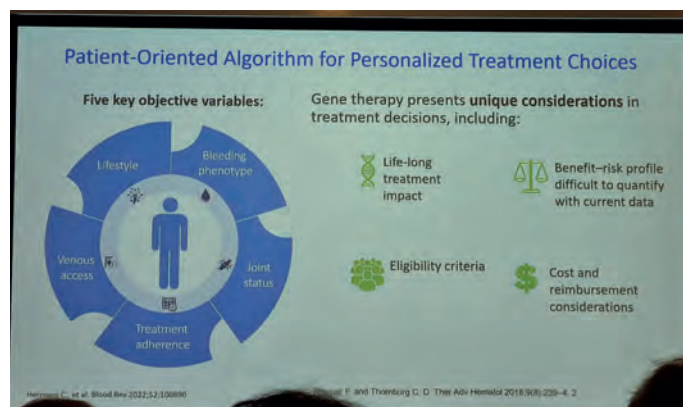




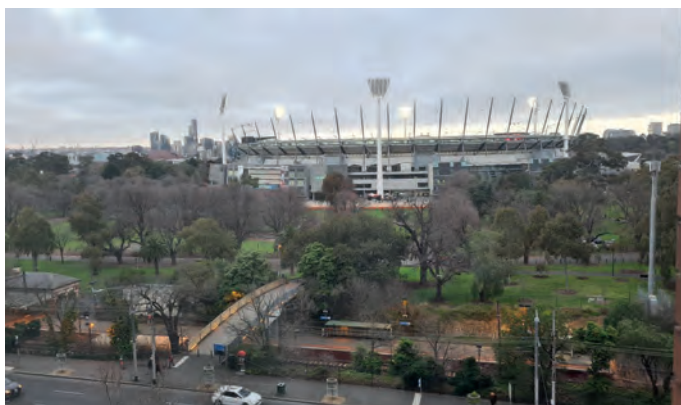
Cont....

bright. The congress was an ideal forum to meet & share information and experiences with other families and health professionals from all over the Australia who have something in common with us – they are affected by a bleeding disorder or strive to improve the lives of those who are affected. If you get a chance to attend a National Conference or World Congress, grab the opportunity. The next World Congress is in Spain next year, and the next Australian conference will be held in Brisbane in 2025. Keep an eye out for more information if you are interested.

Cheryl Ellis



One of the many pics Cheryl took of the plenary presentations  
(above & previous page)



Cheryl's amazing view from her window at the conference venue, Pullman on the Park, Melbourne



## DO YOU KNOW THE UPCOMING COAG CLINIC DATES?

October – 3rd, 17th and 31st

November – 7th, 21st

December – 5th and 19th

Clinic H, Level 1 (Haematology/Oncology Outpatients):

Ph: 6456 0170 If you require further information



## 21st Australian Conference: Darren Tull

The 2023 HFA conference in Melbourne was the first I've ever attended. It was clearly a massive effort to organise the conference and I really appreciate the effort of everyone who contributed (including a few from WA). I have never met so many fellow Hemophilia B people before, and I learnt plenty from chatting to others. There was an impressive cross section of people attending and speaking, which made the event remarkably interesting. It was great to get some insights into what is happening elsewhere and listen to the views of the medical professionals. One highlight was the discussion at the men's breakfast, where topics were openly discussed with a doctor present; we all benefitted from this. Other highlights were getting in trouble from my nurse and doctor for having too many drinks during the conference dinner and Dan Credazzi's unusual MC techniques!

One concern I took from the weekend is the reducing grass-roots participation and support across Australia for our Foundations. The Foundations play a vital role advocating for us in an environment where access to funds is increasingly competitive. I encourage everyone to get involved with their Foundations, as we cannot take our access to top class treatment for granted. If you can, I encourage you to attend a future conference. I hope to attend many more.

*Darren Tull*



*From left to right: Sharri, Darren, Roma & Cheryl enjoying the HFA Conference in Melbourne*





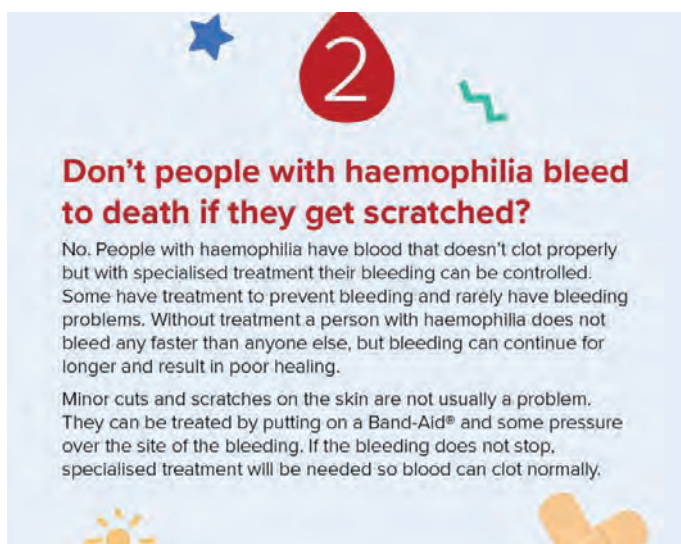
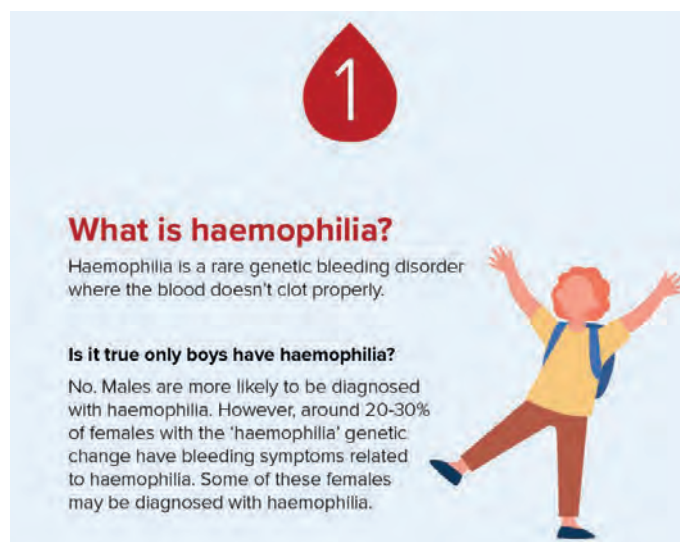
## 21st Australian Conference : Susie Couper

The bleeding disorder world is facing a lot of exciting change. While I think many of us know this on a personal level, attending the 21st Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders made this clear for me on a much deeper level. I came out of conference with a clear sense of progress and hope for improvements for the wider community.

I have always felt that words matter. I work with the written words all day long at work. Accurate, unambiguous language which improves communication and drives the desired result is a process of continual change and improvement. So it isn't surprising then that the names of conferences and support events as well as organisations matter to me.

There is a lot to be proud of and deeply thankful for the tireless work and contribution of countless trailblazers, the people with Haemophilia, their families, their medical care teams, the support organisations. Adopting more inclusive language is not a matter of rejecting this or feeling the work is done, far from it. As a person with VWD and a parent of a person with VWD, it is validating and useful to see more inclusive language being used more widely. This truly reflects the breadth of representation and work that has been underway for many years. HFA has leaned into this as well over the last few conferences, no longer calling them Haemophilia Conferences. I have seen first-hand how HFWA has become more inclusive with simpler clearer language, for example the names we use for our peer events. The US peak body for peer support, the National Hemophilia Foundation has rebranded to the National Bleeding Disorders Foundation. I can see more opportunities for updated language to come, with appropriate consultation.

As for the Conference itself, I found it truly inspiring. We are especially fortunate to have HFA as a powerhouse, bringing together industry, medical, allied health, people with lived experiences. This year, as with every year, there







Cont...

was healthy debate, insightful questioning, and detailed information on new treatments. Over the last few years, I have seen an increasing scope for content on VWD as well as women with bleeding disorders.

I took the opportunity to attend a session on rare bleeding disorders and sessions on Haemophilia treatment and joints as a pay-it-back gesture. I wanted to glean new information and understanding in the same way I expect people living with or treating Haemophilia (and men) did by attending VWD or women's sessions. The passion of the treating professionals for this challenging set of conditions was clear as was the difficulties they face by limited research. The conference always gives us an opportunity to dive deeper into information than we can get at clinic appointments. The sessions are a more engaging and focused way to be informed than trawling online. The session on gene therapy was fascinating and inspiring. In the foyer discussions later, I saw people sharing their varied reactions with each other. Plenty of people said that they came out with a new understanding and were motivated to discuss it further with their HTC. The session specifically mapped out shared decision making, the wide range individual priorities affecting decision making as well as the importance of talking to a wider group of people than just your HTC. Family matters in such a pivotal choice.

There was a fascinating piece delivered by a gynaecologist that I don't think I'll ever forget. She was passionate, dynamic and engaging. Her description of what happens within the uterus to result in menstrual bleeding was a totally new and very graphic analogy. She also shared her learning and research journey over the years, the gaps in medical knowledge, research possibilities and diagnosis of women with bleeding disorders. How amazing to have such a communicator dedicated to helping women live better lives?

I was humbled to be asked to speak in the session on VWD and pleased to speak alongside another person with VWD. We have very different lives with a bleeding disorder, being different genders and having different types. I feel this difference was useful for the session. VWD is

complex and not as widely researched as haemophilia. While there are some similar issues, the differences bear discussing, and I am very appreciative of the efforts of HFA and HFWA on this. The technical aspects of the lab tests required for diagnosis were also covered helping me to understand more of the reasons for the wide variability in results that make diagnosing and treating VWD so difficult. I can only hope that Cont...





an apparent focus on VWD research and treatment could work to improve this. This conference was the first in-person event after COVID.

While we had a virtual conference two years ago, there is absolutely nothing like being there in person. I met new people by striking up conversations with strangers – always a nerve-wracking thing. I feel we are stronger together and making connections in person is such a valuable opportunity. The conference balanced well time between sessions and in the evenings to facilitate this. Coming home, I felt inspired, motivated, and appreciative of the work our whole community has achieved. I am looking forward to seeing possibilities for better treatment and fuller lives for anyone with an inherited bleeding disorder in Australia.

*Susie Couper*

*Gavin Finkelstein President HFA  
presents the HFA Volunteer  
Award to Ben Inglis, Vic.*

*Dan Credazzi, QLD, presents  
Gavin with a Life Governorship  
Award*

*Gavin presents the Jennifer Ross  
Award to Sharon Caris, HFA*







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

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

Jute Shopping Bag \$6.50

Red Shopping Bag \$3



Email your order for the shopping bags to the HFWA office at [office@hfw.org](mailto:office@hfw.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 <https://checkout.square.site/merchant/06461WB19EDA8/checkout/R74ZARTGOWNVOO6YVONMBHMX>

or simply scan the QR code (above) to go straight to the Square checkout  
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**

## Entertainment

Support us today:

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

### Say hello to savings & more

Get your Membership today & enjoy hundreds of offers on dining, shopping, travel & more.

SUPPORT US & BUY NOW

### Say hello to giving

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

INTRODUCING OUR NEW  
TRAILBLAZING APP

 CONTAINERS  
FOR CHANGE



Scheme ID  
**C10338968**

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.

[Containers for Change WA App](#)





## **Men's Breakfast tales: Turquoise Café, North Fremantle Sunday 24th September**

Once again I went to the HFWA men's breakfast. I think there was about 13 blokes that attended, varying from young adults to some senior members of the community

Conversation was once again diverse with treatments, joint issues, treatment center's and services and general ageing with a bleeding disorder, were just some of the topics discussed amongst life in general

The food was great, coffee was good and I think overall everyone enjoyed themselves.

*Dave Bell*

It was a good venue. The breakfast was different, yet good. The staff were very accommodating. Being outside the wind was chilly.

*Dennis Arklie*

*(Below, right) Decanter Café - Sharri, Beryl, Cheryl, Roma, Susie, Ann-Maree & Robin*

## **Women's Breakfast tales: Decanter Café, East Vic Park Saturday 23rd September**

A small but enthusiastic bunch arrived at decanter in Vic Park for our women's breakfast. The menu was incredible with beautiful cold pressed juices enjoyed by all.

As usual, the discussions covered a plethora of topics such as treatments, children, surgeries, Christmas and how to use parking apps.

We would love to have more people coming along so to all of you fabulous women out there who would like to leave their busy lives behind for a few hours, please come and join us. We would love to see you there.

*Sharri Brodie*

Thank you to the ladies who were able to attend the breakfast, we missed those who couldn't make it. We had some great discussions about a variety of topics including the recent AGM, the HFWA presence back at COAG clinic visits at PCH, arnica and the usefulness of it along with brainstorming some exciting events for 2024 to get more of our female members involved. Stay tuned for more details.

*Ann-Maree - Office Coordinator*







## HFWA Christmas Party



Where: **Adventure World**  
351 Progress Drive, Bibra Lake  
When: **Saturday 25 November - 10.30am**  
RSVP: **ASAP - No later than 9 November 2023**

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

Soft drinks and water will be provided, and Santa will visit at 12.00pm - 12.30pm

Look out for your invitation coming to your inbox soon!

There is no cost to current financial members.

