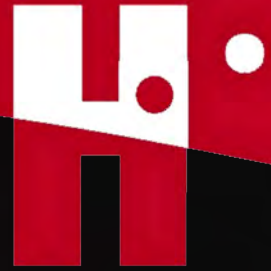


# CONTACT

Newsletter of Haemophilia Foundation WA Inc.

JUNE 2023



Cover Picture: Matagarup Bridge from Burswood side looking over the Swan River to Perth, LIGHTING UP RED for World Hemophilia Day 2023, Picture taken by Cheryl Ellis

Happy June to everyone. We are almost halfway through 2023. Please enjoy this current version of CONTACT

Stock images sourced from pixabay.com unless otherwise noted

## 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)





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#### YOUR COMMITTEE

Gavin Finkelstein (President)	0415 978 031
Cheryl Ellis (Vice-President)	0402 033 652
Robert Butler (Treasurer)	9381 3386
Michelle Dinsdale (Secretary)	0407 197 815

Susie Couper  
Paul Keogh  
Evyn Webster

Profiles of committee members can be found on the website ([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

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.





## HFWA Membership Renewals 2023/2024

The Aim of the Haemophilia Foundation of Western Australia Inc. is to work towards a better quality of life for people with a bleeding disorder and to provide support for their families by:

- ♦ Providing peer support activities to our community
- ♦ Providing information about bleeding disorders to members and the general public
- ♦ Advocating and liaising with government agencies and hospitals on behalf of the bleeding disorders community
- ♦ Contributing directly to the assistance of members in their education and welfare
- ♦ Supporting research and development of new and improved therapies
- ♦ Encouraging the public to become blood donors to the Australian Red Cross Blood Service

It is that time of the year again when Your foundation asks you to renew your membership and update any of your details that may have changed from last year.

The membership form can be found on our [website](#) in a fillable format, or as a printed copy in this newsletter if you receive a hard copy.

Scanning the QR code will take you to our secure payment site to pay your membership or make a donation.



## President's Note

G'day Folks,

There's some interesting articles in the newsletter this month, as well as what's coming up later in the year.

Travel is a big thought on many people's minds now; we have included some great resources from HFA, and an article from some of our community members, Ben & Brianna. Look out for their follow-up article when they return from their trip.

The May Men's and Women's breakfasts had to be cancelled due to low numbers. We will be rescheduling them soon, and please join us at these events, they are held for YOUR benefit.

Have a look at the World Hemophilia Day and Lighting it up Red photos and write-ups on pages 4-6. It's great to see our community members promoting awareness of inherited bleeding disorders.

HFWA memberships are due for the next financial year. What we ask of you, our community, is to please keep your membership up to date (or join - it's only \$25 a year) and support any peer group activities by attending; we welcome any ideas and suggestions on what role the HFWA should have and activities we run to engage and bring our community together.

Consider donating to the HFWA before 30 June; we are a registered charity and all donations over \$2 are tax deductible.

The 21st Australian Conference on Haemophilia, vWD and Rare Bleeding Disorders will be held from 24 to 26 August 2023 in Melbourne, and we would like to see as many people as possible from WA to attend. Until next time, and hope to catch up with as many of you as possible at one of the HFWA's upcoming events.

Gavin





## 21st Australian Conference MELBOURNE 24 - 26 August 2023

### COMMUNITY FUNDING

The Haemophilia Foundation of WA has opened applications for funding to attend the conference. Please click on the link to read the guidelines and to access the fillable form.

Please email this back to [office@hfw.org](mailto:office@hfw.org)

<https://www.hfw.org/get-involved/events/21st-australian-conf>

HFA have also allocated funding to help community members with expenses to attend the Conference.

### FOR MORE INFORMATION

For more information, registration link and details visit

[www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences).

The 21st Australian Conference on haemophilia, VWD & rare bleeding disorders will be held face to face at the Pullman on the Park, Melbourne, 24-26 August 2023.

After a few years communicating and running events virtually and online it will be wonderful to see everyone come together again and at a different time of year to our previous conferences. HFA conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

The program committee is developing a multidisciplinary program which will interest everyone.

Topics will cover :

new developments in care and treatment

Inhibitors

new treatments

gene therapy

living with a bleeding disorder

getting older with a bleeding disorder

women/girls with bleeding disorders

family planning and genetics

von Willebrand disease

rarer bleeding disorders

managing pain

bloodborne viruses

new diagnosis

youth

sport and healthy activities

and.....what's on the horizon?

## Thank you to our sponsors

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Supporter BiOMARIN







## World Hemophilia Day Morning Tea

This year we held a morning tea at City West Lotteries House, which is where the Haemophilia Foundation Office is located.

We had a fantastic turnout, with so many of the tenants stopping by for some delicious treats, dropping in a donation, reading some of our available resources and having a chat with us.

Some of the members that attended were Beryl, Robin, Penny, Charlie, Maddie and Freddie, along with Victoria. Thank you for bringing some delicious treats to share and helping look after the event.

Cheryl and I hosted the morning tea, and we thank Nicky and Fiona from City West Lotteries House for helping us to host the event and for providing a lovely carrot cake.

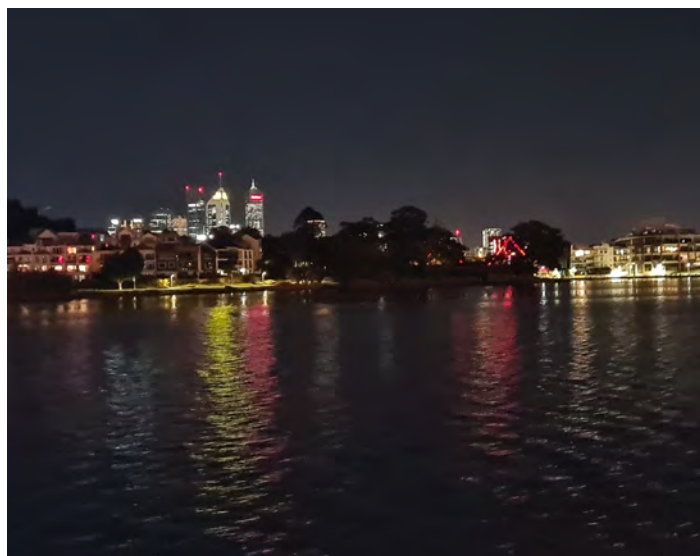
These events help to bring a greater awareness of the bleeding disorders-related problems faced by many around the world, and of course here in our own Western Australian community.

We had many questions about what Haemophilia is and how it is managed.

Enjoy the great photos captured on the day.

*Ann-Maree Foran*  
*HFWA Office Co-Ordinator*





## World Hemophilia Day Lighting It Up RED

Every year on 17 April, World Hemophilia Day is recognised 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.

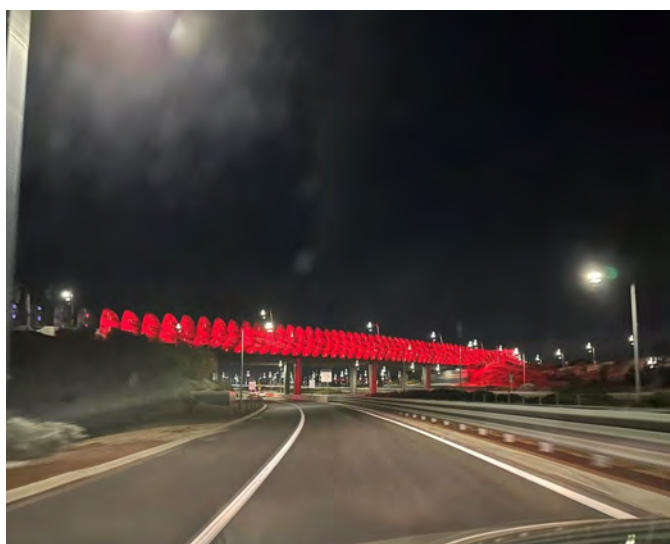
World Hemophilia Day was started in 1989 by the World Federation of Hemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel's birthday.

This year the theme is *Access for All*. The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work with developing countries with their GAP and Twinning Programs and Cornerstone Initiative.

*Did you know: WFH estimates indicate that over 75% of people living with haemophilia worldwide have not yet been identified and diagnosed.*

HFA and HFWA are both WFH member organisations, and many Australian volunteers have been involved with WFH programs.

We are grateful that our community has access to high quality treatment but we recognise that many other parts of the world do not have access to diagnosis, treatment and care. Together as Australians, let's take this opportunity to recognise this special day and put our support behind the worldwide effort for *Access for All*.







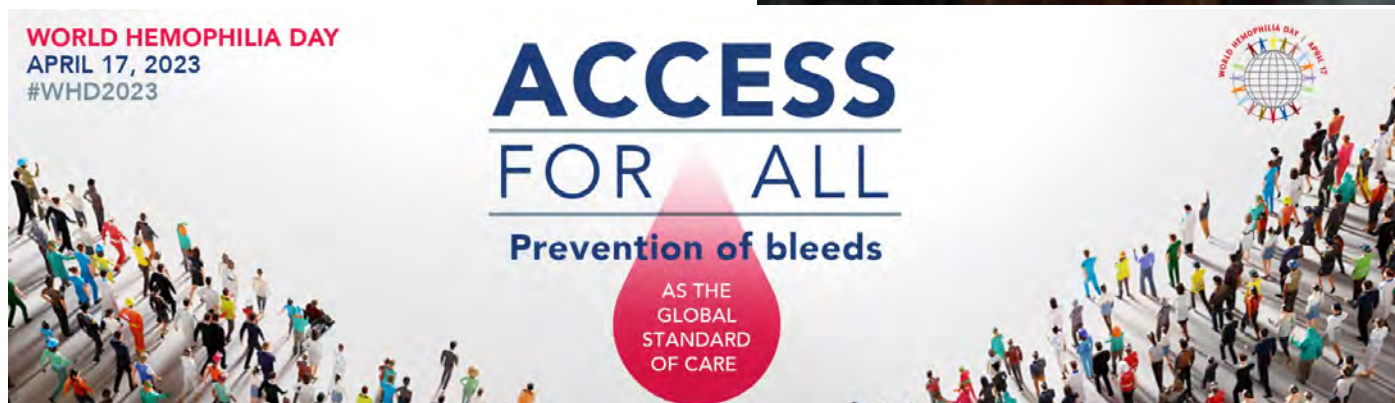
## World Hemophillia Day continued...

Ally Meschenmoser (Finnick's mum), shared a very special event held at Finn's day-care for World Hemophilia Day recently.

The educators printed our colouring sheets for the children and also set up a donation jar. Well done to Finn's day-care family!



Maddie's beautiful hair bow, custom-made for World Hemophilia Day







# Ask Us: Overseas Travel

By Alex Coombs & Jane Portnoy

Dear Ask Us,

*I am planning my first overseas trip now that the borders are open.*

*I have been saving hard, and want to see the world. Do you have any hints or tips, particularly given that I have a severe bleeding disorder? I'm also concerned about travelling with COVID out and about!*

From "Unwordly Traveller"

Hey Unwordly Traveller,

*We guess that the COVID enforced lockdowns and restrictions we've all endured over the last few years have given you time to save and ponder the travel adventure that awaits. You can make your trip very special, and we don't want any unexpected glitches to spoil the whole thing.*

*Of course, sometimes the unexpected happens, so making sure that you are prepared helps...*

## TRAVEL INSURANCE

Travel insurance is strongly advised for those with bleeding disorders, severe and otherwise. If you need treatment, care or hospitalization overseas, this can be expensive - especially in countries that don't

have a Reciprocal Health Agreement with Australia.

*Does your bank or credit card company offer you discounted travel insurance?*



**There is a comprehensive resource published by the government on the Smartraveller website:**

<https://www.smartraveller.gov.au/CHOICE-travel-insurance-guide-COVID-19#:~:text=Several%20travel%20insurers%20now%20offer,to%20medical%20and%20repatriation%20costs.>



**HFA has also recently put together advice for travellers:**

<https://www.haemophilia.org.au/publications/national-haemophilia/2022/no-217-march-2022/travelling-during-covid-19>

*Top Tip from the HFWA Vice President Cheryl Ellis :* Get travel insurance! Some overseas countries are very expensive if you need medical attention, and better safe than sorry. Some travel insurance companies that are better than others for travellers with existing medical conditions, if you aren't sure, ask for advice from some frequent travellers with bleeding disorders





## MOBILE DATA

Make sure that you have checked out data packs for your smart device, and worked out what one suits you. You can often use local WiFi, but sometimes you also need maps, translation apps and currency converters in addition to access to your phone calls. You will also need access to MyABDR if you are recording your treatment.

Global roaming can be very expensive, so it is best to know what the charges are before you go. Often you can get a local plan/SIM card or pay for a travel pack from your Australian provider.

## HAEMOPHILIA TREATMENT & OTHER HEALTH CONDITIONS

Make sure you speak with your Haemophilia Treatment Centre (HTC) medical staff about your trip as early as possible, as they may have local knowledge on some of the countries you plan to travel through. Please request a medication and treatment travel letter with as much

notice time as possible, and discuss what else you might need to take with you (e.g. a cooler bag/small esky for your treatment). Your HTC medical staff will advise if you need to make a clinic appointment, especially if it's been awhile since the team have seen you.

Also research the details of the nearest local HTC in countries of intended travel. You can also contact your own HTC for advice if something happens while you are away. But be mindful of the time differences between Australia and other countries!



**Research what vaccinations you may need. This can be particularly important when travelling to some areas in Asia.**

<https://www.betterhealth.vic.gov.au/campaigns/travel-and-holidays>



**Research the local rules in your destination countries on mask wearing & Covid vaccination cover?**

<https://www.haemophilia.org.au/publications/national-haemophilia/2022/no-217-march-2022/travelling-during-covid-19>





# Ask Us: Overseas Travel

By Alex Coombs & Jane Portnoy

## LANGUAGE

Can you speak the local language? A translation app on your smart device, or a list of local phrases can be really helpful. What is the local word for hospital? Ambulance? Police? Can you seek out local medical care if you or a travel buddy needs it?

Having a few phrases in the local language can also be a way of making local contacts and to see things beyond the usual tourist magnets.



## PLAN FOR COVID & BLEEDS

*Are you travelling with a buddy?*

*What would you do if one of you got COVID or needed to isolate?*

*Does your buddy know about your bleeding disorder?*

*Do you have a plan for if you get an injury?*

## PACKING LIST & TIPS:

- ◆ your ABDR & Medicare card with you
- ◆ treatment if you need it
- ◆ a Medication & Treatment Travel letter from your HTC
- ◆ passport, Covid vaccination evidence on your smart device & printed smart device chargers & converter plugs for the local power outlets
- ◆ spare padlocks & keys for your bags & copies of the keys to the bag padlocks you use
- ◆ as inconvenient as it may be, carry your backpack in front of you
- ◆ use a money pouch or “bumbag” keep your valuables out of sight under your clothing

Don't forget  
to enjoy your-  
self, relax, take  
in the sights,  
sounds, foods &  
culture!





## ALEX & JANE'S TOP TRAVEL TIPS



### Share Your Plans

Share your travel plans with your family, make sure someone has a copy of ALL your documents, including passport, vaccinations, and your itinerary. Upload a backup to the cloud or equivalent.



**CLOUD  
STORAGE  
TIPS**



### Pack Light

Pack lightly, as a heavy suitcase is more challenging and can be expensive if you go shopping for the local trinkets... Fridge magnets or snow globes can be so appealing! Or that bargain "antique" Buddha head from Bali, authentic sports T from your overseas soccer club, or must-have travel coffee mug.



**BANNED  
GOODS**



### Know the Border Rules

Not everything you buy overseas can be brought in Australia due to the strict quarantine rules that protect Australia from overseas pests and microbes. Wood items, especially from some parts of Asia, may contain pests hidden under the paint etc.

You should declare any items you purchased overseas. You will be given a Declaration form on your return flight into Australia to complete. Be honest and up-front at all time - fines can be expensive and Australian Border Force sniffer dogs will welcome you home at the airport. They are not just there to be cute! They also sniff out illicit substance.



**CAN YOU  
BRING IT?**

## CURRENCY

See your local bank or existing credit card company for advice. You can use your own existing debit and credit cards overseas but beware of these being lost, stolen, fraudulently used and/or copied in local ATMs. There are also fees for currency conversion.

You can buy travel cards and load them with a certain amount of spending money to limit potential losses whilst you take in the sights. Pick pocket thieves abound in some countries overseas - they can be so fast that you don't notice! Here are some suggestion to look into:

- ♦ [thecurrencyshop.com.au/travel-cards](https://thecurrencyshop.com.au/travel-cards)
- ♦ [travelex.com.au/travel-money-card](https://travelex.com.au/travel-money-card)
- ♦ [commbank.com.au/travel/travel-money-card.html](https://commbank.com.au/travel/travel-money-card.html)

Alex Coombs and Jane Portnoy are Social Workers at the Ronald Sawers Haemophilia Centre at Alfred Health in Victoria. This article is reprinted with permission from *The Missing Factor: Winter 2022 Issue*, the journal of Haemophilia Foundation Victoria.



## Ben and Brianna's adventure Part 1 : Preparing for travel

Our names are Ben and Brianna; we are both 21 years old and are setting off on an adventure to Paris, London and Singapore at the end of July 2023. We are both so excited to be able to go on this trip, as it has been something we've wanted to do since the pandemic started. Ben was diagnosed with Severe Haemophilia A at birth, but this has not stopped us from leading an adventurous lifestyle and desires to travel the world. With just over a month left till we take flight, here's what we've done and had to consider while planning our holiday.

One of the first concerns we ran into was travel insurance. As any medical conditions must be declared when applying for travel/medical insurance, we had a bit of trouble trying to find a company that would cover Ben's Haemophilia. After asking several Haemophilia Foundation members, we managed to find an insurance company that could cover us both. We found that Allianz Comprehensive Travel Insurance was the best fit for us after Ben completed a medical assessment over the phone.



Next, we needed to get medical certificates to be able to carry Ben's Hemlibra Subcut medication in our hand luggage. This was a very easy process of seeing the Haematologist at Fiona Stanley Hospital and simply requesting a medical certificate.

We were reminded that when travelling with Haemophilia medication, to pack in a hard insulated case that is easily carried and accessible if in an emergency. For the time period that we will be travelling, Ben needs to pack three Hemlibra Subcut injections (One injection per week) plus one spare and one Eloctate injection for an emergency.

Finally, for peace of mind, we've both made ourselves familiar with where the nearest Haematology Centre is, in each city, we are staying. This is done in the case of an accident we know where Ben can get the best aid possible for his condition.

We hope this can help anyone who is deciding to travel with Haemophilia and show them that it isn't hard or scary to plan a holiday with a medical condition. We would like to encourage others to go out and live life to the fullest and enjoy everything this world has to offer. Happy travelling!

Stay tuned for updates on their adventures.

*Article written by Ben Ellis and Brianna Morley,  
published with their permission, June 2023*







## World Hepatitis Day 28 July 2023

In July 2023 Australian landmarks will be glowing green to raise awareness about eliminating viral hepatitis. World Hepatitis Day is marked internationally on 28 July and is one of the World Health Organization's nine official global public health days. Green is used by the global NOhep movement – the colour of life, vitality and progress.

World Hepatitis Day is an opportunity to come together to step up efforts to eliminate viral hepatitis, in particular hepatitis B and hepatitis C. Once again, the theme in 2023 is **Hepatitis can't wait**.

Many people don't know that they have hep C. For example, you could be at risk if you have a bleeding disorder and ever had a blood product before 1993.

Or some people have been cured but still need follow-up for their liver health, especially if they have cirrhosis.

Do you think this might be you? Or someone you know?

By talking to our friends, family or a doctor about testing, treatment and liver health checks we can work towards the goal of viral hepatitis elimination by 2030.



On World Hepatitis Day we are reminded not to wait – know your hep C status, have treatment to cure hep C, where possible, and follow up on your liver health after treatment.

Look out for more information and activities on our website and social media in the week leading up to 28 July.

### FIND OUT MORE

Australian World Hepatitis Day website - [www.worldhepatitisday.org.au](http://www.worldhepatitisday.org.au)

HFA World Hepatitis Day page - [www.haemophilia.org.au/world-hep-day](http://www.haemophilia.org.au/world-hep-day)

*This article is reprinted with permission from Haemophilia Foundation Australia June 2023*



### Starting or Changing your career?

Are you thinking about starting or changing your career? We have recently made substantial updates to the [employment information](#) on HFA's Factored In website for youth.



## New simple haemophilia testing guide

Unsure about genetic testing and factor level testing in haemophilia and how it works in women and girls?

Haemophilia Foundation Australia has published a new education resource, ***Haemophilia testing in women and girls: a guide*** to answer these questions simply and clearly.

The resource is aimed at women, girls and parents of girls and uses relatable stories, infographics and diagrams to tackle some complex information in an accessible way.

How does a woman or girl know if she is affected by haemophilia?

- What are genetic and factor level tests?
- Who should have these tests and when?
- How is haemophilia passed on in a family – and what if there is no family history?

Why do some women and girls have bleeding symptoms or haemophilia and others do not?

HFA developed the education resource in collaboration with women and parents in the Australian community, Haemophilia Treatment Centres and genetics and legal experts. We would like to thank everyone involved for their advice and creative ideas!

[Haemophilia genetic testing, click to learn more](#)



## HOW CAN YOU ACCESS THE RESOURCE?

Visit the HFA website page to:

[Download the entire resource](#)

or

[Read it online magazine-style \(ISSUU\)](#)

or

Download specific sections, eg genetic testing and counselling.

To request print copies (free) email HFA at [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

or call 0398857800





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

Jute Large Shopping Bag \$6.50



Red Shopping Bag \$3

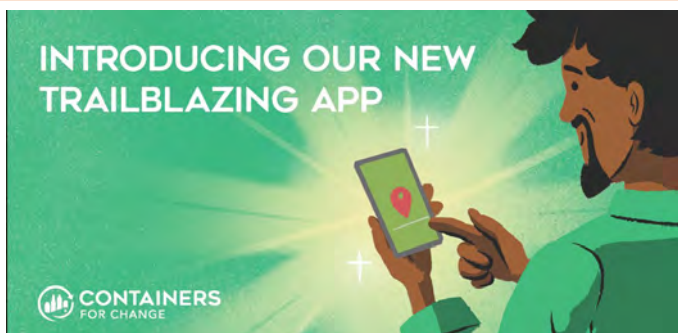


Email your order for the shopping bags directly to the HFWA office at [office@hfwa.org](mailto:office@hfwa.org) with your name, address and phone number or phone 9420 7294 and we will advise when your order can be collected - or we will dispatch your order promptly by mail (postage can be arranged at extra cost)

For fast and secure payment, follow the secure Square credit card payment link below or simply scan the QR code to go straight to the Square checkout

<https://checkout.square.site/merchant/06461WB19EDA8/checkout/R74ZARTGOWNVOO6YVONMBHMX>

INTRODUCING OUR NEW  
TRAILBLAZING APP



The features of the new app include a **Refund Point Finder** map, a **Container Scanner** (great for knowing what is eligible!), a **'Rapid Returns'** section to help add multiple member numbers to your phone's wallet, **tips** for returning, and lots more. We can't wait to start sharing some tips on how to use the brand-new app to increase your fundraising.

 **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

[Containers for Change WA App | Containers for Change](#)



## WHAT IS COMING UP ?

### HFWA Membership Renewals for 2023-24

### 21st Australian Conference Melbourne 24-26 AUGUST

### Bleeding disorders Awareness month 1-31 OCTOBER

**Bleeding Disorders Awareness Month** 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 for Bleeding disorders Awareness month

Stay tuned for the date in October, we will need volunteers and donations of drinks

### HFWA word search

E	S	A	R	T	E	R	I	E	S	R	V	R	B
A	I	L	I	H	P	O	M	E	A	H	O	N	E
C	S	W	I	M	M	I	N	G	C	T	L	G	R
V	R	V	J	A	A	E	A	A	C	D	A	Y	B
E	O	N	O	A	G	T	E	A	S	S	G	C	U
I	T	E	I	T	Z	B	F	M	U	I	N	A	T
N	T	E	N	H	H	R	L	A	N	A	I	C	T
S	N	D	T	L	M	G	S	S	S	R	T	O	E
N	E	L	S	E	G	I	I	C	H	I	T	V	R
B	S	E	I	T	A	D	A	E	I	V	O	D	F
L	T	B	Z	I	S	W	A	N	N	E	L	A	L
E	R	L	Z	C	B	S	L	N	E	R	C	N	Y
E	R	I	L	S	L	K	A	L	B	A	R	R	I
D	T	M	E	W	J	O	O	N	D	A	L	U	P

NEEDLE  
SWAN  
SIZZLE  
BUTTERFLY  
FACTOR  
ROTTNEST  
GENES  
BLEED  
EIGHT  
JOONDALUP  
HAEMOPHILIA  
CLOTTING  
RIVER  
ADVOCACY  
AGM  
VEINS  
KALBARRI  
ARTERIES  
SUNSHINE  
SWIMMING  
JOINTS  
ATHLETICS  
BEACH  
SAUSAGE