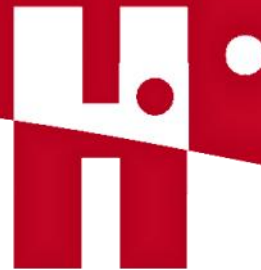


# CONTACT

Newsletter of Haemophilia Foundation WA Inc.

February 2024



RARE IS **MANY**  
RARE IS **STRONG**  
RARE IS **PROUD**



**RARE DISEASE DAY®**

Cover Pictures: Rare Disease Day 29 February 2024

HFWA Management Committee wishes a Happy New Year to all and extends their gratitude to all members and supporters for 2024

Stock images sourced from pixabay.com unless otherwise noted. Permissions granted by those in featured event pictures

**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 proudly acknowledges our Patrons,

**His Excellency The Honourable Chris Dawson AC  
APM**

**Governor of Western Australia  
and Mrs Darrilyn Dawson**



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## YOUR COMMITTEE 2023/2024

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	
Darren Tull	

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)

Hard Copy Printed by Kwik Kopy PERTH

## 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: **Emily Johnston** (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**

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

Hi All,

I hope everyone had a good Christmas and New Year, and have survived the heat. 2024 is well under way; the kids are back at school and things are rolling along.

The Men's Group had an enjoyable breakfast at Decanter in Victoria Park, conversation was robust and varied, food (and coffee) was good, access and parking was great, so we will certainly go back there in the future.

The Women's Group is planning a novel and interesting event for your next outing (keep an eye on your inbox) and I hope as many as possible attend this event.

World Haemophilia Day is on 17 April as always; there will be a number of places lit up to mark the occasion (See page 5 for a list).

The World Federation of Haemophilia Congress is from 21 to 24 April and I look forward to hearing/learning about the new and upcoming treatments in the pipeline, but also catching up with people from around the world and hearing what's happening that may be relevant to us.

Please read the article on the Probe Study (See page 6-7) and the importance of participating in the study even if you haven't previously, it has implications for the world-wide bleeding disorder community. The more people who complete it the better the information it will provide.

A big thank you to all those who nominate Haemophilia Foundation WA as the recipient of their Containers for Change money, we certainly appreciate it.

We are planning our events for 2024. If you have any suggestions, please do not hesitate to contact us with your thoughts.

If you are interested in seeing how the HFWA Committee operates, we are always looking for new faces to join us with no obligation.

Hopefully we will catch up with as many of you as possible at an HFWA function.

Looking forward to the start of the football season but with expectations!!!

Regards,

*Gavin*

## What's on for 2024?

We are planning many events as usual this year and really hope you can make it along.

Perhaps you can commit to at least one event this year, to meet other members of the bleeding disorders community, to participate in our varied conversations, to promote advocacy, or to volunteer for your Foundation?

- ◇ Men's breakfasts
- ◇ Women's brunch and Op shop event April
- ◇ Morning Tea's at HFWA office
- ◇ Family BBQ
- ◇ Parents Sundowner
- ◇ Barefoot Bowls
- ◇ October Sausage Sizzle at Bunnings
- ◇ Family Christmas party

-----

If you are in **NSW**, the HFNSW are celebrating **World Women's Day 2024** special event hosted by Haemophilia Foundation NSW (HFNSW).

When: Thursday, 7th March, from 5:00 PM to 7:00 PM

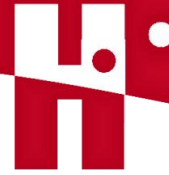
Where: HFNSW's new office at G05 E/ G06 E, Carillon Ave, Newtown, NSW 2042.

The event will feature clinician talks, patient stories, and Q&A sessions related to women and girls and bleeding disorders.

Light refreshments will be provided.

Please RSVP through the following link:

[www.trybooking.com/CPLYW](http://www.trybooking.com/CPLYW)



## Rare Disease Day 2024

This year Rare Disease Day is celebrated worldwide on 29 February to raise awareness and generate change for people with rare diseases.

The 2024 theme of ***Rare is many. Rare is strong. Rare is proud*** reminds us how important it is to come together and connect as a community. This is an opportunity to share personal stories and acknowledge the challenges for our community members who live with a rare bleeding disorder.

Many people with rare bleeding disorders feel very isolated. They may never have met anyone else who has the same condition and sharing personal stories is an important way to feel connected. You will find personal stories of people with rare bleeding disorders on the HFA website [www.haemophilia.org.au](http://www.haemophilia.org.au) and on our social media platforms.

### WHAT IS A RARE DISEASE?

In Australia, a disease is considered rare if it affects less than 5 in 10,000 people.

Around 8% of Australians (2 million people) live with a rare disease.

About 80% of rare diseases are genetic. Diagnosis can often take time because these conditions are complex and doctors do not see them often.<sup>1</sup>

Haemophilia is considered rare. Approximately:

1 in 6,000 males has haemophilia A  
1 in 30,000 males has haemophilia B

Researchers are still gathering data on how many females are affected by haemophilia.

Some bleeding disorders are very rare.



For example, factor X (10) deficiency only affects 1 in a million people.

Type 3 VWD is the rarest form of von Willebrand disease, occurring in 1 in 500,000 people in countries like Europe and the USA.

Sometimes these rare bleeding disorders are not well-recognised. While only several hundred people have been diagnosed with Glanzmann thrombasthenia worldwide, it is thought that others are undiagnosed.

For more information on Rare Disease Day, visit [www.rarediseaseday.org](http://www.rarediseaseday.org)

### REFERENCES

1. Australian Government. Department of Health. What we're doing about rare diseases. <https://www.health.gov.au/health-topics/chronic-conditions/what-were-doing-about-chronic-conditions/what-were-doing-about-rare-diseases> Accessed 20 February 2024
2. Orphanet: the portal for rare diseases and orphan drugs. <https://www.orpha.net/> Accessed 21 February 2023

Prepared by Suzanne O'Callaghan HFA





## Our New Website

Over the past 12 months, HFA and the team at Heartburst have been hard at work modernising and rebuilding the HFWA and all of the states websites. With thousands of pages to move and reorganise, this has been no mean feat! You'll find all the same great content in beautiful new packaging, plus a few new features including:

- Accessibility Toolbar
- 'Find a Resource' search filter
- Improved navigation

This is just the first step, with future plans including further development on the Resources search filter and the inclusion of more personal stories.

PS – if you notice something not working as it should, please let us know and we'll fix it right away.

Email: [office@hfw.org](mailto:office@hfw.org) Below: Image of HFWA home page

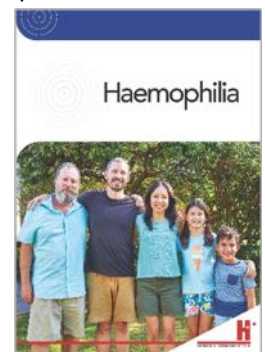


## New Haemophilia booklet

The new HFA **Haemophilia** booklet is now available. Much has changed with new haemophilia treatments and the 2023 edition has been revised completely.

It is a great introductory resource about haemophilia that is very useful for new families and educating others – for example, extended family, schools, employers and health professionals who are new to haemophilia. It covers:

- what causes haemophilia
- diagrams of genetic inheritance and how bleeding occurs in haemophilia
- diagnosis
- treatment (including new treatments)
- carrying the gene alteration
- family planning and pregnancy
- tips on living well.

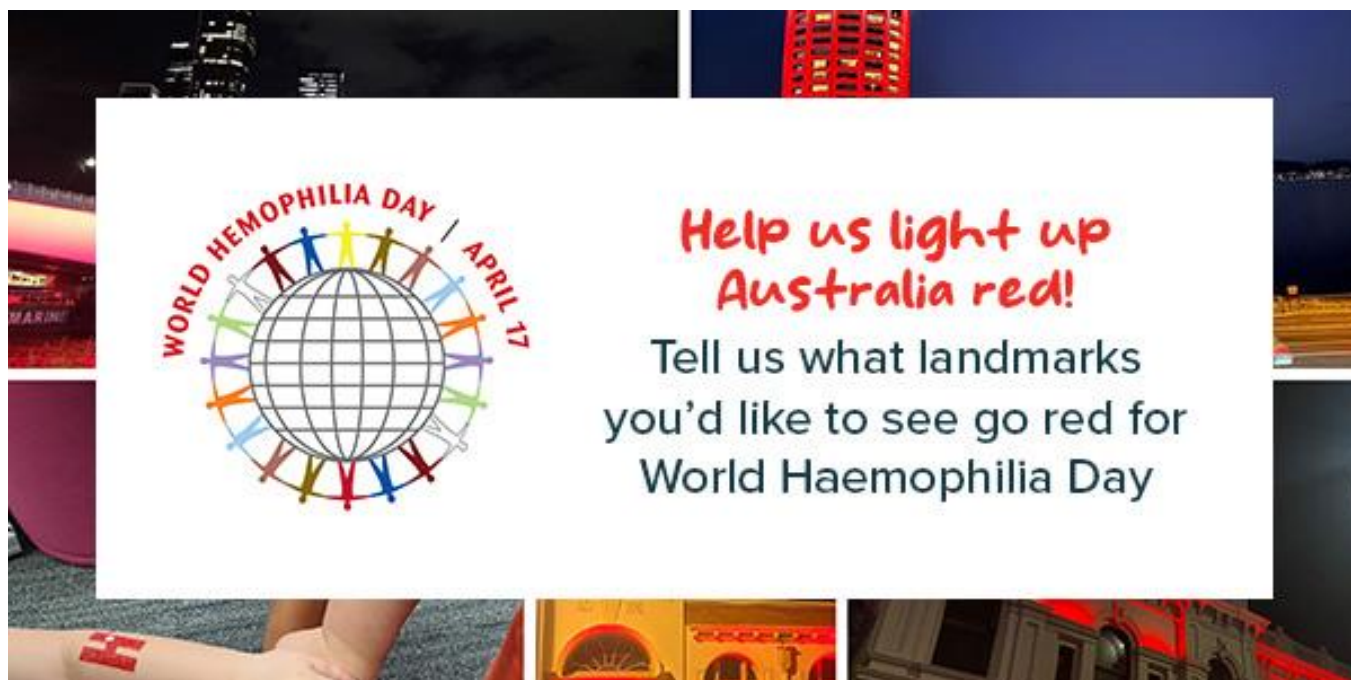


Thank you to all of the community members and health professional experts who contributed to its development.

### Accessing Haemophilia 2023

Download it from the HFA website - <https://tinyurl.com/HFA-haemophilia>

ask HFA to post you a free print copy – [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)



## World Haemophilia Day : **Light It Up Red 2024**

World Haemophilia Day is coming up fast! Recognised each year on 17 April, it's a day for the world-wide bleeding disorders community to come together and increase awareness of haemophilia, VWD and other inherited bleeding disorders.

This year the HFA need your help! On the 17th of April, we want to see landmarks all across Australia light up red in support of the Australian bleeding disorders community. Please send through your suggestions for suitable landmarks to [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) - in particular we'd love ideas for NSW and SA. Or If you have a suggestion for us here in WA [office@hfwwa.org](mailto:office@hfwwa.org)

We are so excited to have the following landmarks participating, we really would love if you can get out and get some photos of the sites :

Council House - 27 St Georges Tce Perth

Trafalgar Bridge - East Perth

Matagarup Bridge

Mount Street Bridge - Crossing Mitchell Freeway

Northbridge Tunnel - Farmer Freeway

Sky Ribbon - Airport traffic interchange, Tonkin Hwy

Joondalup Drive Bridge - Over Wanneroo Road

### **REGIONAL**

*Bunbury:*

Marlston Hill Lookout

Marlseton Waterfront

Koombana Bay - several sites

Guppy Park

Navigators at the Koombana Drive Roundabout

Richmond Reserve

Arrol Crane at Jetty Road

Koolambidi Woola








Did you know?

**PROBE**

Patient Reported Outcomes Burdens and Experiences Study

**We need people without bleeding disorders to participate in PROBE, too!**



 The 2023 PROBE Australia Study provides valuable data on the health and treatment experiences of people with haemophilia vs without a bleeding disorder.

Learn more: [tinyurl.com/probe-study](https://tinyurl.com/probe-study)

@haemophiliafoundationaustralia

## HOW TO DO THE SURVEY

The questionnaire is available:

**Web version** at [myprobe.org](https://myprobe.org)

Or download the **myPROBE app** from Apple Store or Google Play (Android)

Or email [office@hfw.org](mailto:office@hfw.org) or HFA for a **print survey pack**

## FOR MORE INFORMATION

Visit [www.haemophilia.org.au/probe-study](https://www.haemophilia.org.au/probe-study) Or contact Suzanne at HFA:

E: [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au) T: 1800 807 173





## PROBE STUDY



### Why is PROBE important?

HFA is building evidence about the needs of men and women affected by Haemophilia in Australia with the **PROBE Australia Study** and they would really appreciate your help.

### WHAT IS THE PROBE STUDY?

This study is coordinated by Haemophilia Foundation Australia and is an internationally recognised and validated questionnaire. It collects data on the impact of Haemophilia on the quality of life of both men and women who are affected, either because they have Haemophilia or carry the gene. It compares their experience to people who do not have a bleeding disorder.

**So far HFA have only had around 150 men and women complete the PROBE survey – they need at least 400 for good data.**

### WHAT DO WE DO WITH THE DATA?

PROBE data is high quality and credible and HFA and Foundations use it in many ways. You may have seen some of the data from the 2019 PROBE Australia Study in reports and conference presentations. Some examples include:

- In discussions and submissions to government, to advocate for people with bleeding disorders about new treatments and services
- In the HFA Getting Older report, to underline the issues for physical function and pain, and for people with mild Haemophilia, women, hepatitis C
- At the 2023 Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders conference in the plenary on mild Haemophilia
- International meetings to discuss the issues for people with mild Haemophilia
- HFA have had a poster on 2019 PROBE data accepted for publication at the 2024 WFH Congress in Madrid – this is a peer-reviewed publication.

### HOW CAN YOU HELP?

Please consider completing the current PROBE Australia survey as soon as possible – and you don't need to have a bleeding disorder to contribute!

If you don't have a bleeding disorder, you can be a health professional, someone interested in Haemophilia, or any adult Australian really. The comparison group is a slice of the Australian general community.

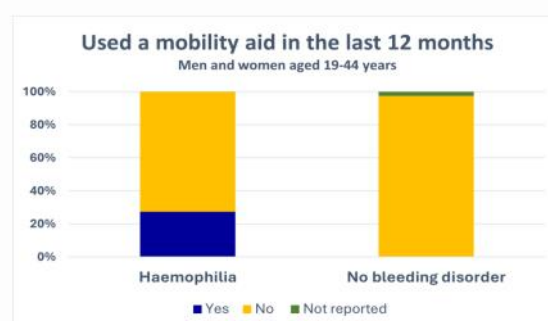
PROBE is voluntary and anonymous, so it is up to you – but we would really value your support.

### HOW CAN YOU HELP?

Please consider completing the current PROBE Australia survey as soon as possible – and you don't need to have a bleeding disorder to contribute!

If you don't have a bleeding disorder, you can be a health professional, someone interested in Haemophilia, or any adult Australian really. The comparison group is a slice of the Australian general community.

## PROBE data speaks for itself







## Back to school or new to school in 2024?:

The HFWA and HFA has a range of resources available in print or online if you have children returning to school at a new school or if they are starting school. We can send you the information to educate and inform the education providers.

We can help you with explaining your child's bleeding disorder, do you need a representative to visit your school or day care for an information session, or would you like some print outs?

[This linked document was produced by HFWA to assist schools with students who have a bleeding disorder.](#)

### On the move with haemophilia



Here are a few links sourced from Haemophilia Foundation Australia Website:

[On the Move with Haemophilia](#)

On the Move with Haemophilia is an online educational resource aimed at parents, teachers and coaches about supporting young people with haemophilia to participate in sport and exercise. It includes information on rehabilitation after a bleed and participation in school activities.

[Starting school or high school with a bleeding disorder](#)

Providing information for schools and childcare is a key role of the Haemophilia Treatment Centre (HTC) with the goal to support parents, allay the fears of educators and for children to have a safe, active and full school life.

[Female Factors : Information for young women with bleeding disorders :](#)

Information about how bleeding disorders affect young women and teenage girls, with FAQs and personal stories. This resource includes explanations about heavy periods and other bleeding symptoms in females.

Click the image link (right) to access great resources for young women and their parents.



[Arved Wasser Memorial Fund](#)

HFWA invites applications for the Arved Wasser Memorial Fund for the 2023/2024 financial year.

Arved Wasser was a valued member of the Haemophilia Society Western Australia as it was known back in 1992. He represented Australia in Chess at the 10th World Individual Deaf Chess Championship in Edinburgh Scotland.

After his passing his estate established with us a Memorial Fund, which we carry on today.

If you have an educational, recreational, work or study related activity you would like to pursue contact the office.

[Click here](#) to read about Karen who received the grant in 2018 to travel to Bendigo for the National Taekwondo Championships

For current financial members we also can provide Medic alert pendant funding and shoe orthotics funding.

If you would like to apply for any of the funding please [email](#) the office for further details.

## Are you up with the 'Socials' ?

LinkedIn



facebook

YouTube<sup>AU</sup>

Instagram

Above links for HFA.

Below is for HFWA

Instagram



## World Congress 2024:

The World Federation of Hemophilia (WFH) and La Federación Española de Hemofilia (Fedhemo) are excited to welcome the global bleeding disorders community to the WFH 2024 World Congress in **Madrid, Spain this year from April 21 to 24.**

This event will be the most comprehensive international event on bleeding disorders in 2024 and will bring people with bleeding disorders and other stakeholders together in one place. The Congress will take place at the IFEMA Convention Centre in Madrid—a world-class venue in a world-class city that's easily accessible to international travelers. On behalf of the WFH and the global bleeding disorders community, we are thrilled to welcome you back to in-person gatherings for an unparalleled opportunity to connect, learn, and collaborate.



## Top 5 reasons to attend the WFH 2024 World Congress

If you're interested in attending the largest meeting for the bleeding disorders community this year, then look no further than the WFH 2024 World Congress. In just a few months, we will welcome people from around the world to Madrid, Spain, to learn about the very latest developments in our field. Participants will include people with bleeding disorders (PWBD), family members, healthcare professionals, researchers, policy makers, advocates, and industry members.

Also available in: [Français](#) [Español](#)

There are many reasons to join us at the WFH 2024 World Congress! Here are just a few to get you excited about collaborating with your colleagues face-to-face April 21 to 24.

### **#1 Increase your knowledge of cutting-edge scientific research and clinical trials**

, and learn about upcoming advances in treatment products and clinical care. Have a look at our [program here](#) to learn more.

### **#2 Share your research and insights**

on patient healthcare issues and multidisciplinary care with colleagues from around the world. Learn more about our late-breaking abstracts [here](#).

### **#3 Set the stage for future collaborations**

with researchers and community advocates on the challenges faced by PWBDs, and the potential solutions that can be developed to improve treatment and care worldwide.

### **#4 Network with thousands of community members**

from around the world, including top researchers, key opinion leaders (KOLs), industry managers, community advocates, and community leaders. Reconnect with old friends and make new ones! Read up about some of the KOLs who will be speaking at Congress [here](#).

**#5 Discover unique Madrid** after Congress and experience a tourist-friendly city that is rich in history, culture and gastronomic delights. Read more about Madrid [here](#).

To learn more about the WFH 2024 World Congress, [click here](#).

Click to visit [wfhemophilia\\_](#) on Instagram

The World Federation of Hemophilia improves and sustains care for people with inherited bleeding disorders around the world.



# CONTACT

Feb 2024

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

email: [office@hfwa.org.au](mailto:office@hfwa.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@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. 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**



Support us today:

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

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

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## Say hello to giving

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

INTRODUCING OUR NEW  
TRAILBLAZING APP

Thank you to the generous  
members who donate their  
Containers for Change money  
who visit the Forrestfield and  
Osborne Park sites !

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](#)





## Fun Stuff :

## Famous people with Haemophilia Gene



GENE THERAPY  
ALEX BORSTEIN  
ALEX DOWSETT  
HEMLIBRA  
RICHARD BURTON  
VWD  
HAEMOPHILIA  
BARRY HAARDE  
DUKE OF ALBANY  
AFL  
CHRIS GORDON

Hey Parents or Grandparents,

Print these out for the kids to complete send them in via email or post.

All entries will be in the next edition of CONTACT and the best ones will get a prize also.

We love to hear from our loyal readers. Let us know if there is anything you would like to see in upcoming editions.

Thanks,

Ann-Maree

Play this puzzle online at : <https://thewordsearch.com/puzzle/6781743/>

