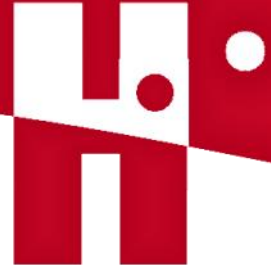


CONTACT

Newsletter of Haemophilia Foundation WA Inc.

August 2024



Haemophilia inheritance in males: the short answer

*(with a little
bit of genetics)*



Cover Picture: Image link to new video resource for teenage males.

In the new video by HFA for teenage males, 'Haemophilia inheritance in males: the short answer', we

HAEMOPHILIA FOUNDATION WA INC.

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

P: 08 9420 7294 E: office@hfwa.org W: 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

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PERTH

Profiles of committee members can be found on the website, at www.hfwa.org/yourcommittee

Office Coordinator Ann-Maree Foran

HFWA Office 2 Delhi Street, West Perth

Phone 9420 7294

Email 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: **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 Folks

I hope this Newsletter finds you well.

HFWA continues to try and find new activities to get the community together. If you have any suggestions, please do not hesitate to send them to us.

The HFWA AGM is on Tuesday , 17 September at

City West Lottery House

2 Delhi Street

West Perth

Please contact us with any queries or if you wish to join the committee.

Everyone who is using any type of product to treat their bleeding disorder should be recording their treatment in their MyABDR (My Australian Bleeding Disorders Registry) app or through the website.

It is essential that My ABDR statistics are accurate; this assists with budgeting, research and stock control - which benefits all users of products.

It was Hepatitis Awareness day 28 July. See details on page 9.

We are beginning to plan for the Christmas Function to be held on 24 November. You will be emailed an invite soon.

Men's and Women's activities continue as usual. Please join us at one of these events and meet some of the 'regulars'.

HFWA committee members continue to attend clinics at PCH; please come up and say hello when you see us there.

Look forward to seeing as many of you as possible at our AGM on 17 September.

Regards,

Gavin



What is MyABDR?

MyABDR is a secure app for smartphones and a web site for people with bleeding disorders or parents/caregivers to record home treatments and bleeds.

It is an internet-based online system that gives you a quick, easy and reliable way to:

- Record treatments and bleeds
- Manage stock of treatment product
- Share the information with your Haemophilia Treatment Centre

Update your contact and personal details.
MyABDR is secure, private and optional.

For people who prefer a paper-based recording system, a MyABDR treatment diary has been developed alongside as an alternative.

MyABDR links directly to the [Australian Bleeding Disorders Registry \(ABDR\)](#), the system used by [Haemophilia](#)





Have you done the PROBE survey yet?

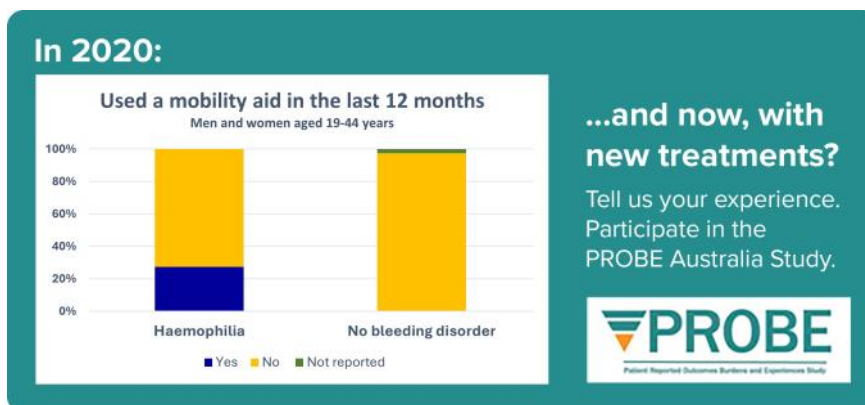
What difference have new treatments made to the experience of haemophilia in Australia?

The **PROBE Australia Study** helps HFA collect the evidence to advocate for new haemophilia treatments. And you can contribute to that evidence.

You can see from our 2020 PROBE study results how many people with haemophilia used a mobility aid like crutches back then – nearly 30% of men and women aged 19-44 years, compared to none of the people without a bleeding disorder in the same age group.

Please consider completing the PROBE survey and tell us what your experience is now.

We currently have about 250 responses. **For strong results we need about 150 more men and women to complete the survey.**



Who can take part?

- ◆ Men and women with haemophilia or who carry the gene
- ◆ AND men and women without a bleeding disorder, like family and friends, health professionals, and other people interested in haemophilia

What do we do with the data?

PROBE data is high quality and credible and we 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:

- Advocacy to government about new treatments and services
The [HFA Getting Older report](#), about issues with physical function and pain, mild haemophilia, women, hepatitis C
- The plenary on mild haemophilia at the 2023 Australian Conference
- International meetings to discuss the issues for people with mild haemophilia

The HFA poster on 2019 PROBE data at the 2024 WFH Congress (a peer-reviewed publication).

Participate in the PROBE Australia Study today and contribute to our real-world evidence on haemophilia!

Find out more at www.haemophilia.org.au/probe-australia-study.



vWD 360 study :

Gene Therapy social research study:

The poster features a light blue background with a molecular structure graphic. At the top center is the logo for vWD 360, which consists of three green circles connected by lines. Below the logo, the text reads 'VWD 360' in green and blue, followed by 'The Lived Experience of People with von Willebrand Disease' in a smaller font. The main heading is 'What is it like to live with vWD?' in a large, bold, dark blue font. Below this, there are two paragraphs of text: 'Haemnet's vWD360 study aims to gain a greater understanding of vWD and how it affects the everyday lives of you and your family.' and 'Help us learn more about the real-life impact of vWD. We'll share the study results with the bleeding disorders community and the medical community.' A green horizontal bar at the bottom contains the text 'For more information and an access code to take part, contact Dr Kate Khair at research@haemnet.com'. At the very bottom, there is a small Haemnet logo and a line of fine print: 'Haemnet is a UK research organisation working in the bleeding disorder community. For more information, visit our website: www.haemnet.com. The vWD360 study has UK ethical approval and is funded by Hemab Therapeutics.'

Do you have **haemophilia B (factor IX deficiency)**?

Or are you a parent, partner or sibling? Interested in sharing your views about gene therapy?

The University of Sydney is conducting focus groups (small group discussions) and interviews around Australia to find out what people with particular blood disorders and their families think about gene therapy. The findings will help government decision-makers assess whether to fund new gene therapies in Australia.

You will be reimbursed \$160 for your time and your travel costs for a face-to-face interview and \$110 for an online interview.

Click on the link below to express your interest in participating in an interview.

[Uni of Sydney gene therapy research link](#)

Participating in research:

Although information on specific research studies is listed on this web site for your information, this is not an endorsement of the research study by HFA.

Participating in a research study is voluntary. Before you take part in a research study, make sure you are satisfied that the study will be in your interests and that your health and privacy will be protected. All Australian human research projects must follow the guidelines made by the National [Health & Medical Research Council](#) and must have approval from a recognised Human Research Ethics Committee.

If you have concerns about a research project, you can make a complaint to the Human Research Ethics Committee that approved the study.

Be part of the social research workup for a clinical trial of an innovative new treatment for VWD. At last we are seeing the beginnings of next steps in clinical trials – very exciting!

Haemnet are recruiting people around the world with VWD to gain a greater understanding of VWD and how it affects their everyday lives. What this study involves:

- An online survey
- An optional in-depth interview and bleeds diary
- Participants will be reimbursed for their time.

Please see the HFA website for further information on this study and others :

[Social Research - Haemophilia Foundation Australia](#)

All research items reproduced from the Haemophilia Foundation Australia website



Fabulous Fundraisers: SINGLETON VILLAGE BAKERY



A huge thank you to the team out at Singleton Village Bakery, who keep a fundraising box on their counter for HFWA. Their very generous customers contributed to a donation of \$500. Cheryl (Vice President) made a little visit down to the bakery on the school holidays to present a certificate of appreciation.

(Right) Behind the counter is Simone and Molly. Thank you very much, we'd like make mention of a special HFWA member, Terri Pullan.

We may have bought a couple of treats, ok maybe more than a couple. Get down there to taste some of their amazing baked goods. You will not be disappointed with the range, quality and deliciousness of all of their items.

Located in: Singleton Village Shopping Centre, shop 8/2 Redwood Ave, Karnup WA 6176



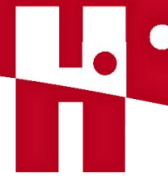
Why Not Organise Your Own Event ?:

HFA has made fundraising super easy so you can have fun whilst raising much needed funds.

By hosting a event raising money for us, you are helping HFA and HFWA provide programs and services and helping people and their families with a

bleeding disorder across Australia. **[Click the LOGO for kids activities linked to the HFA page](#)**

Our supporters have done morning teas, BBQs, cocktail parties, wear red day at school ~_the ideas are endless. Contact Natasha on 1800 807 173 or email ncoco@haemophilia.org.au so we can help you get started.



Women with Bleeding disorders Breakfast event: 13 July 2024

Women with Bleeding Disorders gather for an enjoyable and informative brunch,



On Saturday, 13th July, women living with or parents of those with bleeding disorders gathered at the delightful Decanter Cafe in Victoria Park for a thoroughly enjoyable brunch. This event brought together long-time members and newcomers alike, creating a warm and supportive atmosphere where everyone could share their experiences and ideas.

The few hours spent together were filled with meaningful conversations and valuable insights. Participants eagerly shared their personal journeys, discussing the challenges they've faced and the strategies they've developed to manage their conditions effectively. This exchange of information proved to be incredibly beneficial, especially for those who are newly diagnosed or caring for those with bleeding disorders.

One of the highlights of the brunch was the discussion about potential new treatments. Attendees were excited to learn about the latest advancements in the field and how these innovations could potentially improve their own quality of life. The opportunity to hear firsthand accounts of how others have overcome various obstacles was both inspiring and motivating for everyone present.

The event was not only informative but also a lot of fun. The friendly atmosphere at Decanter Cafe allowed everyone to relax and enjoy each other's company. Laughter and positive energy filled the room as participants connected over shared experiences and built new friendships. The delicious brunch added to the enjoyment, with everyone savoring the delightful food and beverages offered Haemophilia Foundation.

All in all, the brunch was a wonderful success. It provided a platform for women with or connected in some way to patients with bleeding disorders, to come together,

support one another, and learn from each other's experiences. The knowledge shared and the connections made during this event will undoubtedly help all attendees in their journey to manage and support those with bleeding disorders more effectively.

We look forward to catching up with any members who can join us for the Annual General Meeting (AGM) on 17th September at City West Lottery House - Conference Room.

It promises to be another progressive and enjoyable evening.

By Misha Pesnelle-Prout

Women, caregivers to patients to advocates:



This is a photo of Cheryl, Susie and myself taken at the latest women's breakfast. We all first met over 20 years ago at an HFWA event for young families when our boys were just babies.

I'm very grateful to these two dedicated, intelligent and completely fabulous women for their friendship and their kindness over the years and there is nothing that I don't feel comfortable talking to them about (not just bleeding disorder stuff either 😊).

HFWA connected us and I hope HFWA will continue to bring strangers together to share our lives living with a bleeding disorder.

We would love you to join us at the next event.

By Sharri Brodie



HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA INC.



Annual General Meeting

Details for the Annual General Meeting of Haemophilia Foundation WA Inc. is as follows:

Date: Tuesday 17th September 2024
Time: 7:00 pm start
Venue: City West Lotteries House — Conference Room
RSVP: 10 September, Dietary options if required

Agenda

1. Opening and Welcome	7. Office Coordinator's Report
2. Apologies	8. Life Memberships
3. Minutes of 2023 AGM	9. Election of Management Committee - 2024/2025
4. Business Arising	10. General Business
5. President's Report	11. Close
6. Treasurer's Report	

Following the AGM Light refreshments and beverages will be available

Nomination for HFWA Committee

The continued viability and functioning of the HFWA relies on a strong Management Committee. The present committee has a number of long-serving members, and it is critical that we have fresh faces and ideas to steer the Foundation into the future. Contact the office or Gavin if you would like to know more about the Management Committee or how you can assist.

Please tear off and hand to Gavin, Cheryl, Ann-Maree or any of the Management Committee representatives. If you can't join us for the AGM please send your nomination to the office before 17/09/2024

I wish to nominate for the 2024/2025 Management Committee

Name: _____

Address: _____

Signature: _____



Haemophilia inheritance video :

If you were born male and have haemophilia, will your children have haemophilia too?

This is a burning question for a lot of young men with haemophilia but the answer and explanation of why this occurs can be difficult to grasp.

Haemophilia inheritance in males:
the short answer



HFA has developed a 2-minute video for teenage males with haemophilia who have questions about how haemophilia is passed on in a family. It covers:

- ◆ inheritance patterns for males with haemophilia
- ◆ a short and simple explanation of the genetics involved.

Watch the video

- ◆ on the HFA website - <https://tinyurl.com/haem-inherit-male-video>
- ◆ on the HFA YouTube channel - <https://tinyurl.com/YT-haem-male-inherit-video>

HFA is very grateful to the young people with haemophilia and their parents and the health professional experts who reviewed the video – particularly the HFW youth leaders who contributed valuable feedback and advice to its development.

Republished from Haemophilia Foundation Australia

What's coming up?:

We have a few important events coming up, keep a look out on your inbox and the [website](#) for invitations:

AGM 17 September - see page 7



Annual Sausage Sizzle, 27 October, we will require volunteers as usual to cook and serve as well as donations to purchase drinks for sale. Please contact the office for further information or watch your inbox



Family Christmas event 24th NOVEMBER - Maylands Water playground

12.00 - 15.00



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

Ph: 6456 0170 If you require further information and ensure you let the health team know if you can't attend your appointment.

Say Hi to the HFWA reps that are there.

August – 6th and 20th

September – 3rd and 17th

October – 1st, 15th and 29th

November – 5th and 19th

December – 3rd and 17th



World Hepatitis Day:

World Hepatitis Day is marked globally on 28 July. This is part of a global campaign to eliminate viral hepatitis. In 2024 the national theme is It's time for action, reminding us that that hepatitis C and liver health remains an important issue for our community and that acting now is vital.

DON'T PUT IT OFF – TAKE ACTION NOW

Do you know your hep C status? Find out if you don't know.

Hep C can be cured. Treatment is simple.

Do you need liver health monitoring? Ask your doctor.

A healthy liver is vital for all of us.

In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of bloodborne viruses from plasma-derived clotting factor products in Australia is now considered to be extremely low. But many people in our community live on with the consequences of those early infections.

It's estimated that 1 in 5 Australians do not know they have hep C.

For some people with bleeding disorders, it has been a surprise to find out they were exposed to hepatitis C, especially if they only had one or two treatments over their lifetime. This includes:

- women who carry the gene
- women and men with mild haemophilia or VWD

If you ever had a blood product before 1993, including blood transfusions and plasma-derived clotting factor concentrates, you could be at risk of hepatitis C.

Hep C treatments now are radically different to the early interferon treatments - a once-daily tablet, few

if any side-effects and very high cure rates.

Most Australians with bleeding disorders and hep C have now been cured – but some need ongoing care of their liver health.

Were you cured of hep C? Has your liver recovered? You might think it's all OK, but it's easy to miss symptoms of liver disease. Ignoring your liver health can have serious consequences.

If you don't know the state of your liver health when you were cured, contact your hepatitis doctor or your GP to check your liver test results. Find out if you need ongoing follow-up with a liver specialist.

REMEMBER

If you had cirrhosis or extensive scarring before being cured of hep C, you will still need to have a liver ultrasound scan every 6 months long-term.

How can you keep your liver in good shape? Find out more at www.haemophilia.org.au/healthy-liver.

For more information visit www.haemophilia.org.au/world-hep-day or click the image below.



It's time for action.

Find out five ways to keep your liver healthy:

haemophilia.org.au/healthy-liver



Arved Wasser Memorial Fund

Arved Wasser Memorial Fund was established to commemorate the enjoyment Arved Wasser gained from attending and competing in an chess tournament, with a little help from the Haemophilia Society of WA (as it was known at the time).

As a 'pay it forward' gesture, the Arved Wasser Memorial Fund was established by the haemophilia Society of WA & his family as recognition of the importance of being involved in joyful & fulfilling activities, and as a way of thanking the HFWA for helping Arved to achieve something that gave him happiness.

Please contact the [office](#) if your would like apply for the [Arved Wasser fund](#) .

This can be added to Apple or Google wallet through the Containers for Change website –

[https://www.containersforchange.com.au/wa/good-causes-directory?keyword=Haemophilia%20Founda-tion&category=all&scheme_id=wa#findacharityblock](https://www.containersforchange.com.au/wa/good-causes-directory?keyword=Haemophilia%20Foundation&category=all&scheme_id=wa#findacharityblock)

Scan the barcode when you return



Scheme ID

C10338968

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

HFWA Membership Renewals 2024/2025: Did you know, just because you receive the newsletter DOESN'T mean you are a MEMBER?

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

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 .



Support our fundraising and enjoy 100s of everyday savings!

Entertainment is the easy-to-use App packed with incredible savings of up to 50% off and 2-for-1 offers, so you can save on takeaway, dining, shopping, groceries, gift cards, activities and more! And what's even better, 20% of every membership purchased goes to support Haemophilia Foundation Western Australia Inc.!

Buy Membership

Bonus Multi City Membership Upgrade*

12 months

\$70 | SAVE \$50

OR

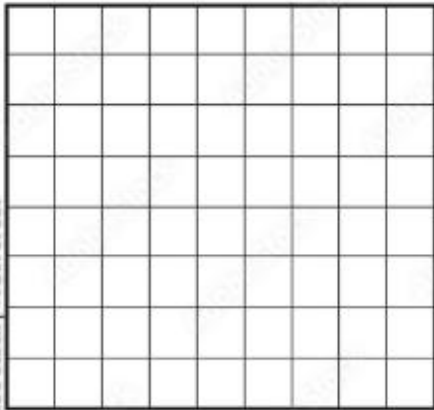
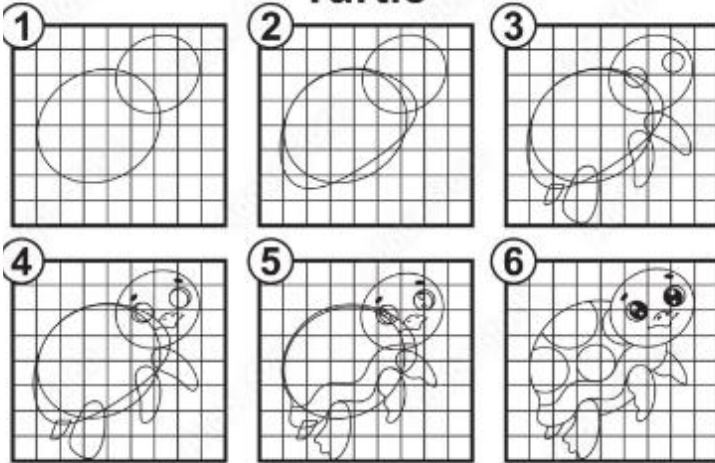
24 months

\$120 | SAVE \$110



HOW TO DRAW

Turtle



Kids fun page :



Bleeding Disorders
Awareness Month
OCTOBER 2024

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

can you find the words?

Bleed	Bruise	Factor	Haemophilia	Moderate
Joint	Mild	Port	Severe	Hereditary
	Treatment	Vein	VWD	

Colour me in

