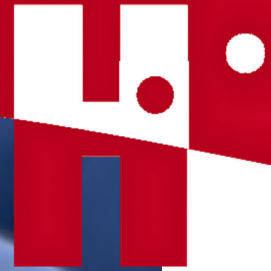


# CONTACT

Newsletter of Haemophilia Foundation WA Inc.

April 2023



Cover Picture: Womens Brunch: Turquoise Cafe, March 2023

Open up the Newsletter to see what's been happening with the HFWA and what's coming up in the Bleeding disorder Community.

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**HAEMOPHILIA FOUNDATION WA INC.**

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## YOUR COMMITTEE

|                               |              |
|-------------------------------|--------------|
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| 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

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## 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  
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

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Hi Folks

## Presidents Report

Hope everyone had a good Easter (or Passover) and you have finished all your Easter Eggs.

HFWA has a few events coming up so make sure you attend those that are relevant to you (see page 11).

It is important to us to have as many people attend events as possible. We are always looking for new ideas for events and would appreciate any suggestions you may have so feel free to send them into the office.

We had a good attendance at the Family Barbecue at Tomato Lake (see photo on pages 6-9). We hope all who came along enjoyed catching up or meeting others and enjoyed the magnificently cooked sausages and food.

HFWA has a limited amount of funding to assist members to attend the HFA Conference held in Melbourne from 24 to 26 August (see the Funding Application on page 4). The HFWA management committee will review each application and allocate funding on a case by case basis - get your funding applications in as soon as possible so you don't miss out. It will be great to have a face to face Conference again to get the latest on what is happening in bleeding disorder treatment, catch up with old friends, meet new ones and engage with all stakeholders in our diverse community.

If you have any questions in relation to HFWA or treatment issues feel free to contact us.

Looking forward to seeing as many of as possible at the next HFWA event.

All the best,

Gavin

## New WWBD resource

The A5 **Guide to haemophilia testing in women and girls** (shorter/simpler version) has now been published and is available for download on the HFA website at:

<https://www.haemophilia.org.au/publications/information-resources/women-with-bleeding-disorders/guide-to-haemophilia-testing-in-women-and-girls>

As you will see from the acknowledgements, there has been a lot of expert advice involved, as well as ideas and feedback from our women's consumer group! We are very grateful to everyone involved – it has made a huge difference to the content and how it was approached.

## HFWA Morning Tea - 17 April



HFWA will host morning Tea on Monday 17 April from 10am at City West Lotteries House.

Please come along and join us, bring a plate if you wish to contribute.

RSVP by Friday 14 April : [office@hfw.org](mailto:office@hfw.org)







## 2023 Conference

The **21<sup>st</sup> 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?

The program will include presentations from people living with bleeding disorders as experts as well as health professionals and other specialist speakers.

The venue has good access in and around the hotel and on the conference floor, with direct lift access. The hotel is suitable to people who use wheelchairs.





## 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).

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Or email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

## When do I need to disclose that I have a bleeding disorder?

By law you don't usually have to tell anyone about having a bleeding disorder or carrying the gene.

There are a few situations where you will be required to give this information if asked. These include:

- ♦ Applying to join the Australian Defence Force or police force
- ♦ Applying for insurance such as Life and Income Protection Insurance
- ♦ Applying for superannuation
- ♦ Applying for private health insurance
- ♦ Applying for travel insurance
- ♦ Traveling – you may be asked questions relating to your bleeding disorder by customs and security officers or other government officials

Applying for or continuing a job where your condition is likely to have a fundamental impact on your ability to do your work or may pose a risk to occupational health and safety.

If you are unsure whether you need to disclose your bleeding disorder it may be helpful to speak with your Haemophilia Treatment Centre (HTC).

If you do choose to tell an employer or service provider, by law they are not able to discriminate on the basis of your condition apart from the exceptions above.

If you need information on discrimination you can contact your state or territory Equal Opportunity or Human Rights Commission, or contact [The Australian Human Rights Commission](http://www.humanrights.gov.au) ([www.humanrights.gov.au](http://www.humanrights.gov.au)).

You can also contact your [Haemophilia Treatment Centre](#), [local Haemophilia Foundation](#) or [Haemophilia Foundation Australia](#).





## World Haemophilia Day Monday 17 April

Every year on 17 April World Haemophilia Day is recognised worldwide 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 Haemophilia 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 international theme is **“Access for All: Prevention of bleeds as the global standard of care”**. The aim is to improve access to treatment and care with an emphasis on better control and prevention of bleeds for all people with bleeding disorders. This means making home-based treatment available as well as prophylaxis treatment to help people with bleeding disorders to have a better quality of life.

***Did you know, WFH estimates that over 65% of people living with haemophilia worldwide have not yet been identified and diagnosed.***

The World Federation of Hemophilia, with the support of volunteers from around the world, does remarkable work to improve access to diagnosis, treatment, care and support for people with bleeding disorders in less well-resourced countries with their GAP and Twinning Programs and the Cornerstone Initiative. HFA is currently connected with the Myanmar Haemophilia Patient Association as a part of the WFH Twinning Program.

Haemophilia Foundation Australia is a WFH member organisation and many Australian volunteers have been involved with WFH programs. HFA has supported many programs over the years and participated in the WFH Twinning Program and various committees that work to achieve the objectives of WFH.

In Australia, our community is fortunate to have access to a range of treatments, care and services. During recent times, some new haemophilia therapies available in Australia have led to fewer or no bleeds and greatly

improved the quality of life of those who have been able to use them. We look forward to more novel therapies in the future for everyone.

We have many locations and landmarks all over Australia **Lighting up Red** in support of World Haemophilia Day. In Western Australia we have the following locations.

Matagarup Bridge, Council house, Trafalgar Bridge, Mandurah Traffic bridge, and more to come. We will list them all on our website.

So go out for the evening and take some photos and talk about why they are **LIGHTING UP RED**

For updated locations keep an eye on HFA website [www.haemophilia.org.au/WHD](http://www.haemophilia.org.au/WHD) and HFA social media platforms.



## Gene Therapy Trials

Participants with Moderate or Severe Haemophilia A needed.

Are you available and interested in participating in a gene therapy trial (if you qualify) for people with moderate or severe Haemophilia A.

Please contact **Marina** (Clinic Trials Co-ordinator) at the Fiona Stanley Hospital Haemophilia Treatment Centre on 0417 939 421 for further information and to register your interest.





## Men's and Women's Events

Our most recent event's were held on Saturday 11th February for Women with Bleeding disorders, which was at the amazing Turquoise Café in North Fremantle. Sunday 12th of February for the Men and Hamptons City Beach, here are some recounts of the events and previous gatherings.

"My mum and I felt so welcome at the women's breakfast- we were amongst like minded women. But the greatest thing Mum and I took away from the catch-up was, what impact the various types of bleeding disorders have on not just the affected generation but throughout all generations- there were grandmothers, mothers and daughters whose male children were affected and then those who were affected by VWB themselves. We learned how there currently wasn't the equivalent to emizuzamab (hemlibra) for VWB sufferers.

It was a very special opportunity to talk to these women- bonus was we got to hold baby Freddie! - *Ally and Lynda* "

"I thoroughly enjoy attending the Women's Breakfasts, and the last one did not disappoint! The food was amazing and the location was great. It always fills me with a sense of pride to be a part of this amazing and supportive community where we are always met with such warm hospitality and can connect and share information with each other. - *Robin*"

"Yep the Men's Breakfast was once again enjoyable, it's good catching up with new and old friends  
It's funny years ago we all sat around reminiscing about life without treatment, to the advancements in treatment such as Cryo to AHF to Bio state to recombinant. From the 2000's most guys were on the one same product to manage their haemophilia

Today's conversation about treatments was varied, as many guys are on different products to manage their haemophilia, albeit many are on clinical trials. And the current ease of dispensing and administering products (sub cut), most now using it weekly compared to on demand or every 3rd day routine we once had.- *Dave*"

"I look forward to the men's breakfasts as it gives me a chance to connect with people who I've met through HFWA, and just touch base with what's happening in the space of haemophilia. - *Dom*"

"I like to see old and new faces. Too bad there isn't a cocktail style breakfast where we can mingle more instead of stay seated.- *Sharri*"

"I just had a tooth extraction yesterday and my bleeding issue was well contained which was not the case prior to this procedure. The bleeding management was changed for the better.

As always the "men's breakfast" is something I look forward to, not for the food as such but for the info I glean from various conversations. My gut feeling approach seems to fall on the wayside even though it has helped me manage my bleeding....sort of win some and lose some.- *Dennis* "







It was a beautiful autumn Sunday for the HFWA family BBQ on 12 March at Tomato Lake. 25 or so people came along for a chat, a sausage sizzle and (for the little people) a run around the playground. Gavin tackled the temperamental public BBQs, while others toughed it out sitting around relaxing in the shade with a cool drink. It was a great chance to catch up with other members and families. For those who ventured for a walk around the lake, "bin chicken headquarters" didn't disappoint! Apart from being a good social outing, it's always valuable to hear how others in the community are managing, to swap stories and advice, and hear about the latest treatment options coming through the pipeline. Hopefully see you at the next one! *Dustin & Hana, Penny (6) & Nora (4)*

We had 24 of our community members (and 1 delightful dog Tippy) come along to the first Family BBQ of the year at Tomato Lake in Belmont. The weather was perfect and the location was fantastic, not busy or crowded. With clear and close access to the carpark, playground, toilets and the bbq. We had the ever useful President Gavin cooking the bbq under the watchful eye of Dom, Will, Dustin and Bill along with a couple of magpies. The kids played some fun games and the adults all got to have a chat. I brought along many different resources for members to take home if they wanted. Treatments, life, and planning of upcoming events were discussed. I had a great time meeting everyone that came along.

Thank you, Ann-Maree

## Family BBQ 12th March

Thank you for organising the get together today, Tomato lake Park was a nice calm location, Pam and I enjoyed catching up with all the attendees.

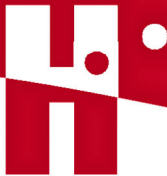
Special thanks to Gav for the BBQ work and Ann Maree and Cheryl for setting up the food and drinks.

### *Bill and Pam*

Please enjoy the pictures from recent events over the next 3 pages.















## My perspective

I am writing this for the HFWA newsletter and community because I wish to acknowledge the important support the Foundation has provided for myself and my parents for many years.

My parents were distressed when they discovered, in the early 1980s, (I was about a year old) that I have haemophilia. Back then treatment was not close to what it is now. The Foundation provided parents with access to people to check in with and share experiences. The introduction of home treatment, which was facilitated by the Foundation, was a massive improvement as it removed the need for queuing in emergency and explaining our condition to doctors every time we needed treatment. When I was growing up, the Foundation allowed me to meet lifelong friends such as Gavin, who gave me much good advice and who still helps me today.

I grew up in a period of transition. Initially, treatment was not completely effective. We had a period where many people with haemophilia got viruses from their treatment. It has been amazing watching the treatment improve and younger people with haemophilia no longer having to suffer disabling joint issues. The HFWA has always been essential for supporting us through these periods.

I believe that in the past the HFWA played a bigger role for people with haemophilia as, week-to-week, life was much more challenging than now. People with haemophilia are now more-or-less sorted with modern medicine, and as a result, HFWA plays a lesser role in our lives. The knock-on effect is that the HFWA is suffering reduced support.

I think the reality is that the HFWA is still critical for people with haemophilia and their families, and we should make sure it has a future. Without the HFWA, there would not be a group of people available to help others and also no-one to assist with lobbying the government to assist us get the best treatment possible.

Australians with haemophilia are lucky as our expensive treatment is paid for by the government. From 2000 to 2019, government health expenditure increased from about 14.6% to 16.25% of GDP. A rough estimate is Alprolix (factor 9) costs about \$200k per annum for each person. Subcutaneous and other modern treatments cost even more. But we live in a time where government spending is always under pressure. Many other developed nations don't have it as good as us, and we shouldn't take government support for granted. We need active and effective foundations to ensure we have continued access to the best treatments.



The committee is on a mission to try and bring more like-minded people together and make HFWA a stronger and more effective organisation. In a small attempt to assist, I have attended a few committee meetings (it is a welcoming & relaxed atmosphere), and there was discussion of what events we can have to get people together. I have suggested that we have an event at a bowling club, where hopefully people can enjoy a bowl if they like, kids can play, and all can enjoy food and refreshments. I know the committee will welcome other suggestions. I look forward to seeing some of you at future HFWA events.

Darren Tull



## Arved Wasser Memorial Fund

As a parent of a previous recipient of Arved Wasser funding I want to encourage families to consider applying this year.

We received funding for drum lessons for our child with a bleeding disorder. With a young family, I found balancing the budget challenging. Recreational, extra-curricular expenses fell into the 'discretionary spend' bucket and was often really hard to justify. With the support of HFWA through the Arved Wasser fund, our child was able to participate more broadly in life, try new things and live a full life exploring new experiences.

The end of semester concert was a fabulously memorable experience. I still recall how delightful it was to see them as a performer, as an enthusiastic student and a group participant completely separate to their day to day existence or anything to do with their bleeding disorder.- Susie Couper

Arved Wasser Memorial Fund was established to commemorate the enjoyment Arved Wasser gained from attending and competing in a 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.

The Metropolitan Chess Club holds an annual tournament to honour Arved Wasser and his achievements.

Please contact the office if you would like to know more about the Arved Wasser Memorial Fund.



## Guess who's coming to Insta ?

Instagram

The HFWA will soon be on Insta, keep up to date with the latest news and happening of the HFWA, HFA and other states. If you take any photos on Monday 17th April of the Light UP Red monuments in Perth send them in for us to post.



Did anyone manage to catch episode 3 in season 12 which deals with a newborn case of haemophilia? Lorna Pryce comes into the maternity clinic with her doting mother and later in the episode, gives birth to baby Ian. As the pair recover after the birth, [Dr Patrick Turner](#) (Stephen McGann) notices that Ian has a cephalohematoma, a birth injury caused by trauma to the infant's head. "It's simply a bruise under the scalp from where we had to give him a tug with the forceps," he explains.

## Save the date

**Mens breakfast:** 20th May 8.30am, watch the website and inboxes for your invites coming soon.

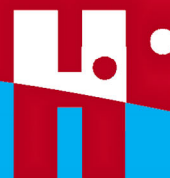
**Women with Bleeding disorders breakfast:** 21st May, watch the website and your inboxes for invitations.

Attendance to these events are free to current Haemophilia Foundation Members.

We will be sending reminders in June for 2023/24 membership renewals.







# YOUTH NEWS

## Haemophilia – the spice of life



My name's Willem. I am 20 years old and I have severe haemophilia A.

**Willem talked to HFA about being part of his local community, making friends and trying out new skills.**

**Have you been involved in any local foundation activities?**

I have been to camps in my youth and more recently to some of the men's breakfasts and Christmas parties. It's been good to participate in the community.

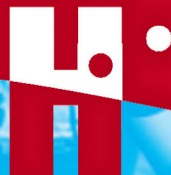


The camps were great – an introduction to haemophilia, meeting other kids my age and learning from them and older people.

**What were the camps like?**

The camps were great – an introduction to haemophilia, meeting other kids my age and learning from them and older people. It's a good place to make friends and I still keep up with them.





## Willem's story



It's a good place to make friends and I still keep up with them.



I have also done the Bunnings sausage sizzle events. A good hands-on experience.

## What other Foundation activities are you involved in?

At the men's breakfast we have a good social time but we also talk about new treatments, how they are progressing and hear how the new treatments are going for the people who are on them.

I have also done the Bunnings sausage sizzle events. It's a good confidence booster for a young person to know you are capable of doing these events – a good hands-on experience to talk to people and answer their questions. It's also a great way to educate the community so that they understand the experience of living with haemophilia today and know how to treat people with haemophilia that they meet.

### Read more

Check out the personal stories from other young people with bleeding disorders on:

- Factored In, the HFA youth website - [www.factoredin.org.au](http://www.factoredin.org.au)
- The HFA YouTube channel - <https://tinyurl.com/HFAYouTube>

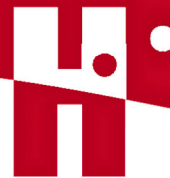
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*Stock images: Helena Lopes for Pexels.*

# CONTACT

April 2023

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To order your bags and arrange collection

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Email your order for the shopping bags directly to the HFWA office on [office@hfw.org](mailto:office@hfw.org) with your name, address and phone number 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



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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.

## Event feedback & suggestions:

We recently asked attendees at some of our events if they had any suggestions for events and activities, to have throughout the year, here's what came back:

- \* Picnics : with cuddly animals/face painters/ magician
- \* Bowling
- \* Mini golf
- \* Fishing charter
- \* Beach day
- \* Flight Club/ Axe Throwing
- \* Movie Night



# Easter

## WORD SEARCH

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| G | O | Z | J | F | T | S | R | L | R | G | P | E | S | T |
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SUNDAY  
TRADITION

