

CONTACT

Newsletter of Haemophilia Foundation WA Inc.

April 2024



Cover Pictures: World Haemophilia Day 17 April 2024 Light It Up Red. Top Left : Joondalup Bridge, The Bell Tower, Bunbury Waterfront.

The Management Committee thanks everyone who got out and about to take the WHD photos and share on social media. Stock images sourced from pixabay.com unless otherwise noted. Permissions granted by those in featured event pictures and the photographers of images.

HAEMOPHILIA FOUNDATION WA INC.

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

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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



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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);
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Hi Everyone,

President's Report

What's on for 2024?

I'm writing this report in between sessions on the final day of the World Federation of Haemophilia Congress.

It has been an interesting and informative Congress with numerous topics and much learnt

Two topics where there has been a big emphasis on are Gene Therapy and Women with Bleeding Disorders, treatment, management and clinical trial participation.

Gene Therapy is becoming a more mainstream form of treatment but unfortunately a successful outcome cannot be guaranteed.

One session involved a pool of successful recipients of gene therapy, one with minimal benefit and someone who declined to take the opportunity when offered.

Another session was about women with bleeding disorders and the treatment/access to treatment and the recognition of the need to treat.

Also, the participation of women in clinical trials especially for vWD products and as patients with mild haemophilia and the push to recognise heavy/long periods as a bleeding event.

Congress is also a great opportunity to catch up with friends made over the years and meeting new people and seeing where the trends of haemophilia, bleeding disorders treatments are going. discussing issues such as engaging with the community, the need of a strong representative organisation to advocate on behalf of the community.

We have a Men's Breakfast coming up on Sunday 19 May at 8.30 am (see invite to the right for further details)

This year's Light it Up Red for World Haemophilia Day was a great success we had a record number of sights lit up in WA but unfortunately a couple of hiccups that we hope to resolve for next year see the photos on pages 1-8

I look forward to seeing you at a future HFWA event.

Regards ,

Gavin

We are planning many events as usual this year and really hope you can make it along. Without attendees and interest, the events wont have reason to run.

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? We are thinking.....

- ◇ Men's breakfasts
- ◇ Women's Event later this year
- ◇ Family BBQ
- ◇ Parents Sundowner
- ◇ Barefoot Bowls or Escape room event for youth and young adults.
- ◇ October Sausage Sizzle at Bunnings
- ◇ Family Christmas party, Outback Splash or Maylands Water playground

Send me an email office@hfwa.org if there is something you would like to suggest.

Thanks

Ann-Maree, Office Coordinator.





World Haemophilia Day 2024

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.

In 2024 the international theme is **“Equitable access for all: recognizing all bleeding disorders”**. The World Federation of Hemophilia (WFH) vision of Treatment for All is for a world where all people with inherited bleeding disorders have access to care, regardless of their type of bleeding disorder, gender, age, or where they live.

Did you know, WFH estimates that over 75% 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.

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 with a bleeding disorder.

Read on to see some of the images captures in WA by our community.

A poster for 'Light It Up Red 2024' in Western Australia. It features a map of Australia with the date '17 APRIL' and the slogan 'Light It Up Red 2024'. The poster lists metro and regional sites for the event. The HFA logo is in the bottom left, and the text 'WESTERN AUSTRALIA' is at the bottom.

Light It Up Red 2024

17 APRIL

METRO SITES:

- COUNCIL HOUSE,
- TRAFALGAR BRIDGE,
- FRASER AVE KINGS PARK,
- BELL TOWER,
- MATAGARUP BRIDGE,
- MOUNT STREET BRIDGE,
- NORTHBRIDGE TUNNEL,
- SKY RIBBON, JOONDALUP DRIVE BRIDGE

REGIONAL:

- MARLSTON HILL LOOKOUT,
- KOOMBANA BAY FOOTBRIDGE AND FORESHORE,
- MARLSTON WATERFRONT, GUPPY PARK,
- NAVIGATORS AT KOOMBANA DRIVE ROUNDABOUT, RICHMOND RESERVE, AAROL CRANE, KOOLAMBIDI WOOLA

HFA

WESTERN AUSTRALIA

A poster titled 'Australia is lighting up red!' featuring a map of Australia with red location markers. It includes the World Haemophilia Day logo, the date '17 APRIL 2024', the hashtag '#WHD2024', and the slogan 'RECOGNIZING ALL BLEEDING DISORDERS'. The HFA logo is in the bottom left.

Australia is lighting up red!

WORLD HAEMOPHILIA DAY
17 APRIL 2024
#WHD2024

RECOGNIZING ALL BLEEDING DISORDERS

HFA

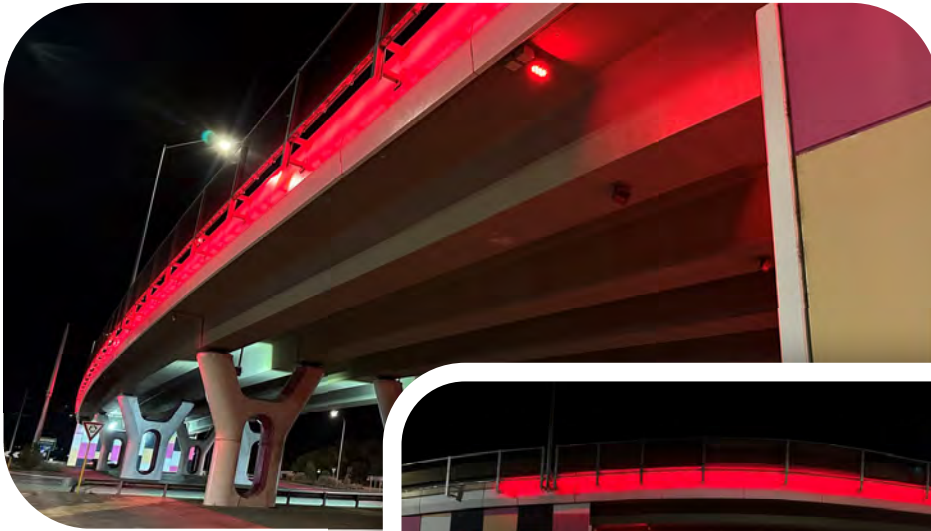
©haemophiliafoundationaustralia



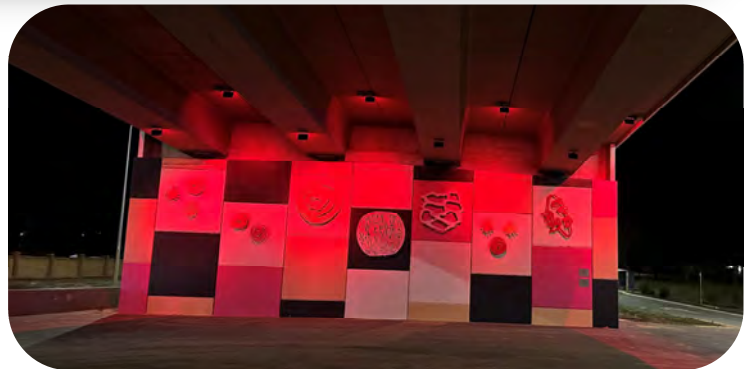
World Haemophilia Day 2024

The management committee would like to extend their gratitude to the talented and intrepid photographers who managed to get out to the landmarks and share them with us. Robin, Dom, Charlie, Maddie and Freddie Dique (The Bell Tower, Matagarup Bridge), Michelle Dinsdale (Joondalup traffic Bridge), Sara and Bruce Tomlinson (Bunbury landmarks), Pam and Bill Aitkins who happened to be in Adelaide so they got some sweet pictures.

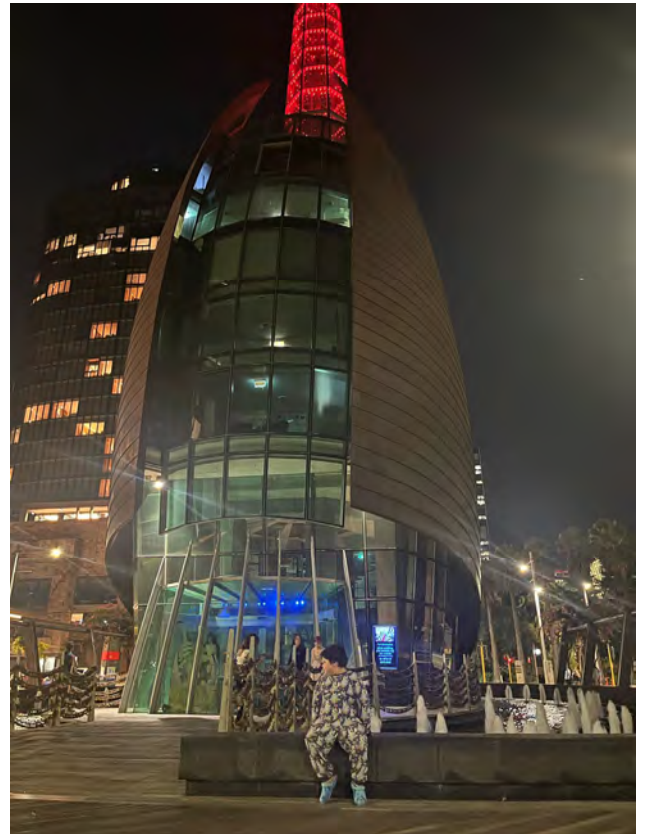
Did you get some selfies? Post them and tag @haemophilia_foundation_wa_inc



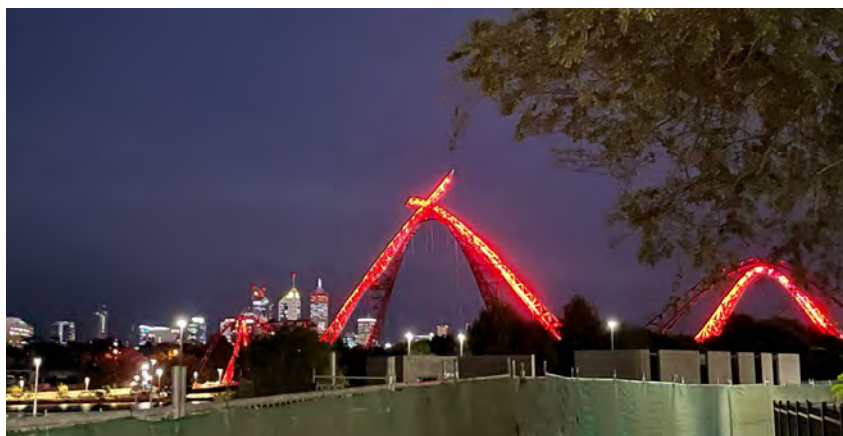
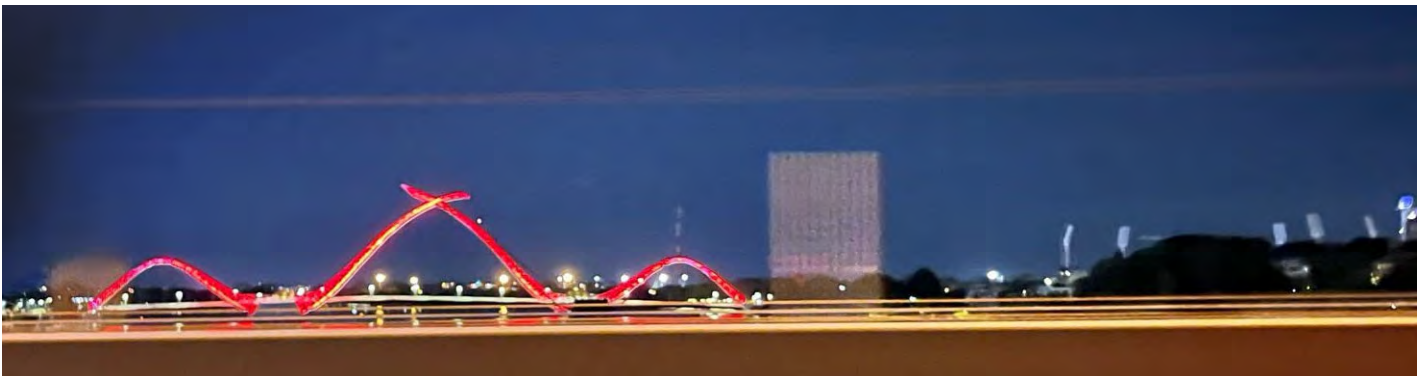
*Three angles of
Joondalup traffic Bridge.
M Dinsdale.*

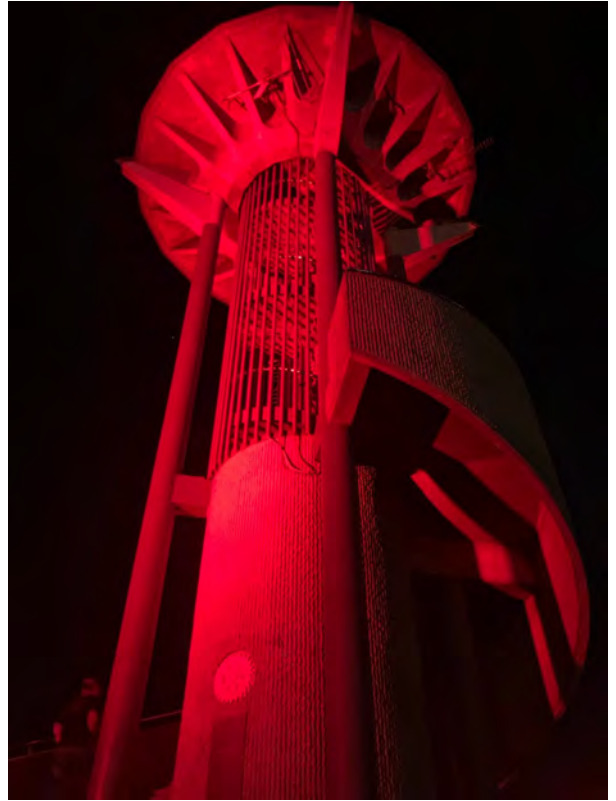


Left: Fraser Ave, Kings Park



Charlie D, representing HFWA at the Bell Tower once again, on a night time adventure to see the Red Landmarks. Thanks Charlie and parents!





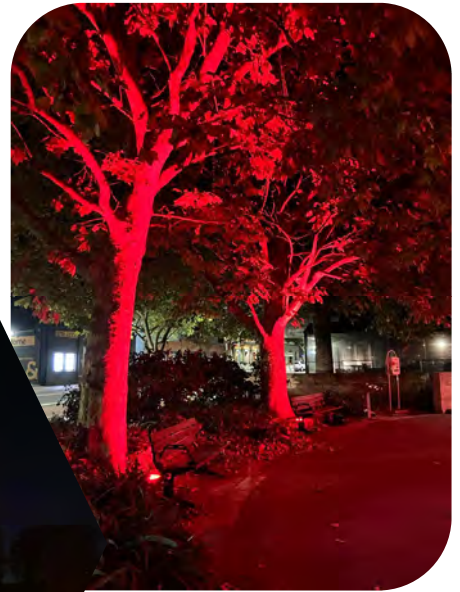
Top left: Regional sites, Koombana Bay foreshore. Right: Marlseton Hill Lookout. Below: Marlseton and the moon. Bottom right: Guppy Park,



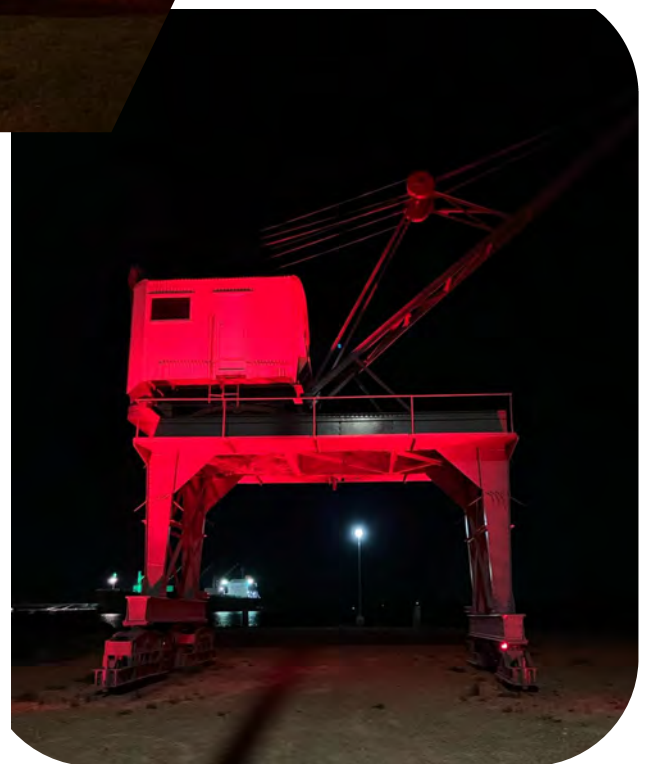
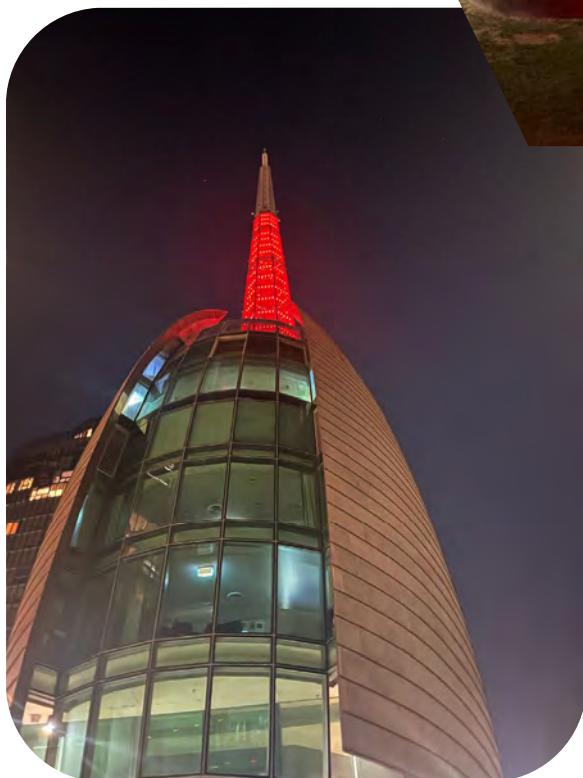


[Wardandi Boodja](#) is a five-and-half-metre steel bust sculpture representing a Noongar face and South West families.

Bottom right: Arrol Crane, Bunbury

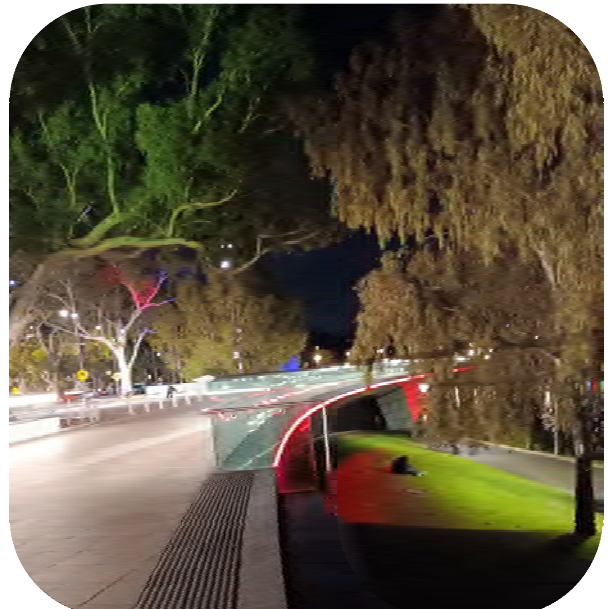


Below: The Bell Tower





Top Left clockwise: South Australia - Bill and Pam at Parliament House and Riverbank Lighting feature.





Women with Bleeding disorders Op Shop Event : 20 April 2024

When I got the invite from HFWA to come have some fun shopping while helping the planet I knew it was an offer too good to refuse.

They had me at "come shopping!"

So on a lovely sunny autumn Saturday I headed off to Cottesloe for the perfect shop-tile-you-drop op-shop experience.

The morning kicked off with an inspirational presentation from Loraine Martin, "Australia's op-shop queen" which showed us all the tips and tricks for successful op-shopping. Her top tips were to 'be patient and ignore sizes'.

Who would have known that styling and accessorising with belts, scarves, bags and jewellery could be so much fun - when you know how.

Armed with our empty HFWA tote bags and our new treasure hunting skills this bunch of budding fashionistas set off to find bargains and do our bit for the planet to keep things out of landfill.

Moving from room to room we searched for hidden gems. Feeling the thrill of digging up designer clothes, snazzy shoes and beautiful bags. Not to mention uncovering handy homewares and some truly unique items.



There was so much to choose from, many barely used and even brand new items with the original price tags still attached. Not that we needed them because

still attached. Not that we needed them because everything was at bargain, value-for-money prices.

As we found out ...op-shopping (& catching up with friends) was thirsty work so it was lucky that our HFWA buddies had thought of everything and had lots of refreshments at the ready.

Re-fueling during our op-shop adventure was also made easy with a delicious morning tea and a table loaded with tasty treats. It also gave us a chance to sit down, compare our finds and share a laugh over some of the more unusual discoveries.



Some of the wonderful attendees

Sadly all good things must come to an end so after a few hours of unearthing treasure we headed to front desk with our precious "bounty" to complete our purchases. What a great day.

We all left with full bags, happy smiles and a sense of satisfaction that not only had we saved money but by ethically shopping we were also caring for the environment.

A big thank you to Loraine and the awesome team at [Solaris Cancer Care Op Shop](#). As converted op-shop devotees we know we'll be back to see you all again.

Thanks

Nici Burgess

Article continued on next page.



Op Shop continued.

Lorraine's tips:

IGNORE SIZES

Sizing is so different in charity stores because there are garments from manufacturers from all over the world. So ignore what the tag says, try it on and get a feel for the fit and the fabric.

LOOK FOR LABELS

I do this not because I am a label queen but because often the fabric is a better quality and the garment will have a better second life down the track.

DISREGARD THE LOCATION

Posh suburbs don't mean better stock. Often charities sort and stockpile at one big location then send everything out to all areas so the stock is evenly distributed anyway.

ALTER THINGS

This is a big one. Sometimes people throw something out because its missing buttons or its too long. Altering is cheap so its worth spending a few dollars on some buttons if it means getting more life out of it.

BUY LEATHER

Always keep an eye out for leather. Belts, jackets or shoes, whatever. Leather can be conditioned. It has such a long lifespan. I can't believe anyone ever throws out leather.

WEDDING AND FORMAL DRESSES

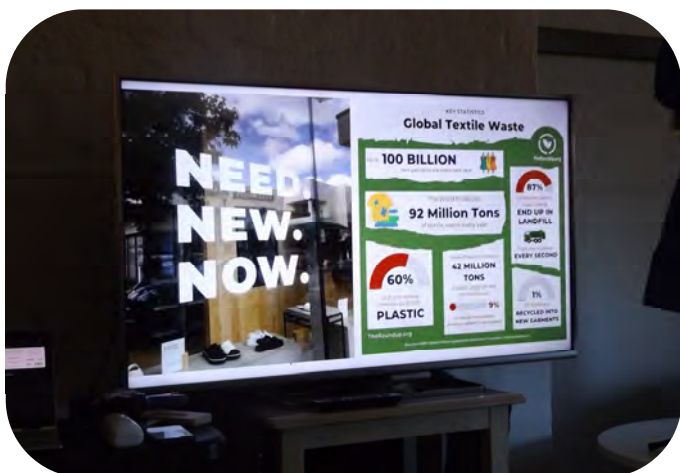
It's always worth looking at these in a charity store. These dresses are, with few exceptions, only worn once. So amazing things can be found.

MAKE A LIST

Whenever you think of something you need or want, put it in a list in your phone. Then, when you're shopping you can refer to it.



Above: Sharri Brodie and Loraine to the right of picture



BE MINDFUL OF FABRICS

Retail fashion today is all nylon and polyester and that stuff is basically like plastic. It doesn't break down in the ground. In op shops look for fabrics like cotton, linen and silk - you can often find great things of really high quality that aren't going to harm the environment.



Absorbing all the knowledge for future shopping missions



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 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 you would like apply for the [Arved Wasser fund](#).

Containers for Change HFWA barcode:

Scan the barcode when you return



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->

HFWA Membership Renewals 2024/2025

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 almost that time of the year again (30 June) 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 contact the office to complete a membership over the phone.



DO YOU KNOW THE UPCOMING COAG CLINIC DATES?

April - 30th,

May - 7th, 21st ,

June - 4th, 18th

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

Ph: 6456 0170 If you require further information'

Say Hi to the HFWA reps that are there.

We love a good chat, and are there to help and support.