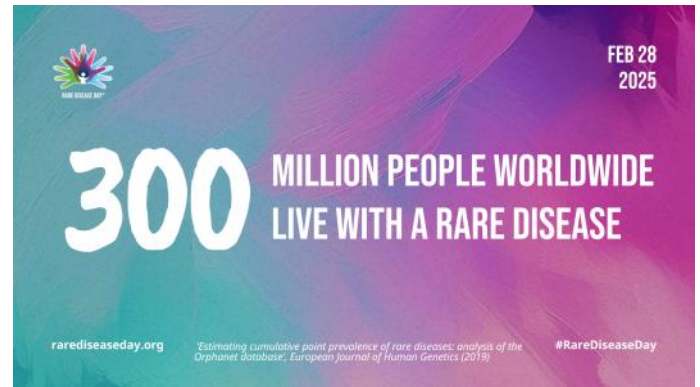
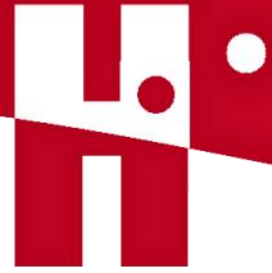


# CONTACT

Newsletter of Haemophilia Foundation WA Inc.

February 2025



Cover Picture: HFWA Christmas Party Nov 20254 (Maylands Waterland), Rare Disease day 28 February Happy New Year to all of you! HFWA Management Committee extends their gratitude to all members and supporters and it is shaping up to be a busy 20255.

Stock images sourced from pixabay.com unless otherwise noted

## HAEMOPHILIA FOUNDATION WA INC.

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

P: 08 9420 7294 E: [office@hfw.org](mailto:office@hfw.org) W: [www.hfw.org](http://www.hfw.org)

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 20254/20255

Gavin Finkelstein (President)	0415 978 031
Cheryl Ellis (Vice President)	0402 033 652
Darren Tull (Treasurer)	
Michelle Dinsdale (Secretary)	0407 197 815
Robert Butler	9381 3386
Susie Couper	
Misha Pesnelle-Prout	
Office Coordinator	Ann-Maree Foran

Profiles of committee members can be found on the  
HFWA Office 2 Delhi Street, West Perth

Phone 9420 7294  
Email [office@hfwa.org](mailto:office@hfwa.org)

## PERTH CHILDREN'S HOSPITAL CONTACT DETAILS

Clinic H, Level 1 (Haematology/Oncology Outpatients: Ph: 6456 0170)

Medical Staff: **Dr Tina Carter** Ph: 6456 0170

Nursing Staff: **Natalie Gamble-Williams** and **Stacey Hutchison**

Social Worker:



## 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.



Hi Folks,

Things are starting to ramp up at HFWA.

We continue to have good attendances at Women's and Men's activities, and we are always looking for new ideas for venues and activities.

We are planning a few different activities that will hopefully interest you; if you have any ideas, please don't hesitate to contact Ann-Maree at the office by email.

We have a record number of landmarks being lit up for World Haemophilia Day on 17 April (see page 5 for a state-wide list). If you can go and see any venues for Light it up Red, please send in any photos you capture. It's pretty special to see.

If you need someone to talk about bleeding disorders, contact the office. Cheryl and I can be available to speak on behalf of our community.

Please note that the HFA Conference is from 16 to 18 October in Brisbane. It would be great to get as many people as possible to attend; more information will be available soon, so "watch this space".

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 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 My-ABDR treatment diary has been developed alongside as an alternative.

MyABDR links directly to the [Australian Bleeding Disorders Registry \(ABDR\)](#), the system used by [Haemophilia Treatment Centres](#) for clinical care of their patients.

### Can you help with the PROBE Study?

We really appreciate the support our community has been giving to the PROBE Australia Study. This is a very important study for the bleeding disorders community and a big project! HFA has been recruiting for the last year or so – but is not quite finished.

Still needed:

- About 95 people WITHOUT a bleeding disorder – particularly men
- About 50 people with haemophilia – both men and women



### Why data from people WITHOUT a bleeding disorder?

It's simple. For the data to be meaningful, it needs to be able to compare the lives of people WITH haemophilia and WITHOUT a bleeding disorder.

Please consider sharing the study with your friends and extended family.

### How to do the survey

It's easy! Go to:

- [myprobe.org](http://myprobe.org) for the web version
- Or download the myPROBE app from Apple Store or Google Play (Android)
- Or ask HFA for a print survey pack



### ANY QUESTIONS?

Visit [www.haemophilia.org.au/probe-Australia-study](http://www.haemophilia.org.au/probe-Australia-study)

Or contact Suzanne at HFA: 1800 807 173 or

[socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au)





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

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

**Do you have a young person who is 18 and transitioning to Fiona Stanley Hospital treatment center this year? Please reach out so we can help with this transition.**

*Say Hi to the HFWA reps that are there.*

Here are the clinic dates for the first half of 2025.

- Feb – 4<sup>th</sup>, 18<sup>th</sup>
- Mar – 4<sup>th</sup>, 18<sup>th</sup>
- Apr – 1<sup>st</sup>, 15<sup>th</sup>, 29<sup>th</sup>
- May – 6<sup>th</sup>, 20<sup>th</sup>
- June – 3<sup>rd</sup>, 17<sup>th</sup>

*Are you a newly diagnosed family and would like to meet other families? Please speak to the Treatment team or fill in the interest form for contact.*

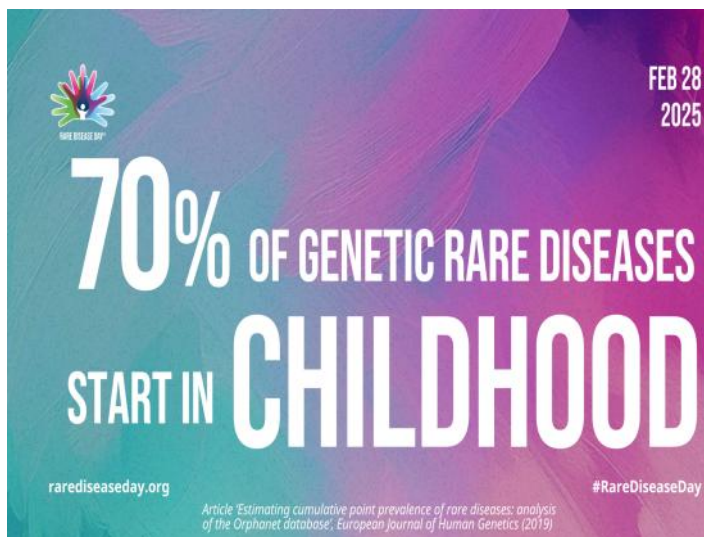
Perhaps you are a family who have now established a routine with your treatment and would like to participate in new family events to share your experiences.... Again please reach out staff or email [office@hfwaw.org](mailto:office@hfwaw.org)



### Navigating challenges at school:

For young people who have a chronic illness such as a bleeding disorder, navigating the school years can involve significant challenges. Thankfully, supports are available.

Paediatric social worker walks us through how you can work with your HTC, teachers and school to provide a positive environment for your young person.





## 2025 International Women's Day:

The medical community has known for some time that women and girls can be carriers of hemophilia or can have von Willebrand Disease or another rare bleeding disorder.

But it's only in the last few years that there has been an acknowledgement that that women and girls can have hemophilia as well, that they do experience symptoms, and that these symptoms can seriously affect their quality of life. In the U.S.A, women and girls with VWD face an average of a 16-year delay between symptom onset and diagnosis. Furthermore, research shows that WGBD are disproportionately affected by bleeding disorders due to the bleeding challenges of menstruation and childbirth. They are often at an increased risk for several associated conditions, including iron deficiency and anemia, and face greater barriers to accessing care in general due to stigma, gender bias and sexism.

This lack of knowledge related to women and girls in the bleeding disorders community is a clear indicator that more needs to be done to identify and support these individuals. Want to learn more, get involved, and stay up to date? Join WHF on March 7, 2025, from 8 a.m. to 9:30 a.m. EST for the annual [WFH International Women's Day webinar](#).

*Reproduced from World Hemophilia Foundation website. Full article and website found here.*

[Women and girls with bleeding disorders face continuing challenges | World Federation of Hemophilia](#)



REGISTER NOW

EN with live interpretation in FR, SP, RU & AR

DATE:  
March 7th, 2025

TIME:  
8:00-9:30 AM



Bleeding disorders are rare and health professionals may not be familiar with them – or know that women and girls have bleeding symptoms too. Educating yourself about your bleeding disorder, getting a diagnosis and a treatment plan from a specialist Haemophilia Treatment Centre (HTC) and preparing for emergencies and procedures with your HTC – this will make a huge difference to your treatment experience.

Many women find that sharing experiences and strategies that have worked for them is a great way to build their confidence with self-advocacy. Many local Foundations have women's peer support groups where women can talk with others who have had similar experiences and understand what it is like.

[Visit The Female Factors page to find out more about:](#)

- Women and peer support
- HFA education resources for women

*Reproduced from Haemophilia Foundation Australia website. Full article and website above*



## World Haemophilia Day 2025:

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 Haemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel's birthday. This year the theme is *Women & Girls Bleed too*. The World Federation of Haemophilia, with the support of volunteers from around the world, does remarkable work with developing countries with their GAP and Twinning Programs and Cornerstone Initiative. HFA is currently connected with the Myanmar Haemophilia Patient Association as a part of the WFH Twinning Program.

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

## Light It Up Red :

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

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

World Haemophilia Day April 17  
#WeBleedToo #WHD2025

Access for all  
wfh.org/whd

**Light It Up Red 2025**

REGIONAL:

**METRO SITES:**

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

MARLSTON HILL LOOKOUT,  
KOOMBANA BAY FOOTBRIDGE AND FORESHORE,  
MARLSTON WATERFRONT, GUPPY PARK,  
NAVIGATORS AT KOOMBANA DRIVE  
ROUNDABOUT, RICHMOND RESERVE, AAROL CRANE,  
KOOLAMBIDI WOOLA  
GREAT NORTHERN HIGHWAY PORT HEDLAND INTERCHANGE BRIDGE

WESTERN AUSTRALIA







## What's on in 2025 :

We have a variety of events planned for this year, catering to all ages—from the young to the young at heart, including parents and young adults. We would love to see more of you at these events. Your ideas and suggestions for future events are always welcome. While we strive to make our events accessible to everyone, sometimes it can be challenging to meet all needs.

Here's a taste so you can save the dates in your calendar

### Men's events

Breaky - Sunday 4th May

-----  
Breaky- Early November

-----  
Lumberpunks - date to be confirmed

*Please contact the office as soon as you can to register your interest.*



### Women's events

High Tea, National Hotel Fremantle - Saturday 29 March  
3pm

*Please contact the office as soon as you can to register your interest.*

-----  
June - Mini Golf

### Combined event

18 + Sundowner Windsor Hotel - Saturday 5 April 3.30 pm - 6.30pm

*Save the date and contact the office as soon as you can to register your interest.*

-----  
Breaky - Sunday 3 August

### Young families event

Coming soon

*Register your interest with the treatment team and reps at your next clinic or email the office*



### COMMUNITY EVENTS

World Haemophilia Day morning tea - Thursday 17 April 10.00 am

*City West Lotteries House, RSVP essential.*

Light it Up Red 17 and 18 April: WA sites see page 5

*Please let the office know if you can visit a site on the night to take some pictures*

-----  
Bleeding Disorders awareness month - October:

Includes our Annual Bunnings sausage sizzle

&

[Australian Bleeding disorders Conference - 16-18 October Brisbane](#)





## HFWA Christmas Party 2024

On Sunday 28 November 2024, we held our annual Christmas party at Maylands Waterland for something different from our usual (North) Outback Splash and (South) Adventure World venues . We had a fabulous day it was hot but filled with plenty of water fun.

We had 52 attendees with 21 children, this included 4 newly diagnosed families who attended their first HFWA event. This was excellent to see post-covid. Thank you to Natalie and Shirley at PCH for helping us reach those new families.

We hope you have you at more events.

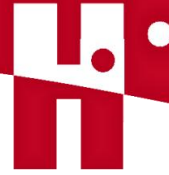
We are still working hard to reach new families that may have slipped through the HFWA coverage during the period of non contact at the treating hospitals. When you come along to our events please take the time have a chat and welcome the new faces, remember what that was like.....

Well here are some great pics captured.

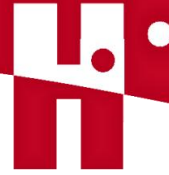
Thank you to everyone who helped prepare the event and on the day.















## Arved Wasser Memorial Fund:

*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.

Please contact the [office](#) by **23rd MAY** if you would like to be considered for the [Arved Wasser fund](#) for distribution early June and see pages 11 and 12. This is a great way to ensure your child with a bleeding disorder can access sporting endeavours, and extra curricular activities to enrich their life.

## Men's breakfast February:

We had 16 attendees along with some young tackers who came along with their Dad!

The venue was good, The Waterwall Restaurant at the Pagoda Como, hardly anyone there and we had a long table which was great so people moved around and interacted with each other.

As usual variety of conversations were had such as:

Aging, Treatment - Simplicity over time,

Products new/current, Gene therapy : One of the young guys said it's important to know the history

Services available at FSH and the gaps and delays with referrals

Work /FIFO

Trials and the inclusion of women

Travel, Hep C, Life in general

Overall it was decided they would like to visit the venue again.

Thank you to those who attended, it was the largest one for a little while.

## HFWA Membership:

*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 over time. Please contact the office to check your details.





## **Arved Wasser Memorial Fund Guidelines 2024-25**

1. a) For such time as the fund remains sustainable, a nominated sum shall be made available each financial year. This amount may be reached by way of a single grant, or several smaller grants. Closing date for applications will be listed on the application form. Funds will be approved and paid to recipients by Friday 30 June 2025, where possible.

b) These grants will consist of a nominated sum from the Arved Wasser Memorial Fund, and an amount equal to this sum, (i.e. 50% of total) coming from HFWA general funds.

c) Monies to be available for these grants, and any conditions hereto, shall be decided at the sole discretion of HFWA committee.

2. The recipient of any grant from this fund must reside in Western Australia and have a bleeding disorder. Family members are not eligible.

3. a) HFWA Members will be invited to make application on the accompanying form or request an application form from the HFWA Office Coordinator on 9420 7294 or by email [office@hfw.org](mailto:office@hfw.org)

b) HFWA shall define a period of time in which applications should be lodged each year. At the conclusion of this period, fair and equal consideration will be given to all applications. If none are received, or approved within the allotted time, applications may be lodged any time until the end of the current financial year.

c) If, in any financial year that the fund is operating, no grants are approved, or the total of those approved is less than the sum nominated by the HFWA committee, such monies shall remain in the fund to be 'rolled over' into the following financial year. They shall not be available for any other purpose, unless so designated by HFWA committee.

4. Applications should be made by the person concerned or in the case of a minor, by a parent or legal guardian.

5. The sitting committee of HFWA shall consider each application according to individual circumstances. A decision on any application/s shall be at the discretion of said committee. Any such decision will be final.

6. These grants are not intended to subsidise regular primary or secondary school fees, for example, 'every day' school curriculum. Additional tuition or courses, or skill-building activities (e.g. photography, music or scuba diving) may qualify.

7. There shall be no restriction on how the grants may be used, with regard to further education, such as TAFE or university courses.

8. These grants are not intended for medical treatments or procedures.

9. These grants may be given for sporting or recreational activities. There shall be no restriction on how the grants may be used. However, preference will be given to an applicant seeking assistance (e.g. travel or equipment subsidy), in order to attend a special event such as a major championship, training facility, seminar or meeting, relation to their chosen sport or activity.

10. Wherever and whenever possible, monies from these grants shall be paid directly to the 'third party' involved (i.e. the person or body providing the goods or services being considered). Unless presented with exceptional circumstances, monies will be paid to applicants as reimbursement of costs on presentation of proof of payment.





**ARVED WASSER MEMORIAL FUND APPLICATION FORM**

The Haemophilia Foundation of Western Australia (HFWA) invites applications for the Arved Wasser Memorial Fund for the 2024-2025 financial year. If you would like to apply for funding, please complete this application form. Please read the grant guidelines carefully before completing.

The Fund was established to give people with a bleeding disorder access to limited financial assistance, should they wish to pursue any educational, recreational, or work-related study or activity. Conditions are explained in the guidelines. Criteria for eligibility may loosely be described as any means of 'self-betterment'

Application form is to be completed by the applicant (or parent / legal guardian if under 18 years of age) and returned to HFWA City West Lotteries House, 2 Delhi Street, West Perth WA 6005, or via email ([office@hfwa.org](mailto:office@hfwa.org)) **before 5pm (WST), Friday 23 May 2025**

<p>Name of applicant _____</p> <p>Age of applicant _____</p> <p>Name of Parent/Guardian _____ (if applicable)</p> <p>Address _____</p> <p>Email _____</p> <p>Contact Number _____</p> <p>Amount Requested \$ _____</p> <p>Please give a brief description of how this grant will be used:</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>If insufficient space, attach a separate sheet.</p> <ul style="list-style-type: none"><li>• I make this application in good faith, having read and understood the information and application guidelines.</li><li>• I shall accept and abide by any decision made by the Haemophilia Foundation of Western Australia, relating to this application.</li></ul> <p>_____</p> <p>Application/Parent/Legal Guardian</p> <p>_____</p> <p>Date</p>
--



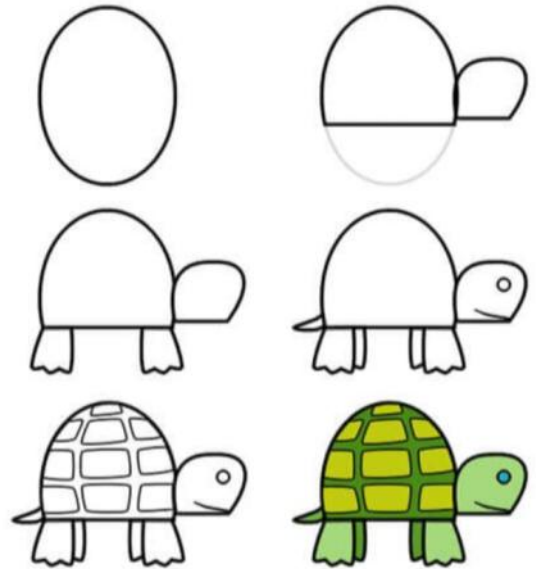
# Kids fun pages

## Famous people with Haemophilia Gene

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

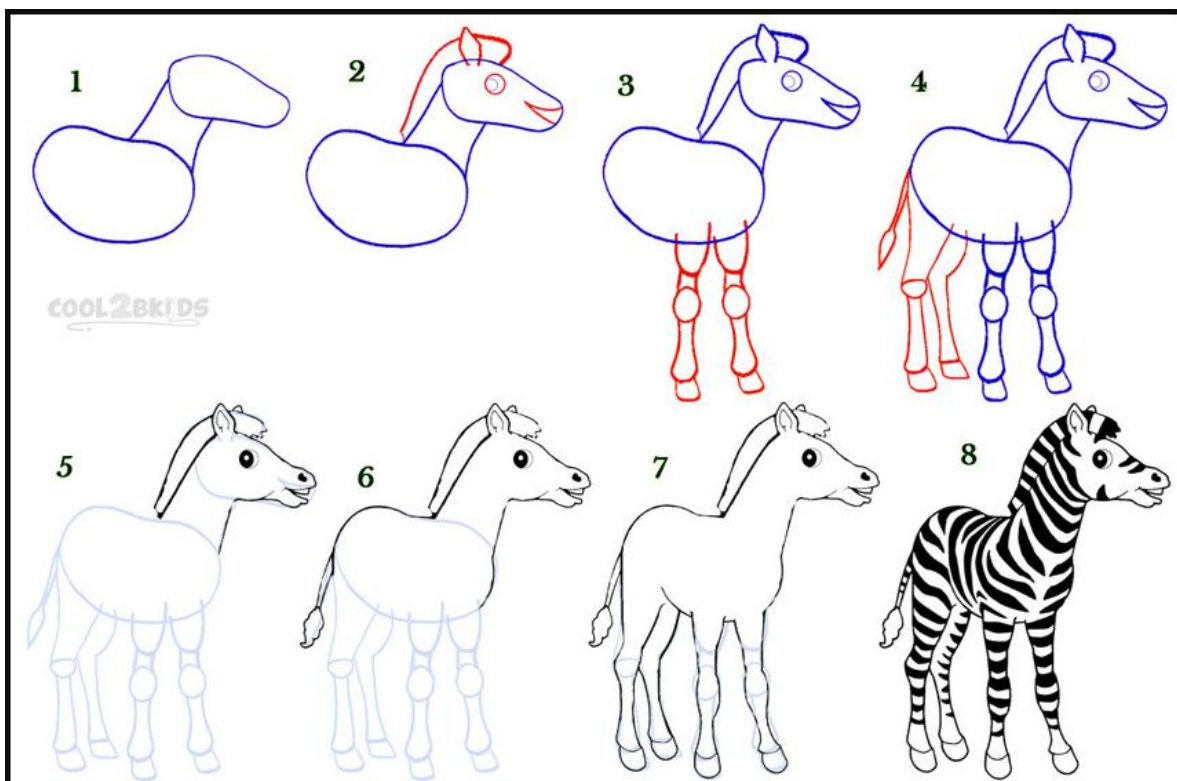
GENE THERAPY  
 ALEX BORSTEIN  
 ALEX DOWSETT  
 HEMLIBRA  
 RICHARD BURTON  
 VWD  
 HAEMOPHILIA  
 BARRY HAARDE  
 DUKE OF ALBANY  
 AFL  
 CHRIS GORDON

Can you draw a turtle ?

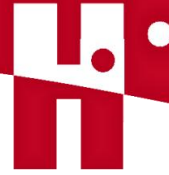


Play this puzzle online at : <https://thewordsearch.com/puzzle/6781743/>

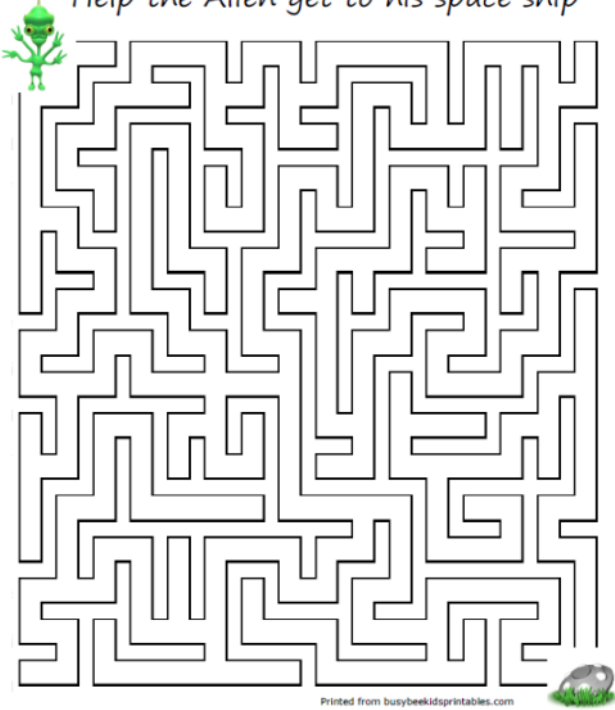
Can you draw a Zebra ?



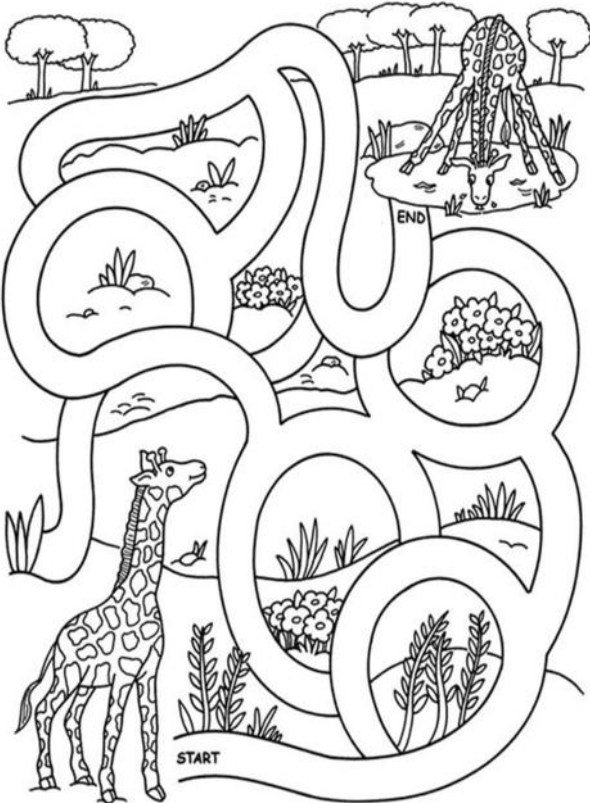




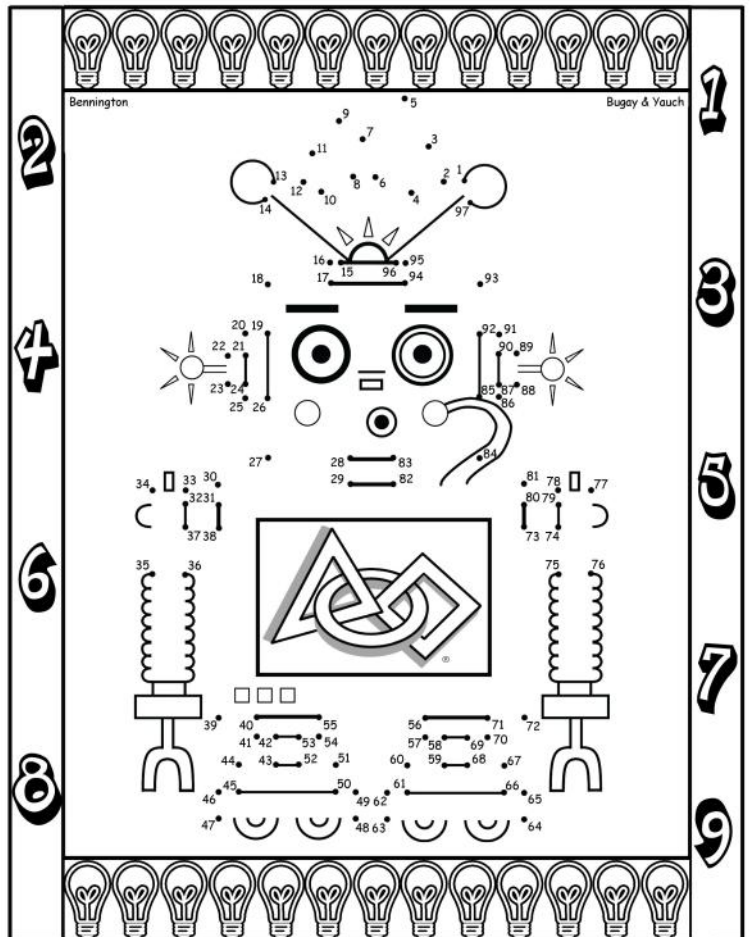
Help the Alien get to his space ship



Printed from busybeekidsprintables.com



The giraffe at the start of the path wants to join her friend at the water hole. Please find the way for her.





Scheme ID

C10338968

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%20Foundation&category=all&scheme\_id=wa#findacharityblock

Scan the barcode when you return



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

HFWA has quality shopping bags available to purchase to support our state programs.

To order your bags and arrange collection

email: office@hfwawesternaustralia.org.au



Support us today:

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

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