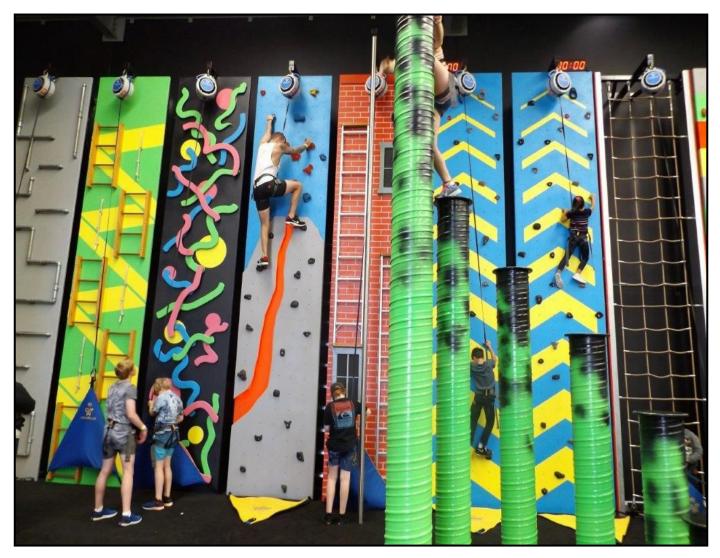
# Contact



Newsletter of Haemophilia Foundation WA Inc.

August 2018



#### HAEMOPHILIA FOUNDATION WAINC.

City West Lotteries House, 2 Delhi Street, West Perth WA 6005 Phone: 08 9420 7294 Email: office@hfwa.org Website: www.hfwa.org Contact

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#### Inside This Issue

**Entertainment Books** 

#### Presidents report **HFWA Annual General Meeting** Bunnings Sausage Sizzle MyABDR Privacy and Security HFWA Shopping Bag Fundraiser 2018/2019 Membership Form **Curtin Guild Donation** Men's/Women's Breakfast Reports Youth Event - Belinda Prophylaxis Article - Gavin Nail Polish Fundraiser W.A.Y Article and Photos - Pam What's On PCH Details and Maps

#### Your Committee

3	Gavin Finkelstein (President) Cheryl Ellis (Vice President)	0415 978 031 0402 033 652
4	Robert Butler (Treasurer)	9381 3386
5	Shane Meotti (Secretary)	
6	Susie Couper Belinda Broughton	
7	Pamela Wall	
8/9	Brian Wall Dale Spencer	
10	Profiles of committee members	can be found on the
11	website, www.hfwa.org 'Your C	Committee'.
12	HFWA Office Coordinator Haemophilia Foundation WA	Office
13	Ph: (08) 9420 7294	

Email address: office@hfwa.org

Cover picture The Simulation Centre Climbing Wall Fun

Office Hours: Monday to Thursday 10am—3pm.

#### PERTH'S CHILDREN'S HOSPITAL CONTACT DETAILS

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

Medical Staff: Dr Tina Carter Ph: 6456 0170

Nursing Staff: Natalie Gamble-Williams and Stacey Hutchison (Monday -

Thursday, 8:00am—4:30pm) Ph: 6456 0170 or 0466 318 286

After Hours (EMERGENCIES ONLY) Ph: 0410 717 816

Social Worker: Charlotte Bradley-Peni (Monday to Thursday, 8:00 AM - 4:30 PM, adults and paediatrics,

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contact for appointment) Ph: 6152 6525

ABDR Data Manager and Clinical Trial Coordinator: Marina Goruppi

#### 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, Lara Olson

Social Worker: Charlotte Bradley-Peni (Monday to Thursday, 8:00 AM - 4:30 PM, adults and

paediatrics, contact for appointment) Ph: 6152 6525

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.

**Contact** Augu

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#### **President's Report**

Hi Everyone,

It is disappointing that we had to cancel our fundraising movie event, due to lack of numbers and the clash with Father's Day. Pity, because it looked like a funny film but hopefully we will be able to reschedule for another film next year.

We are getting close to finalising the name of the **NEW** Haemophilia Treatment Centre (HTC) at the Perth Children's Hospital, when it is to officially open it would be great to get as many people to attend as possible.

We continue to have good attendances at the Men's and Women's Breakfasts, if you haven't attended one and have a bleeding disorder, are a carrier, or are a parent it's well worth coming along. Also our youth group (ages 10 to 25) gets together every few months to enjoy some great activities - these are always great ways to meet and chat with other members.

We are still looking for volunteers for our annual Bunning's Sausage Sizzle (at Homebase Wembley) on Saturday 13 October, if you have a couple of hours to spare we would appreciate it if you could help us out.

Thankyou to all those whom have renewed their memberships, membership renewal was due on 30th June. Included in this issue is our membership form for renewal or contact Kelly at the office for further enquires.

Save Sunday 2 December for our annual Christmas / End of Year get together.

That's about it at the moment; look forward to catching up with as many of you at an HFWA event in the near future.

Gavin



#### **HFWA ANNUAL GENERAL MEETING**



#### **Notice of Annual General Meeting**



# The HFWA Annual General Meeting will take place on

DATE and TIME: Thursday, 4 October 2018 at 7.00 pm

VENUE: Conference Room 1, City West Lotteries House,

2 Delhi St, West Perth

**AGENDA:** 1. Opening

- 2. Apologies
- 3. Minutes of the 2017 AGM
- 4. Business Arising
- 5. President's Report
- 6. Treasurer's Report
- 7. Appointment of Auditor
- 8. Secretary/Office Coordinator's Report
- 9. Election of Management Committee 2018/2019
- 10. General Business

11. Close

RSVP: By Monday, 1 October, 2018

=	
I wish to nominate for the 2018/2019 HFWA Management Committee.	
Name:	
Address:	
Signature:	
Date:	

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# **Bunnings Sausage Sizzle**Saturday 13 October 2018

#### Calling all volunteers and generous donors!

Come and have a fun time with HFWA at our annual Bunnings Sausage Sizzle. HFWA has been cooking up a storm and fundraising for the last umpteen years at **Bunnings Homebase in Subiaco** as part of World Haemophilia Week.

We would like to hear from those who can come along for a couple of hours to help on the day (any time between 7.30 am and 4.00 pm).

Plenty of volunteers are needed. Those 500 sausages won't cook themselves. Sign up early to get your preferred time - don't miss out!

Everyone always has a great time.

We are also looking for generous people to donate soft drink cans or bottles of water to sell on the day lemon squash, Coke (any sort), Fanta, lemonade or water.

#### **REMEMBER** we are fundraising for Youth Events!

To let us know how you can help by volunteering or donating drinks please ring the office on 9420 7294, email the office at office@hfwa.org or complete the form below and return it to the office.



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Some of our happy volunteers at last year's very successful and fun sausage sizzle

₹	••••
Would like to volunteer at the Bunnings Sausage Sizzle between the hours of	
Would like to donate soft drink or water, quantity	
My contact details are:	•
• • • • • • • • • • • • • • • • • • • •	·

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#### MyABDR Privacy and Security

With privacy and cyber security in the news at the moment, it is a good time to have a reminder of the security and information protection arrangements in relation to MyABDR.

Firstly, there is no link between ABDR and My Health Record, which are completely separate systems.

MyABDR links only to the Australian Bleeding Disorders Registry (ABDR), the system used by Haemophilia

Treatment Centres (HTCs) for the clinical management of their patients.

#### How is my health data protected with MyABDR?

MyABDR and the ABDR have been developed to have an extremely high level of data protection. They have one of the highest levels of security available in Australia and are not connected to any other database. Data protection includes:

highly secure user passwords, and a PIN for the MyABDR app encryption for data transfer between MyABDR and the ABDR three levels of firewall for the ABDR and 24 hr security monitoring very limited direct access to the ABDR and only to authorised users.

#### Who can access my personal information?

Only authorised staff from your HTC, the National Blood Authority (NBA) and the Australian Haemophilia Centre Directors' Organisation (AHCDO) can directly access your data, and only to perform specific roles.

If you have consented, your HTC team may send some of your personal health information and treatment plan from the ABDR to other health services involved in your care, if relevant - for example, if you are having surgery and your surgeon and haematologist are liaising about treatment to prevent bleeding. This process is also very important if you need emergency treatment for a bleed and go to a different hospital to your usual HTC hospital.

#### Any concerns?

If you have any concerns about MyABDR and ABDR data, don't hesitate to speak to your HTC team, HFA (T: 1800 807 173 or <a href="https://haemophilia.org.au">hfaust@haemophilia.org.au</a>) or the NBA MyABDR Support team (T: 13 000 25663 or <a href="mayabdr@blood.gov.au">myabdr@blood.gov.au</a>).

There are great benefits for your health and wellbeing to recording with MyABDR and it is important to us that you feel confident using it!

#### **READ MORE**



Be prepared.
Plastic bags banned from July 1.





# Support Haemophilia Foundation WA and help save the environment. #BYOBAG Jute Large Shopping Bag 42 cm W x 33 cm H \$6.50 Red Shopping Bag 33 cm W x 35 cm H \$3.00

# HFWA are selling quality shopping bags to support our state program.

TO ORDER YOUR BAGS and arrange collection: email office@hfwa.org or call <u>08 9420 7294</u>

I would like to orde I would like to orde Total \$	
	credit card details below or deposit the total with your Surname as your reference to:  Haemophilia Foundation of WA Inc. BSB: 086 488 Acct No: 03 523 3031
PLEASE NOTE	THAT CREDIT CARD DETAILS WILL NOT BE RETAINED AFTER PROCESSING
Card Type: Card Number: Expiry Date: Name on Card:	Visa MasterCard AMEX Diners  CVV:
Name:	
Address:	
Telephone:	Email:

August 2018

## H

#### Haemophilia Foundation of WA Inc.

APPLICATION FOR 2018/2019 MEMBERSHIP						
	New [		Renew	al 🔲		TAX INVOICE ABN 42 961 282 521 GST Registered
Title						
First Name						
Last Name						
Address						
Telephone						
Email						
			if you would p (94207294)			ewsletter electronically.
Please indicate:						
Person with bleed	ing disord	er				
Grandparents			Pa	rent of Child		
Nurse			Do	ctor		
Other			☐ Sp	ecial Interes	t	
Please return this membership form via email or to the address below:  Individual Family (includes immediate family members) - Membership \$25.00 (GST inclusive)  Extended family members need to take out their own membership.  Membership fee can be waived in special circumstances - Please contact the HFWA office on 9420 7294.						
I would like to make a donation of:						
\$25 \$50 \$100 or \$ Donations over \$2.00 are tax deductible						
Direct Deposit	Acct Na	me: The Had	emophilia Foun	dation of WA	Inc.	Cheque enclosed
	BSB: 086 488 Acct No: 03 523 3031 Ref: Please inc. your name e.g. John Smith					
Signature:				Date:		
	OFFICE USE ONLY	RECEIVED	REC. NO.	ENTERED		HFA

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#### Haemophilia Foundation of WA Inc.



APPLICATION FOR 2018/2019 MEMBERSHIP Family History						
Please list all family r	members to be included in	HFWA membership.				
Name						
Date of Birth						
Please indicate diagr	nosis details:					
Haemophilia A		Haemophilia B				
von Willebrand D	Disorder	☐ Carrier				
Other Factor Def	ficiency	No Bleeding Disorder				
Severe	■ Moderate	☐ Mild ☐ vWD Type				
Relationship to Memb	ber:					
Name						
Date of Birth						
Please indicate diagr	l nosis details:					
Haemophilia A		Haemophilia B				
von Willebrand D	Disorder	Carrier				
Other Factor Def	ficiency	No Bleeding Disorder				
Severe	Moderate	☐ Mild ☐ vWD Type				
Relationship to Memb	ber:					
Name						
Date of Birth						
Please indicate diagr	nosis details:					
Haemophilia A		Haemophilia B				
von Willebrand D	Disorder	Carrier				
Other Factor Def		No Bleeding Disorder				
Severe	Moderate Moderate	☐ Mild ☐ vWD Type				
Relationship to Member:						
Name						
Date of Birth						
Please indicate diagnosis details:						
Haemophilia A	Haemophilia B					
von Willebrand D	Disorder	Carrier				
Other Factor Def	ficiency	No Bleeding Disorder				
Severe Moderate Mild vWD Type						
Relationship to Member:						

#### **Curtin Student Guild Fundraising June/July**



HFWA Committee Member Shane Meotti with Ann-Maree from the Curtin Student Guild.

A huge thanks to the Curtin Student Guild for choosing us. We received a fantastic donation of \$300.10. All donations are greatly received and go to supporting the bleeding disorders community events.

"The staff in our cafes have chosen to have charity boxes in place of tip jars at each site. Our customer service team encourage guests to drop their loose change into the box when making a purchase at one of the cafes. Each month the donations are collected for a different charity, all of which are chosen by the Supervisors and staff as a group (we have seven cafés, so they all collect for the same charity each month). As we have a team member with close connections to the Haemophilia Foundation and community, it was decided that we would collect funds for HFWA throughout the months of June and July. It's a little bit that we can contribute to the great work that you do."

Kelli Edwards Manager Food and Beverage

#### Men's Breakfast Report

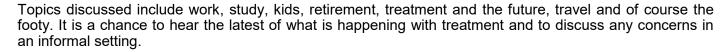
On Sunday 5 August HFWA held its regular Men's Breakfast at the Waterfall Restaurant, Pagoda in Como.

As usual it was great to see new faces, catch up with others we haven't seen for a while, have a chat and do it whilst "breaking bread".

We now include dads of guys with bleeding with disorders and are thinking of including siblings in the future.

We usually talk about what is happening in peoples lives. We have a group of guys at different stages of life, with difference in the issues they face,

what they enjoy doing, the plans they have for the future and how to minimise the impact of a bleeding disorder in their future plans.



If you haven't attended a Men's Breakfast before it's well worth attending.

Gavin Finkelstein

#### Women's Breakfast Report



Seven wonderful women joined Pamela and myself for a delightful breakfast at Nicholson's Bar and Grill Restaurant on Sunday, 5 August. What we all have in common is that we are affected in some way by an inherited bleeding disorder.

As usual, we discussed a wide range of topics. These included the services provided by the Haemophilia Treatment Centres at Fiona Stanley Hospital and Perth Children's Hospital and the importance of attending appointments. HFWA's fundraising efforts and our upcoming Youth events were discussed. Birth control and menorrhagia issues; other bleeding symptoms such as sore joints and bruising; sporting

choices for children with a bleeding disorder; travelling with a bleeding disorder and issues for carriers were other topics on the day.

The Women's Breakfasts take place approximately every three months, and are advertised in the newsletter and on our website. The Women's breakfasts are free to HFWA members, as are all the peer group activities offered by the HFWA.

We are always open to suggestions from members about what sort of events you would like to attend. For example, would you like to have a high tea or lunch instead of breakfast? Let me know.

It is always fantastic to catch up with everyone, and I look forward to seeing more faces at the next brekky.

Cheryl Ellis

#### **Youth Event - The Simulation Centre**



Hey everyone!

This month we held our youth event at the Simulation Centre in Bibra Lake. Our youth had the opportunity to test their skills on race car driving, clip and climb walls and the gamer's den which was filled with Playstations, Xboxes and Wiis. For most of our youth events we try to have a theme or something we can share with our youth, however with this event I found our youth showed us a thing or two.

Braxton who was a little worried of heights managed to show us he could climb the very top of the clip and climb wall, doing this all by himself. Cooper was fantastic in the gamers den, he managed to whizz through and help set up the games for his fellow team mates. This meant our mentors could relax for a moment and enjoy a sneaky coffee. It was really good to see everyone, old and new, working together and enjoying their time. I'm looking forward to the next youth event where hopefully we can learn even more about our youth.

#### Belinda

#### **Prophylaxis**

"Prophylaxis - it doesn't matter how old you are when you start, there are benefits"

This article is purely my own opinion and is not meant to be followed as professional advice. I highly recommend that individuals discuss their personal circumstances, disorder, severity etc. with their treating clinicians at their Haemophilia Treatment Centre.

Sheepishly, I must admit to going onto regular prophylaxis (prophy) only in the last 12 or so months. Previously, unless I was on a clinical trial, I have always treated on demand, even though often being questioned by clinicians and friends who are on prophy. I guess I'll plead laziness up until now. It took me long enough to self infuse so I must be a slow learner and many will say that I am.

Having started on prophy last year, it has made a difference, even though I hadn't been getting many bleeds, the amount of general soreness that I experienced in my target joints (ankles and elbows especially) has diminished. Also, the number of times I need to treat for joint soreness that isn't arthritis-related has stopped.

We all have our own way to do our treatment, and it is important to treat and treat regularly if we are on prophy. It's only when you aren't compliant that you start to feel the effects - be man (or woman) enough to admit that you need it, remember you still have a chronic medical condition that is minimised by complying with your prescribed treatment plan.

Gavin Finkelstein

#### Haemophilia

- A rare inherited genetic bleeding disorder where blood doesn't clot properly because there is not enough of a protein in the blood called factor VIII (8) or IX (9) that controls bleeding
- · It's incurable and can be life threatening without treatment
- Treatment can help prevent organ damage from bleeding, and arthritis and joint problems from repeated bleeding into muscles and joints
- Most people diagnosed with haemophilia are male
- Some women also have haemophilia and/or bleeding problems
- Men with haemophilia will pass the gene causing haemophilia on to their daughters
- Women can carry the gene and pass it on to their children

#### Von Willebrand disorder (vwb)

- A bleeding disorder where there is not enough of an essential blood clotting protein (called von Willebrand factor) for blood to clot properly or the factor doesn't work the way it should
- Both men and women have VWD
- · VWD is more common than haemophilia

#### **Affected Australians**

In Australia there are more than 5,600 people diagnosed with haemophilia, von Willebrand disorder or other related bleeding disorders

#### Nail Polish Fundraiser (& more colours coming soon!)

### HFWA nail polish is back!



Looking for that personalised gift with a real message for family and friends?

Look no further!

HFWA bring you the nail polish all your friends and family will love, for the great price of \$20.00 a bottle.

It is a beautiful red, perfect for fingers and toes out and about with spring approaching.

It has a great message and our very memorable logo.

Coming soon in time for Christmas - 3 bottle gift packs for festive sparkle! Watch your email for further details...



#### **Order options:**

Transfer your payment into our bank account

BSB: 086488 Acct No: 035233031

With your name and "polish" as the reference and email us (office@hfwa.org) with your order details

or

Phone the office: 08 94207294 to pay by credit card Available from the HFWA office, get in quick they won't last long!

#### **WA Youth Event - The Simulation Centre**

The second WA Youth (WAY) event for 2018 was held Sunday, 12 August at The Simulation Centre.

As always, it was great to catch up with some familiar faces from within our Youth group and discuss how things were going for them at school/home and in general. Our first event was held in conjunction with the HFWA camp and consisted of a Swan river kayaking journey. We were excited to welcome some new members who had turned 10yrs old, meeting the age requirement to join WAY and explore some great Youth events, topics and social gatherings.



The group was in for a treat as The Simulation Centre had recently moved to a bigger and better location, adding some new, amazing and exciting activities to the range they already had on offer. Once everyone had gathered and had been inducted and tagged with identifying wrist bands, they were led into the first area of activities. This consisted of a 9D cinema, slot cars, interactive sports games and car racing.

Next up was the cyber centre where the Youth got a chance to choose a game to play from an assortment of 15 systems. Player's den it certainly was. It was amazing and satisfying for the Youth Committee to see some of the longstanding members of our youth take the time, and make the effort, to welcome and include the newest members of youth to the group. The transition into a supporting role seems to have evolved naturally with time and maturity in age.

The high ropes, climbing activities and parkour area were next. After harnessing up and briefing the Youth were off. With timed obstacle climbing wall, some decided to race each other whilst others worked on beating their own times. Climbing a wall vertically with short steps, ladder rails and rock climbing steps all

presented different challenges. It was great to see speed increase, fear overcome and individual challenges evolve into to peer challenges. Not all participated in the climbing challenges and that's OK. Some just wanted to hang with new friends and learn about what WAY is all about, the events they've attended and things to look forward to.

After nearly three hours of fun, chats, food, and laughing it was time to wrap up another Youth event for 2018. After everyone said their goodbyes, and the pick-ups were made for youth that had

been dropped off, we felt inspired to be part of such a great community.

All attending commented that they look forward to the next Youth/Family Christmas Event at Outback Splash in December. All ages invited, welcomed and Encouraged.

A very special thanks to Justine and her wonderful team at The Simulation Centre for making yet another WAY Event amazing.

Pam















2018

# WHAT'S ON?



# Thursday, 4 October - 2018 Annual General Meeting 7.00pm

Conference Room 1, CWLH, 2 Delhi Street, West Perth, WA, 6005

# Saturday, 13 October - 2018 Bunnings Sausage Sizzle 8.00am - 4.00pm

Homebase Bunnings, 55 Salvado Road, Subiaco, WA, 6008 Come and join our friendly volunteers for a Sausage Sizzle!



# Sunday, 2 December - 2018 Christmas Party Save The Date!

The Maze/Home of Outback Splash 1635 Neaves Road, Bullsbrook, WA 6084



2018: quarterly youth events quarterly men's group World Hemophilia Day

quarterly women's groupBleeding Disorders Awareness Weekparents and family meetings

#### Perth Children's Hospital - New Contact Details



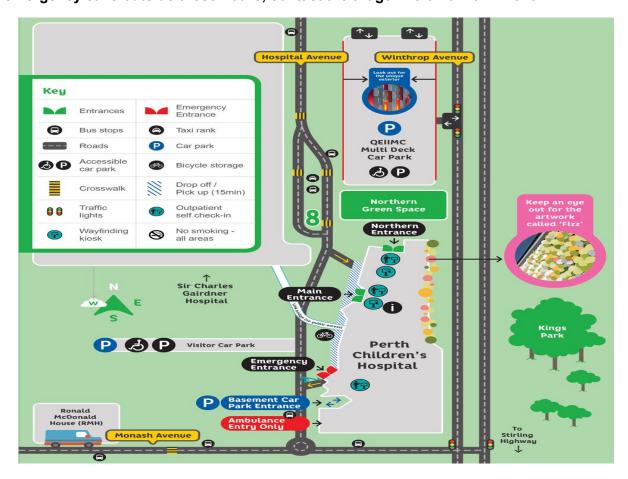


#### \*\*\*Princess Margaret Hospital is NOW CLOSED\*\*\*

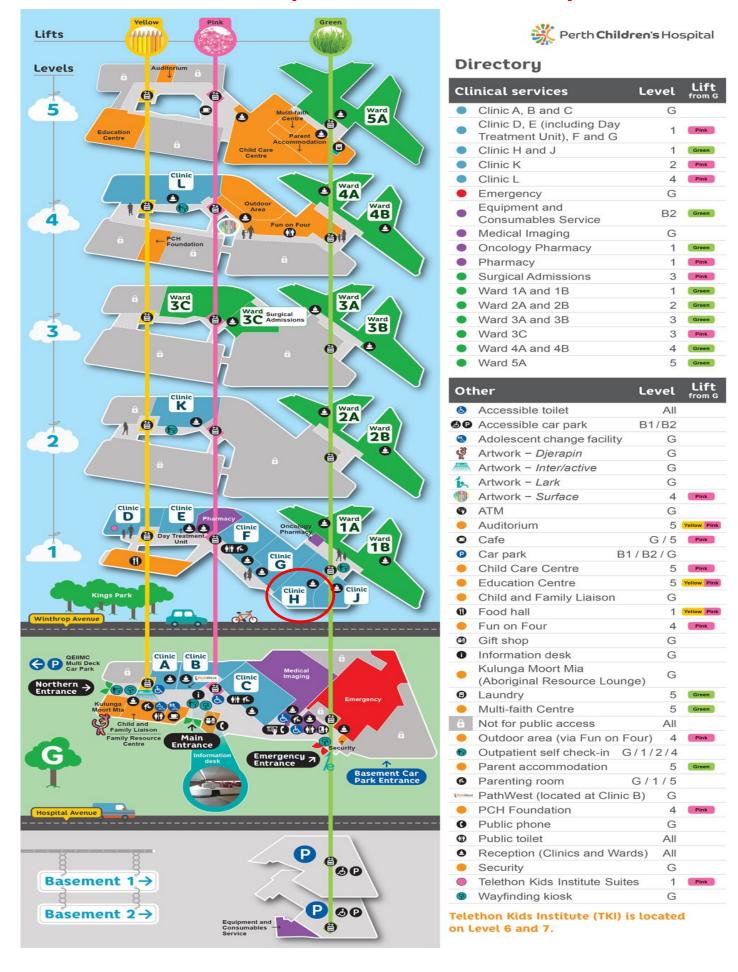
The paediatric Haemophilia Treatment Centre is located in Clinic 'H' Level 1 in the green lift zone

Perth Children Hospital Clinic H, Level 1 15 Hospital Avenue Nedlands WA 6009

The clinic front desk number is 6456 0170 Haematology Clinic Nurse (Natalie/ Stacey) phone number is unchanged - 0466 318 286. Note: This line is only Monday - Thursday 0830 - 1630. For emergency calls outside these hours, contact the triage line on 0410 717 816



#### Perth Children's Hospital - Internal Site Map



#### **Entertainment Books 2018/2019**

# Haemophilia Foundation Western Australia Inc. is raising funds. Here's how you can help...

We're raising as much as we can to support Youth Group Activities and while the new 2018 | 2019 Entertainment Books will be available from 1<sup>st</sup> May 2018, the Entertainment Digital Memberships are here now. Instantly access hundreds of valuable offers OR pre-order your Entertainment Book today and receive over \$180 worth of Early Bird offers.



#### Haemophilia Foundation WA

Contact: Kelly Phone: 08 9420 7294 Email: office@hfwa.org

To order your Book or your Digital Membership securely online visit:

www.entbook.com.au/847b23

	Al	ternatively,	please	complete	your	details	below:
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Name:			hone:	
Email:				
Address:			State:	Postcode:
Perth Edition \$70 including ( Post my order \$12.00			Membership(s) \$	
Payment Type: CASH	VISA	MASTERCARD	CHEQUE (payable	c to Haemophilia Foundation $WA$ )
Credit Card Number:	/	/	Expiry Date: _	/ CVV*: *CVV is the 3 digits on the back of your credit card
Cardholder's Name:			Signature:	