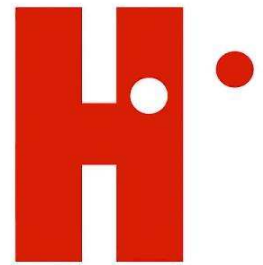


Contact



Newsletter of Haemophilia Foundation WA Inc.

October 2018



HAEMOPHILIA FOUNDATION WA INC.

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

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Your Committee

Gavin Finkelstein (President)	0415 978 031
Cheryl Ellis (Vice President)	0402 033 652
Robert Butler (Treasurer)	9381 3386
Shane Meotti (Secretary)	
Susie Couper	
Dale Spencer	

Profiles of committee members can be found on the website, www.hfwa.org 'Your Committee'.

HFWA Office Coordinator
Haemophilia Foundation WA Office
Ph: (08) 9420 7294

Email address: office@hfwa.org

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

Cover picture

HFWA Sausage Sizzle at Bunnings Subiaco

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, 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.

President's Report

Hi Folks,

I hope this issue of HFWA's Contact Newsletter finds everyone well and looking forward to the end of the year and all the celebrations associated with it.

We held our AGM on 4 October (see page 6 for report), We farewelled Pam and Brian Wall, and Belinda Broughton who has left the state. We thank them for their commitment and service to our community, especially the Walls, who took on the ginormous tasks of developing a youth program in addition to organising and facilitating two community camps - these efforts are much appreciated.

We only had six people nominate for our committee when we can have up to ten; it is important to have all groups within our community represented on our committee - so if you are interested in joining the committee please contact us to discuss what it entails.

Please note the HFWA Community Christmas/End of Year Party will be held at Outback Splash/The Maze, Bullsbrook on Sunday 2 December. We look forward to as many of you attending as possible, especially our youth members. There will be plenty of activities to keep everyone busy throughout the day - see flyer on page 14 for more details.

Unfortunately, we have lost the services of Kelly in the office, and thank her very much for the time she spent with us; she certainly made things easier for me to follow in the office (which isn't an easy task). We wish Kelly all the best for the future.

Please note that there is a Men's Breakfast on Sunday 20 January 2019 at 8.30am at the Waterwall Restaurant, Pagoda Como and a Women's Breakfast on 20 January 2019 at Straits Cafe, Rendezvous Hotel Scarborough. It would great to get as many of you there as possible, as it is a easy and enjoyable way to catch up or meet other members and find out what's happening in the HFWA and the bleeding disorders community generally.

Our fund-raising efforts in 2019 will be concentrated on raising money to send as many people as possible to the National Conference in Sydney between 10 and 12 October 2019. More information to come soon.

Wishing everyone a Happy Christmas (or whatever you celebrate!!) and a happy, healthy 2019.

Gavin

Just **\$70** giving you over **\$20,000** of value!

Available Now!

Contact HFWA Office for how to get your book or digital membership

Presentation to Curtin Midwifery Students - Sharri Brodie

In September myself and Gavin (as my personal assistant) attended Curtin University to present an information session about bleeding disorders to midwifery students.

I started with a brief “what” and “how” session on Haemophilia and von Willebrand disease, but wanted to spend most of my time talking to the group about what was relevant to their chosen careers as midwives.

I spoke about how some Haemophilia carriers can have a variety of symptoms and also how women with vWD manage their condition. I spoke about childbirth and how post-partum bleeding and bruising could be a sign of a bleeding disorder.

I discussed how women who know their bleeding disorder status can plan ahead and communicate with medical staff to get the best care with minimal (or hopefully no) complications during pregnancy and birth. I spoke about haematomas in newborns with particularly emphasis on the possibility of cerebral haemorrhage. I read excerpts from other women’s experience and also shared my own stories relating to women’s health.

The group and their lecturer were very grateful for our time and asked several questions which we tried our best to answer.

If you know of a group of people, perhaps school or your workplace, where you would like to spread the word and talk about your connection to bleeding disorders, HFWA can provide you with plenty of help and resources to promote awareness and educate as many people as we can.

If this is something you would like to do but you aren’t fond of public speaking, contact the office and we can find someone suitable to represent our community on your behalf.

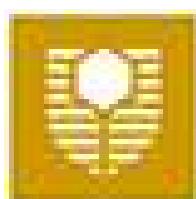
Ignorance is fear and knowledge is power, so let’s get out there and spread the word on who we are and what makes us so amazing.

Sharri Brodie

A HUGE thank you to Sharri for presenting to this group of Curtin Midwifery students. Thank you also to Brooke Thomson from Curtin School of Nursing, Midwifery and Paramedicine, for inviting us to present to the students.

As Sharri has said, HFWA encourage everyone to raise community and workplace awareness of bleeding disorders.

If you would like some resources to help you to talk about your (or your family member’s) bleeding disorder, or someone experienced in public speaking to accompany you (for moral support), contact the HFWA office by email (office@hfwa.org) or on 9420 7294.



Curtin University

This newsletter is kindly printed by Fuji Xerox

Bunnings Sausage Sizzle

Saturday 13 October 2018

On Saturday 13 October, several wonderful and dedicated helpers ventured to Bunnings at Homebase Subiaco to take part in the annual HFWA sausage sizzle. This is a fundraising and awareness event we organise each year as part of HFWA's activities for Bleeding Disorders Awareness Week, which was 7 – 13 October 2018.

Despite the forecast of 100% chance of rain, people turned out to buy and consume our tasty sausages from Avon Valley Beef Company in fresh buns. All up, we sold approximately 500 sausages in buns.

Thank you to all who donated soft drinks and money and visited us at Bunnings. A special thank you to our sizzling helpers - Neil, Jenny, Jaspa, Kirsty, Lexi, Julene, Englebert, Roma, Sharri, Aaron, Will, Joss, Pam, Brian, Aaliyah, Vince and Xavier, and of course our dedicated committee members Shane, Bob, Gavin and Susie for all their hard work. We couldn't do it without all of you!

Cheryl Ellis



HFWA AGM and New Committee - Shane Meotti

The Foundation's Annual General Meeting was held on Thursday, 4 October 2018 at City West Lotteries House. Unfortunately only fourteen members attended, and given that eight of those were current serving committee members, this was a little disappointing. The HFWA has served our community for over 25 years, and the long term survival of this great organisation will only occur through the continued engagement of our members in Foundation activities.

The year ahead also sees a reduction in the numbers on the Management Committee, with just six nominations received and duly elected to the Management Committee for 2018-19. However, the Foundation remains in good hands, and we are hopeful that others will join the Committee during the coming year. There are four vacancies on the Management Committee and we encourage members of the HFWA, who are interested and available, to contact the office or Gavin Finkelstein directly for more information. The Management Committee meets on the third Tuesday of every month, and anyone interested is welcome to attend a meeting as an observer to see what it is all about.

Gavin Finkelstein also acknowledged the great work of the retiring Committee members and noted the Foundation's gratitude to them. Belinda Broughton has moved to the eastern states, and both Pam and Brian Wall are stepping down from the Management Committee due to work commitments. All three were part of the HFWA Youth Sub Committee that staged a fantastic community camp earlier this year and a number of successful youth activities over the past year. Pam and Brian Wall's leadership and enthusiasm has been integral in developing the Youth Program, and we are very fortunate and pleased that they will remain part of the Youth Sub-Committee for the year ahead.

During the meeting a question from the floor was raised regarding the HFWA shoe subsidy and increases to subsidy amount. This matter was taken to the October Management Committee meeting and it was agreed that the Foundation will maintain both the shoe and medic alert subsidies to members at their current levels to ensure that membership fees are not increased and to preserve the Foundation's funds for peer support activities.

At the October Management Committee Meeting, the Office-bearers and Committee positions were elected for the year ahead and the Management Committee for 2018-19 comprises as follows:

President: Gavin Finkelstein
Vice President: Cheryl Ellis
Treasurer: Bob Butler
Secretary: Shane Meotti

Council Delegates:
Gavin Finkelstein and Cheryl Ellis (Alternate Delegate)

Public Relations:
Gavin Finkelstein and Cheryl Ellis

Newsletter Sub Committee:
Susie Couper (Chair), Cheryl Ellis, Shane Meotti and Beryl Kerr

Youth Sub Committee:
Dale Spencer (Chair), Pam Wall and Brian Wall

Blood Borne Viruses Liaison:
Gavin Finkelstein

The 2017-18 Annual Report will be available soon on the HFWA website www.hfwa.org

**Be prepared.
Plastic bags banned
from July 1.**



HAEMOPHILIA FOUNDATION WESTERN AUSTRALIA



**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 **08 9420 7294**

I would like to order _____ Jute large bags
I would like to order _____ Red bags
Total \$ _____ (postage can be arranged at extra cost)

Please complete credit card details below or deposit the total with your Surname as your reference to:
Acct Name: **The 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:

☐

Visa

☐

MasterCard

☐

AMEX

☐

Diners

CVV:

Card Number:

Expiry Date:

 /

Name on Card:

Name: _____

Address: _____

Telephone: _____ Email: _____

HFWA Nail Polish Gift Packs

In Stock Now

**3 bottle gift packs for festive sparkle!
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, now in a gift pack for the
great price of **\$40.00****



**Gift packs contain Helen's Melons (red) and two
colours of your choice from:**



**Emerald Green, Rose Gold,
Silver Sparkle, Metallic
Maroon, Black, White, Top
Coat or Base Coat.**

Perfect for fingers and toes out and about for Christmas.

Each bottle has a great message and our HFWA logo.

Order options:

Transfer your payment into our bank account

BSB: 086488 Acct No: 035233031

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

or

Phone the office: 08 94207294 or Cheryl (0402 033 652)

**Very limited stock -
don't miss out!**

News from HFA

Female Factors: information for young women with bleeding disorders

We are very pleased to announce the release of **Female Factors**, HFA's new resource for young women.

HFA worked with experts to answer the questions of young Australian women about how bleeding disorders affect females. The information is presented in a magazine style – colourful and easy to read.

Go to:

<https://www.haemophilia.org.au/publications/women-with-bleeding-disorders/young-women>

to:

- Read it online as a magazine
- Download the entire PDF
- Or download specific sections.

Print copies will also be available from HFA, local Foundations and your Haemophilia Treatment Centre.

Many thanks to the young Australian women affected by bleeding disorders who contributed personal stories and tips and focus-tested the resource!

For more information or to order a print copy, contact HFA on:

E: hfaust@haemophilia.org.au

T: 1800 807 173



You may notice that HFA is now starting to use the term **von Willebrand disease** for **VWD** instead of **von Willebrand disorder**.

This is part of our commitment to align with the **Global VWD Call to Action** and the development of the **VWD diagnostic and clinical management guidelines**.

For many years the Australian bleeding disorders community has preferred the term **von Willebrand disorder**, although the medical diagnosis is **von Willebrand disease**.

Our involvement in the global effort to standardise the VWD diagnostic guidelines means we are adopting the internationally accepted term **von Willebrand disease**, which is also used by the World Federation of Hemophilia.

If you have any questions about this change, please feel free to contact HFA on hfaust@haemophilia.org.au or call 1800 807 173.

Men's Breakfast Invitation

Gavin Finkelstein and Dale Spencer would like to invite you to the next Men's Breakfast

VENUE: Waterwall Restaurant, Pagoda Resort, 112 Melville Parade, Como WA 6152

TIME: 8.30am

DATE: Sunday, 20 January 2019

RSVP: by Tuesday 15 January to:
the HFWA office on 9420 7294 or office@hfw.org
or Gavin on 0415 978 031 or gavfinkelstein@gmail.com

The Men's Breakfast is funded by HFWA and free to financial members



Women's Breakfast Invitation

Cheryl Ellis and Susie Couper would like to invite you to the next Women's Breakfast

VENUE: Straits Café, Rendezvous Hotel Scarborough, 148 The Esplanade, Scarborough, Perth, WA 6019, Australia

TIME: 8.30am

DATE: Sunday, 20 January 2019

RSVP: by Tuesday 15 January to:
the HFWA office on 9420 7294 or office@hfw.org
or Cheryl on 0402 033 652 or vice_president@hfw.org

The Women's Breakfast is funded by HFWA and free to financial members



Perth Children's Hospital - Contact Details

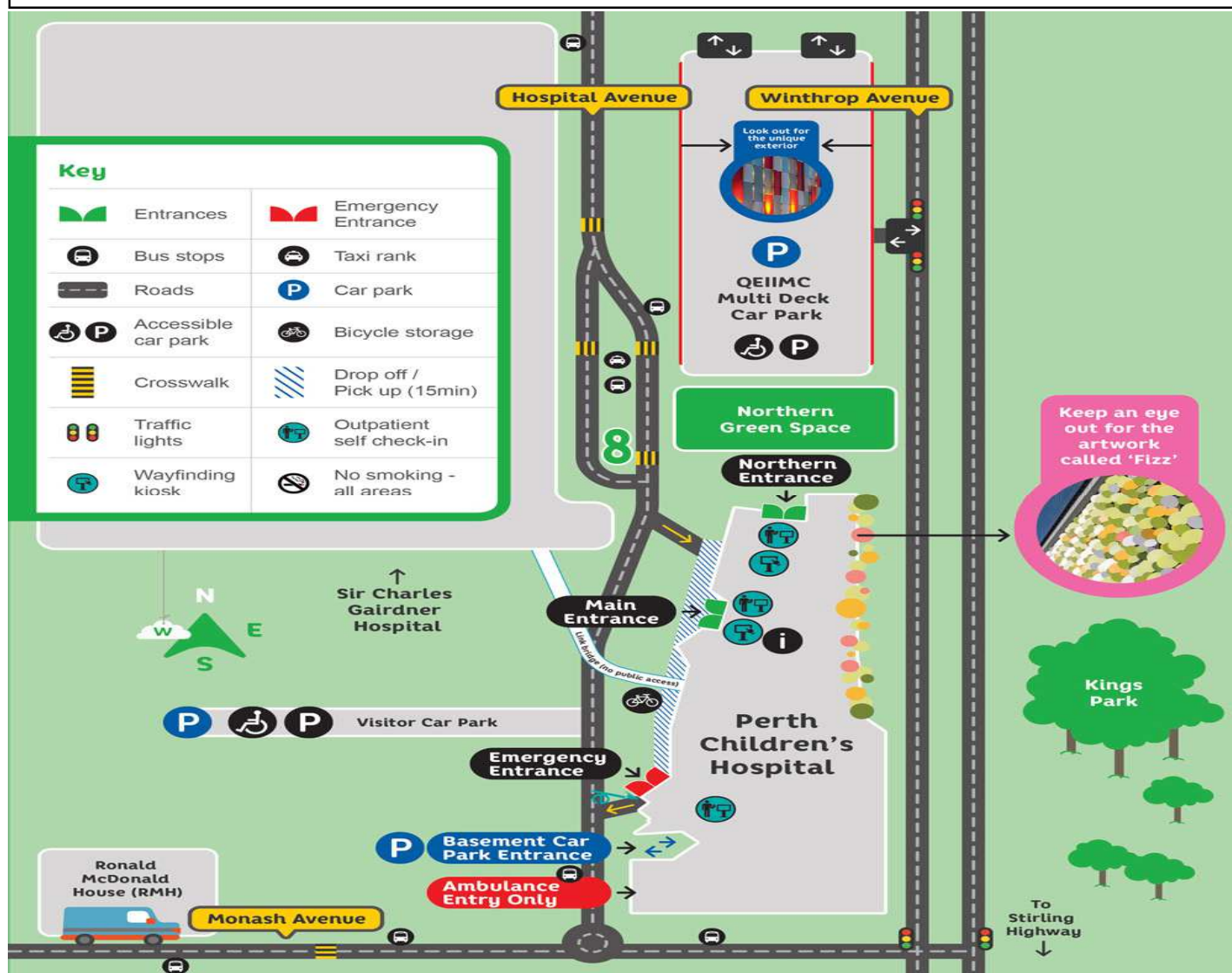


*****Princess Margaret Hospital is NOW CLOSED*****

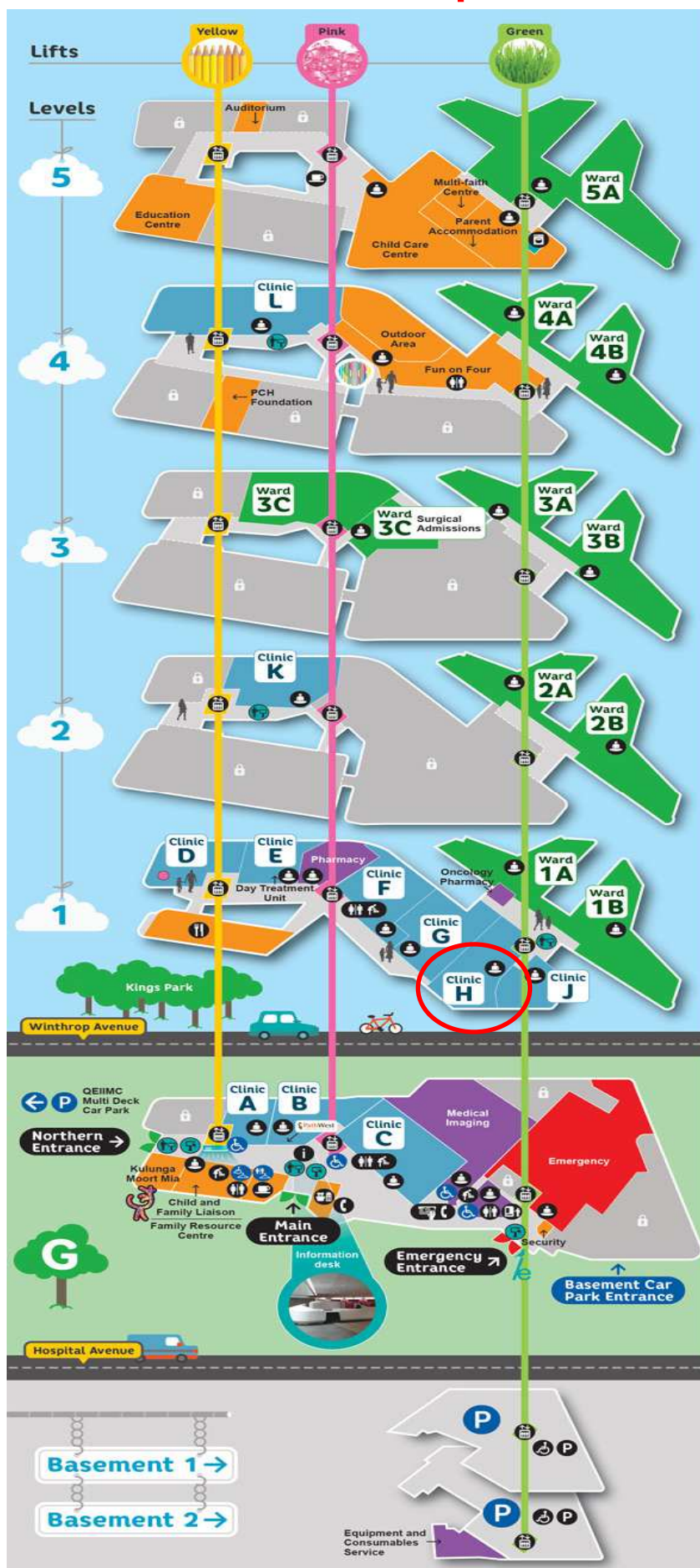
The paediatric Haemophilia Treatment Centre is located in Clinic 'H' Level 1 in the green lift zone

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



Directory

Clinical services	Level	Lift from G
Clinic A, B and C	G	
Clinic D, E (including Day Treatment Unit), F and G	1	Pink
Clinic H and J	1	Green
Clinic K	2	Pink
Clinic L	4	Pink
Emergency	G	
Equipment and Consumables Service	B2	Green
Medical Imaging	G	
Oncology Pharmacy	1	Green
Pharmacy	1	Pink
Surgical Admissions	3	Pink
Ward 1A and 1B	1	Green
Ward 2A and 2B	2	Green
Ward 3A and 3B	3	Green
Ward 3C	3	Pink
Ward 4A and 4B	4	Green
Ward 5A	5	Green

Other	Level	Lift from G
Accessible toilet	All	
Accessible car park	B1 / B2	
Adolescent change facility	G	
Artwork – Djerapin	G	
Artwork – Inter/active	G	
Artwork – Lark	G	
Artwork – Surface	4	Pink
ATM	G	
Auditorium	5	Yellow Pink
Cafe	G / 5	Pink
Car park	B1 / B2 / G	
Child Care Centre	5	Pink
Education Centre	5	Yellow Pink
Child and Family Liaison	G	
Food hall	1	Yellow Pink
Fun on Four	4	Pink
Gift shop	G	
Information desk	G	
Kulunga Moort Mia (Aboriginal Resource Lounge)	G	
Laundry	5	Green
Multi-faith Centre	5	Green
Not for public access	All	
Outdoor area (via Fun on Four)	4	Pink
Outpatient self check-in	G / 1 / 2 / 4	
Parent accommodation	5	Green
Parenting room	G / 1 / 5	
PathWest (located at Clinic B)	G	
PCH Foundation	4	Pink
Public phone	G	
Public toilet	All	
Reception (Clinics and Wards)	All	
Security	G	
Telethon Kids Institute Suites	1	Pink
Wayfinding kiosk	G	

Telethon Kids Institute (TKI) is located on Level 6 and 7.

Online exercise and sport resources for young people with bleeding disorders



On the Move with Haemophilia is a new online educational program about supporting young people with haemophilia to participate in exercise and sport. It is aimed at parents, teachers and sports coaches and includes a set of videos and a fact sheet.

Click below to access the resources:

Video program <https://app.propatient.com/visits/on-the-move-with-haemophilia>

Toolkit/fact sheet invivoacademy.org/wp-content/uploads/2017/01/OTMWH_toolkit.pdf

It is also available on the HFA website, under **Publications**.

The program covers:

- the benefits of regular exercise for people with haemophilia
- factors to consider when choosing suitable exercises and sports
- how to encourage regular and appropriate exercise
- steps to take when a young person has a bleeding episode at school or during sporting activities
- rehabilitation and returning to exercise or sports after a bleeding episode.

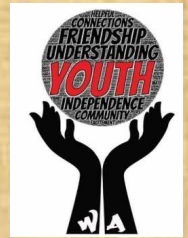
On the Move with Haemophilia was developed by InVIVO Academy in collaboration with Haemophilia Foundation Australia and Haemophilia Foundation of New Zealand.

HFA would like to thank Ali Morris (Senior Musculoskeletal Physiotherapist) and Dr Tina Carter (haematologist/HTC Director) from the Perth Children's Hospital and Helen Dixon (Expert Physiotherapist Haemophilia) from Wellington Hospital, New Zealand, for their expert advice in the development of these resources.

On the Move with Haemophilia was supported by Pfizer's Independent Grants for Learning and Change through an independent medical education grant.



HAEMOPHILIA FOUNDATION
WESTERN AUSTRALIA INC.



Family Christmas/End of Year Party

The Maze – Home of Outback Splash

SUNDAY, 2 DECEMBER 2018

Gates open 10am, meet at The Pavilion by 10.30am

1635 Neaves Road, Bullsbrook (9571 1375)



All members are welcome to attend our annual Christmas/end of year event!

W.A.Y. Western Australia Youth event held in conjunction, giving all families an opportunity to see what an amazing bunch our youth are and check out what's coming up next year for our younger members.

We have reserved **The Pavilion** at **The Maze** for picnic lunch. Please bring along chairs and/or a picnic blanket, and either bring or buy your lunch on site (**no BBQs available**). HFWA will supply soft drinks and water.

HFWA will supply presents for immediate family members aged 12 and under, to the value of \$10-\$15 (see form next page). If you wish to provide a gift for other children for Santa to present to them on the day, please bring it wrapped and labelled with their name.

Please return the form to the office by email to office@hfw.org
or by post to 2 Delhi Street, West Perth WA 6005 by **Monday 19 November 2018**.

RSVP is necessary so that Santa's Elves can make the presents.



Christmas Party - Attendance and Gift Form

I/We will be attending the Christmas Party at The Maze, Bullsbrook on Sunday 2 December 2018

Name/s of attendees:

Number of people attending:

Daytime Phone:

Email:

I give permission for photographs of my family taken at the Christmas party to be published in the HFWA newsletter. Yes/No (please circle).

Gifts for the following member's children (12 years or under):

Name:

Age:Boy/Girl Preferred Gift:

Name:

Age:Boy/Girl Preferred Gift:

Name:

Age:Boy/Girl Preferred Gift:

Name:

Age:Boy/Girl Preferred Gift:

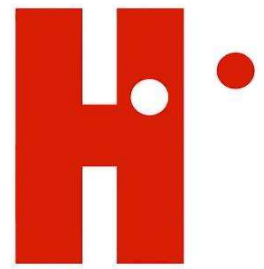
Name:

Age:Boy/Girl Preferred Gift:

Name:

Age:Boy/Girl Preferred Gift:

2018/19

**WHAT'S
ON?**

Sunday, 2 December - 2018 Christmas Party and Youth Event**The Maze/Home of Outback Splash****1635 Neaves Road, Bullsbrook, WA 6084**

See the Invite and RSVP form on pages 14 and 15

Sunday, 20 January 2019 - Men's Breakfast

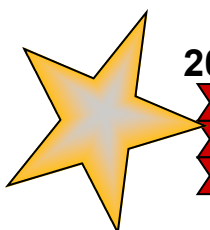
See page 10 for your invitation

Sunday, 20 January 2019 - Women's Breakfast

See page 10 for your invitation

10 - 12 October 2019**19th Australian and New Zealand Conference on Haemophilia
and Rare Bleeding Disorders**

Watch this space for more details

**2018/19:**

- ◆ youth group events
- ◆ quarterly men's group
- ◆ World Hemophilia Day

- ◆ quarterly women's group
- ◆ parents and family meetings
- ◆ Bleeding Disorders Awareness Week