Contact Newsletter of Haemophilia Foundation WA Inc. February 2019

Santa visited Outback Splash



HAEMOPHILIA FOUNDATION WAINC.

City West Lotteries House, 2 Delhi Street, West Perth WA 6005 P: 08 9420 7294 E: office@hfwa.org W: www.hfwa.org

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Cover picture

Santa with a very happy little member

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 6527

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 6527

ABDR Data Manager and Clinical Trial Coordinator: Marina Goruppi

Entrance to the Cancer Centre is on the outside of the building

Haemophilia and Haemostasis Centre

Level 1 Cancer Centre

Fiona Stanley Hospital 102-118 Murdoch Drive

Murdoch WA 6150

Postal Address (address all correspondence as Private and

Haemophilia and Haemostasis Centre

Level 1 Cancer Centre

Fiona Stanley Hospital

Locked Bag 100, Palmyra DC WA 6961



Confidential);

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 everyone had a good festive season and a relaxing new year.



Things are ramping up here at HFWA for 2019, we have already held a Men's and a Women's Breakfast in the blistering heat (40 degrees), which I guess is to be expected in January in Perth.

If you are a parent of a young child with a bleeding disorder and would like to meet like minded people be sure to attend the Young Parent/Family Morning tea at McDonalds in South Perth on Wednesday 20 March, See page seven for further details.

This year the 19th Australian Conference on haemophilia, vWD and rare bleeding disorders will be held at Novotel Manly, Sydney on 10-12 October. There will be more information about the conference in the coming months.

Sadly we said goodbye to Kelly last year and Mel (who previously worked in the office a few years ago), has come back a couple of days a week to fill-in. Mel works for another organisation on a roster basis, so her days in the office will vary. Please be aware that the office@hfwa.org email will be monitored in between for any urgent issues and Mel will get back to you with regard to all non-urgent matters when she is in. I can always be contacted on 0415 978 031 for any urgent matters.

I would like to thank Kelly for the great work she did while with us and wish her well for the future.

In December the National Blood Authority announced that they will include Extended Half-Life (EHL) factor VIII and factor IX products, treatments for haemophilia A and B, in the national tender for clotting factors and related products.

For more information about this decision and the tender, see the news item on the NBA website: https://www.blood.gov.au/extended-half-life-clotting-factor-products-included-national-blood-arrangements

Membership renewals fall due on June 30 every year. To find out if you are currently a financial member, please contact the office on 9420 7294 or email: office@hfawa.org.

Be part of HFWA

As a member, you become part of the HFWA and HFA community.

We invest our funds back into our members and the HFWA community.

Benefits

You are entitled to receive our quarterly newsletter, peer support activities, access to our library resources, subsidized Medic Alert emblems and shoe subsidies.

Creating a better community

By being a member, you support the work we do towards a better quality of life for people with a bleeding disorder and provide support for their families.

Gavin Finkelstein President



Wednesday 17 April 2019 will mark World Haemophilia Day!

Light it up Red!

Perth Bell Tower will once again be lit up Red to commemorate World Haemophilia Day. To celebrate, post photos on the HFA Facebook page of you and your friends at the landmark.

HFWA 2018 Christmas Party

On Sunday 2 December 2018, we went to Outback Splash and the Maze in Bullsbrook for the HFWA Christmas party.

We had a good turnout of community members; some of whom we only get to catch up with annually at the Christmas parties. It's always great to see everyone, chat about the year's happenings and see how much the kids have grown! We also had a new family come to the party to meet other community members. Hopefully they had a great time and gained some insight on how other families live with haemophilia.

Santa turned up on a golf cart with a bale of hay to sit on and loads of presents for the kids, then the kids had Zooper Doopers followed by more swimming, getting lost in the Maze, looking at Koalas and bouncing on the giant jumping pillow.

Thanks to all who attended, and especially thanks to Melanie, Sharri & Toyworld Midland.

Cheryl Ellis



HFWA 2018 Christmas Party













Light your Home up Red Competition



Wednesday 17 April 2019

Every year on April 17, World Hemophilia Day is marked around the world in order to increase awareness of haemophilia and other inherited bleeding disorders.

World Hemophilia Day was started in 1989 and the World Federation of Hemophilia (WFH) chose April 17 in honour of WFH founder Frank Schnabel, who was born on that day.

The World Federation of Hemophilia (WFH) was established in 1963 by Frank Schnabel, a Montreal businessman born with severe hemophilia A. His vision, as he stated, was to improve treatment and care for "the hundreds of thousands of haemophiliacs" worldwide through a new international organisation.

Working with leaders from a group of national patient associations, Schnabel convened a global meeting in Copenhagen, Denmark, on June 25, 1963. There were representatives from 12 countries: Argentina, Australia, Belgium, Canada, Denmark, France, Germany, Japan, the Netherlands, Sweden, the United Kingdom, and the United States.

Hemophilia World, April 2013

This year landmarks around Australia will "Light it up Red" to commemorate World Hemophilia Day and we are running a "Light your Home Red" competition.

Entries are now open with members encouraged to join in raising awareness of World Hemophilia Day. First prize is a gift pack comprised of: 2 x shopping bags, red wine, gift card, nail polish and chocolates.

To apply, email us your name, a contact phone number and email address to office@hfwa.org.

Entries close 4pm 10 April 2019.

"Light your Home Red" on the night of 17 April 2019, take a photo and submit your photo to office@hfwa.org.

Judging will take place by HFWA Committee Members on Tuesday 23 April 2019.

The winner will be announced on the HFWA website and in the April edition of the Contact Newsletter.

Competition Terms & Conditions

- 1. Only members of HFWA aged 18 years of age and older are eligible for the competition.
- 2. The winning household will receive a gift pack.
- 3. Judging will take place on Tuesday 23 April 2019. by HFWA Committee Members.
- 4. The Judge's decision is final and no correspondence will be entered into.
- 5. HFWA reserves the right to disqualify any entry that contain(s) images deemed to be offensive or inappropriate.
- 6. The prize is not redeemable for cash.
- 7. All photos become the property of HFWA and will be published on the HFWA website and the Contact Newsletter and may be used in future promotional material.
- 8. By entering into the competition, the participant is deemed to have accepted these terms and conditions.



HFWA

Young Parent/Family Morning Tea

Come and join us for a catch up!

Meet old and new friends and enjoy a coffee while the kids play.

Date: Wednesday 20 March 2019

Where: McDonalds South Perth (cnr Berwick St and Canning Highway) Time: 10am

RSVP: by Wednesday 13 March to office@hfwa.org or 94207294

Any queries please call Cheryl On 0402 033 652 Look Forward to seeing you all there!

PROBE Study update from HFA



Some of you have helped to test the print and online survey for the PROBE (Patient Reported Outcomes Burdens and Experiences) study. This is a multi-national study on the impact of living with a bleeding disorder, treatment outcomes and quality of life. HFA has joined other haemophilia organisations around the world to participate in this study and build a collection of robust patient-reported data – crucial to help HFA understand current issues for our community, and to quantify and represent these issues to governments or treatment and service funding bodies in a credible way.

PHASE 2 RESULTS

21 countries participated in phase 2 of the PROBE study in 2016-17. This tested:

- Whether the survey questions would capture consistent responses if they were repeated twice in the same community (e.g. Australia)
- The stability of the online survey

Australia contributed a total of 103 survey participants.

People with haemophilia/carry the gene -51 (required = 50)

People without a bleeding disorder (controls) -52 (required = 50)

An important learning from this phase was that larger numbers of survey participants will be needed at a country level to provide meaningful data. Participants were grouped as controls and into haemophilia severity, e.g. mild/moderate/severe. When comparing the different groups of participants, the sample sizes were found to be too small for stable results at a country level, but could be demonstrated at a regional level – for Australia, this was the Western Pacific Region, including Japan, Vietnam, Australia and New Zealand.

The results validating the PROBE study at a regional level are available on the PROBE study website – www.probestudy.org. Feedback about the online survey has been used to fix bugs and make enhancements for the phase 3 version. The international team set up a simple and user-friendly dashboard to display the country and region data for the participating national haemophilia organisations. Testing the dashboard and providing feedback was an exciting time for us as we realised the great potential of this data for HFA – both to understand the issues for our community and represent them to funding bodies and decision-makers. This questionnaire is about haemophilia, but a survey on VWD is also planned for the future.

NEXT STEPS

Phase 3 is planned to begin at the end of 2018. It is the final 'real world' stage of implementing the haemophilia survey around the world – where we invite the wider Australian bleeding disorders community to complete the questionnaire. This will be Australia's opportunity to collect current data about the experience of our community. As you can see, it will be important to gather as many survey responses as possible. Surveys will be available in print and online. Stay tuned for more information!

Our thanks to Dr Liz Bishop, Michael Kirby Centre for Public Health and Human Rights, Monash University who continues to provide oversight of the ethical process.

For more information about the PROBE study in Australia, visit the PROBE section on the HFA website - https://www.haemophilia.org.au/research/probe-study.

Or contact Suzanne O'Callaghan at HFA:

E: socallaghan@haemophilia.org.au T: 1800 807 173

Arved Wasser Funding Report - Karen Doyle

I would like to thank the HFWA Committee for granting me the Arved Wasser Funding, which made it possible for me to take part in the 2018 National Taekwondo Championships in Bendigo.

I have been doing Taekwondo for the past fourteen years. My daughter started and I spent a lot of time sitting in the waiting room, my journey began as a fitness mum then progressed onto Taekwondo. I started doing Freestyle Taekwondo which is a physically challenging style of Martial Arts (Korean Kickboxing), where I achieved the Rank of third Dan. After four years of training in Martial Arts I started training in Traditional Taekwondo, I am currently ranked third Dan and will be promoted to the Master Rank of fourth Dan in December. In my years of training I have had some very severe joint and muscle bleeds due to the nature of the sport, requiring many transfusions, but overall, I have developed muscle strength and flexibility that helps with my overall joint health.

I have also been teaching Taekwondo for the last twelve years; our classes are available for three to six-year olds and seven-year olds to adults. I also have classes that are specifically for students with Special Needs (five to twenty-one years).

I am part of the Competitive Poomsae Team (Patterns) and have competed at a club, state and national level. I also compete in Competitions to qualify for International competitions, finishing fifth in the Selections for Oceanias held in Fiji in 2016.

I am currently second in the State and National Champion. One of my students is an International Para Athlete.

Recently I was in Bendigo, where the Australian National Championships were held. I achieved National Champion in Individual Poomsae and Bronze in Family Pairs Poomsae.

Bendigo is a thriving Community with many large Hospitals that stock fviii, which is why I chose not to take the product with me. Travelling causes discomfort in my joints and immobility and swelling for some time.

I enjoy doing the technical side of Taekwondo, but as part of our Grading Syllabus we are required to spar, and sometimes when the syllabus requires we break boards.

Karen Doyle



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Please Apply:

If you have an educational, recreational, work or study related activity you would like to pursue, please look for the Arved Wasser Memorial Fund information and Application Forms on page 13-14 of this newsletter.

Women's Breakfast Report

On Sunday 20 January 2019, I joined nine other lovely ladies for the Women's Breakfast at Straits Café at the Rendezvous Hotel in Scarborough. It was a very hot day with great views of the ocean and all the activity on the Scarborough foreshore.



These breakfasts are valuable to women with inherited bleeding disorders as they are a source of support and a forum to raise concerns about their and their families bleeding disorders. Many topics are discussed, not only about bleeding disorders, but other topics that concern women in today's busy society and of course it is nice to catch up with friends and talk about what we have been up to since we last saw each other.

We discussed things, such as services provided by the Treatment Centres; access to Social Worker; menorrhagia; family planning; transition; upcoming fundraising events; upcoming conferences and World Congress and new resources.

The women's breakfasts are held throughout the year and we are always happy to welcome new members along, so keep an eye out in future newsletters for the invitations to these and other events.

Beryl Kerr













Men's Breakfast Report

The first Men's Breakfast for 2019 was held on Sunday 20 January at the Waterwall Restaurant in Como. It was a very hot day so thankfully we arrived early and the restaurant was airconditioned. Despite the weather we had a reasonable turnout and a mix of regular and new faces.



These breakfasts are an important part of the HFWA Peer Support program for men and they enable guys from different age groups with bleeding disorders to meet with their peers in an informal environment. The topics discussed are usually many and varied and centre around their lives and the impacts of their bleeding disorders and related issues. The breakfasts provide an excellent opportunity to ask questions and share knowledge and experiences in a positive way.

We also have a few fathers of kids with bleeding disorders attend which provides them with a safe environment to ask questions and share their own experiences as well.

The breakfasts are held regularly so if you are interested in coming along please let myself or Mel in the Office know.

Gavin

Female Factors—new young women's resource

HFA has released **Female Factors**, an innovative new resource for young women and teenage girls.

This was developed to answer the questions of young Australian women about how bleeding disorders affect females – but in a magazine style that is fresh and engaging. There are personal stories, quotes and tips.

HFA worked with haemophilia and gynaecology experts, who put together easy-to-read information for young women.



The booklet has explanations about heavy periods and other bleeding symptoms in females, covering all bleeding disorders. It answers FAQs - such as what's 'normal' and what's not normal, or why girls with haemophilia have different bleeding patterns to their father or brothers - and gives frank but reassuring answers to some of the questions young women worry about.

HOW TO ACCESS IT

Female Factors is available in multiple formats

- On the HFA website www.haemophilia.org.au under PUBLICATIONS
- On Factored In www.factoredin.org.au under INFO > GIRLS
- You can read the entire booklet online as a magazine in ISSUU, download it, or download specific sections
- Print copies are also available from HFA, local Foundations and your Haemophilia Treatment Centre.

Many people were involved in developing **Female Factors**. Both young women and their parents and health professional experts suggested what topics to cover, reviewed it thoroughly and wrote new content or gave personal experience to answer questions.

Special thanks go to the young Australian women affected by bleeding disorders who contributed their personal stories and tips and focus-tested the design!

FOR MORE INFORMATION

To find out more about Female Factors or order copies, contact HFA:

E: hfaust@haemophilia.org.au

T: 1800 807 173.

If you would like a copy of these publications, please email the HFWA office on office@hfwa.org and we will send them to you.



New resource—Telling Others

How do you tell a new partner about your bleeding disorder? Or your daughter that she may have a bleeding disorder or carry the gene? When are you required to tell someone about your bleeding disorder?

Telling others about bleeding disorders: information for women, girls and their parents is the latest resource in HFA's The Female Factors project.



- Visit the HFWA website under PUBLICATIONS > WOMEN WITH BLEEDING DISORDERS to view it online or download it.
- Contact HFA, HFWA or your Haemophilia Treatment Centre for print copies.

Telling others includes:

- The pros and cons of telling others
- The range of situations where you might disclose
- Talking to your daughter about her bleeding disorder
- How to prepare to disclose
- When you are required to disclose
- Personal stories and tips from other Australian women and parents

DISCLOSURE AND THE LAW

HFA has also developed information about disclosure and the law for both women and men in consultation with legal experts. This is available on the HFWA website under ABOUT BLEEDING DISORDERS > DISCLOSURE.



KEY POINTS

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

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

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

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

Thanks to the many people who contributed to the development of **Telling Others**: Marg Sutherland, health educator, who wrote it; the women, parents, health professionals and legal experts who reviewed it; and the women and parents who very generously shared their experiences and tips in personal stories and quotes.

Arved Wasser Memorial Fund

INFORMATION AND APPLICATION FORM

HFWA invites applications for the Arved Wasser Memorial Fund for the 2019/2020 financial year. If you would like to apply to the fund please complete the Standard Form of Application, and return to HFWA no later than Friday 31 May 2019.

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".

Guidelines

- a) For such time as the fund remains sustainable, a nominated sum (e.g. \$1,000) shall be made available each financial year. This amount may be reached by way of a single grant, or several smaller grants.
 - b) These grants will consist of a nominated sum from the Arved Wasser Memorial Fund, and an amount being 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.
- The recipient of any grant from this fund must reside in Western Australia, and have a bleeding disorder. Family members (including carriers) are not eligible.
- a) Members will be invited to make application, (e.g. notice in newsletter) however; financial membership of HFWA shall not be a prerequisite for any applicant.
 - 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.
- These grants are not intended to subsidise regular primary or secondary school fees, with regard to "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, in 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 not be paid to applicants.

Arved Wasser Memorial Fund

STANDARD FORM OF APPLICATION*

- * 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.
- * Please read grant guidelines carefully before completing.

Name:							
Address:							
	Postcode:						
	Telephone:						
Amount Requested: \$	-						
**(Please give a brief explanation of how this money will be used).							
 If insufficient space, please attach a separate sheet. I make this application in good faith, having read and understood the guidelines pertaining to such. I shall accept and abide by any decision made by the Haemophilia Foundation Western Australia Inc. Management Committee, relating to this application. Signature of Applicant (or parent/legal guardian if under 18 years of age). 							
Applicant/Parent/Legal Guardian	Date						

HFWA are selling quality shopping bags to support our state programs.

To order your bags and arrange collection email: office@hfwa.org.au or call: 9420 7294.



Jute Large Shopping Bag 42cm W x 33cm H



Red Shopping Bag 33cm W x 35cm H

\$3.00

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						
Name:	<u> </u>						
Address:							
Telephone:	Email:						
Card Type: Card Number:							
Expiry Date:	CVV:						
Name on Card:							

HFWA NAIL POLISH GIFT PACKS

In Stock Now

Three bottle gift packs available.

Looking for that personalised gift with a real message for family and friends? Look no further!

Gift Packs

Telephone:

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



Assorted Colours

Helen's Melons, Emerald Green, Rose Gold, Silver and White.



I would like to order	Gift Packs with the followin	Gift Packs with the following colours:							
I would like to order	Bottles of the following cold	ours:							
Total \$	(postage can be arranged at extra	a cost.							
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	Phone the office: 08 9420729	4 to pay by credit card							
Name:									
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Email:



Haemophílía Foundatíon WA Fundraíser



The Famous Haemophilia Quiz Night Returns in 2019

After a four-year hiatus the HFWA Quiz Night is returning. Those who came to our Quiz Nights in 2012 and 2015 will know that HFWA turns on a night full of fun and great prizes. Our Quiz Night subcommittee has begun to put this year's event together and we are aiming for a date in mid-November so please watch this space in the next newsletter and in the HFWA eNews for more details.

Our Quiz Nights are critically important to our fundraising efforts and this year's event will be no exception. The ever popular HFWA Community Camp will be held again early next year which is a major undertaking for the Foundation. Then later in the year the WFH 2020 World Congress is being hosted in Malaysia. Having a World Congress so close will be a great opportunity for us West Aussies to attend and, as with the 2014 World Congress in Melbourne, HFWA will be aiming to assist as many of our members to attend as possible.

As we get closer to November we will also be looking for volunteers to help and for donations of prizes.

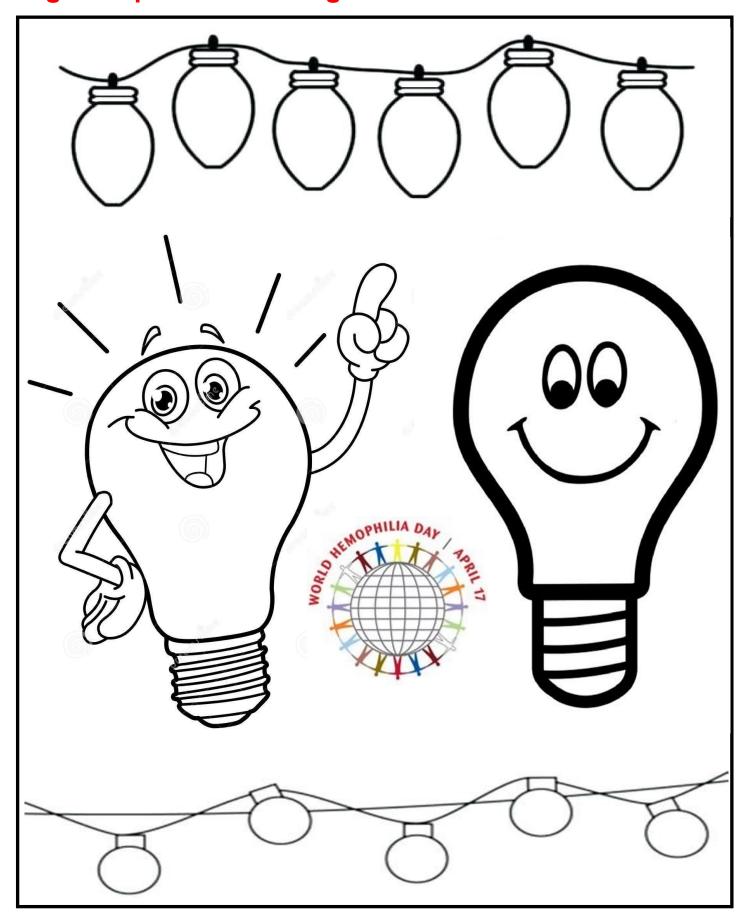
Venue to be Confirmed

More info to come

(Booking forms available August)



Light it up Red Colouring Sheet

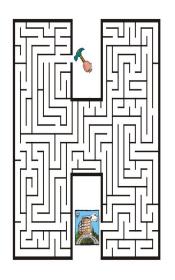


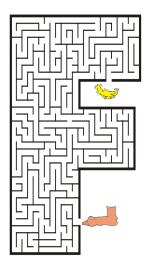
Kids Corner Word Search & Maze

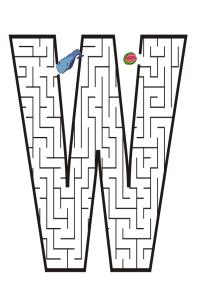
Science of Light

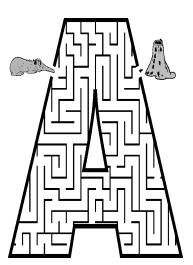
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RAINBOW AUSTRALIS SPECTRUM PRISM OBJECT LIGHT VISIBLE. REFRACTION REFLECTION SHADON AURORA RAYS EYE. NATURAL. SURFACE. OPAQUE STARS POLLUTION BEAM EMIT









2019

WHAT'S ON?



Wednesday, 20 March 2019 - Young Parent/Family Meeting
McDonalds South Perth
See invitation on page 6

Sunday, 14 April 2019- Women's Breakfast Details released soon Sunday, 14 April 2019 - Men's Breakfast Details released soon

Wednesday, 17 April 2019 - World Haemophilia Day See details on page 3 and competition on page 6

Save the date

April 2019 - Entertainment Books Fundraiser

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

13-19 October 2019 - Bleeding Disorders Awareness Week

Saturday 19 October 2019 - Bunning Sausage Sizzle

Saturday Mid November 2019 - HFWA Quiz Night