

Contact



Newsletter of Haemophilia Foundation WA Inc.

May 2019

Perth “Lit it Up Red”



HAEMOPHILIA FOUNDATION WA INC.

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

Cover picture

Perth Landmarks Lit up Red for World Hemophilia Day

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 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



It was World Haemophilia Day on 17 April and several things happened in WA to mark the date. We had Optus Stadium, Matagarup Bridge, Crown, The Swan Bell Tower and The Trafalgar Bridge light up in red to recognise World Haemophilia Day. The venues all looked awesome; a big thanks to Melanie and Litsa for organising all the venues, see photos throughout the newsletter.

On Sunday 14 April, we had a High Tea for the Women's Group and a Men's Breakfast to Celebrate World Haemophilia Day; see the reports on page nine.

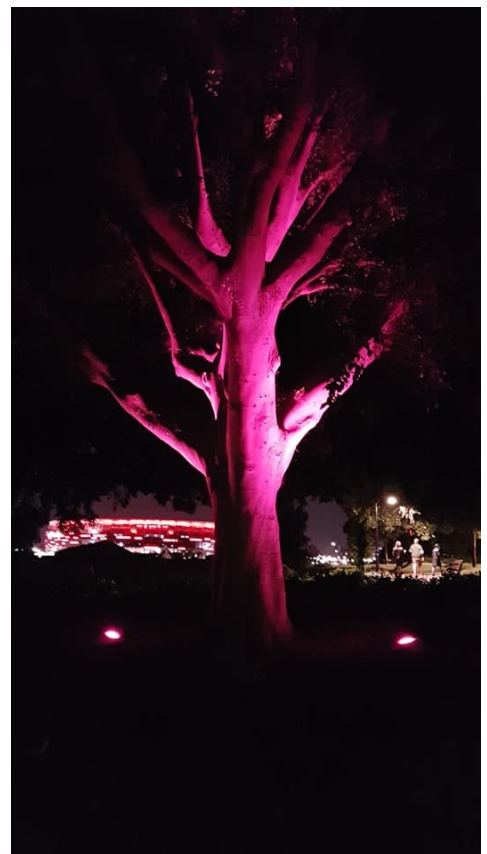
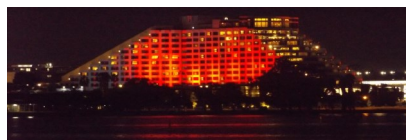
We eagerly await the announcement from the NBA for blood and treatment products for people with bleeding disorders; this announcement has been delayed for an extended period of time. Since the last tender, there has been substantial change in the market, with a significant increase in the number of treatment products registered, and it is well past time to have a tender. With the disappointing news from MSAC in relation to Hemlibra® (emicuzumab), we are eager to see the best outcome for everyone accessing treatment products.

We are holding a combined youth event for various ages and a catch up for parents on Sunday 19 May (the day after the federal election); it would be great to see as many of you there as possible to catch up, have a chat and a good time.

There is a limited amount of funding available to help members attend the 19th Australian Conference on Haemophilia, vWD and Rare Bleeding disorders to be held in Sydney from 10 to 12 October 2019 (see application for funding form enclosed). It will be a fantastic opportunity to catch up with old friends and meet new ones in a great environment, and to get the latest updates on what is happening in all matters relating to bleeding disorders in Australia.

Until next time.

Gavin Finkelstein
President



WORLD HEMOPHILIA DAY 2019 OUTREACH AND IDENTIFICATION

World Haemophilia Day was celebrated around the world on 17 April 2019. This year, the World Federation of Hemophilia (WFH) focussed on reaching out and identifying new members of the bleeding disorders community. For many years, the WFH has supported outreach projects in different countries and conducted educational events for both lay and health care professionals in conjunction with our national member organizations (NMOs).

The WHD2019 campaign featured examples of WFH outreach initiatives such as organising regional workshops, raising awareness of bleeding disorders through media coverage or training health professionals and collecting data. It combined these examples with submissions from our community about outreach efforts in their own regions or ideas about what would be helpful for future initiatives.

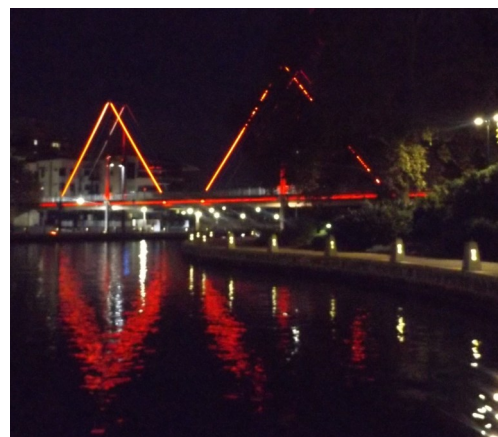
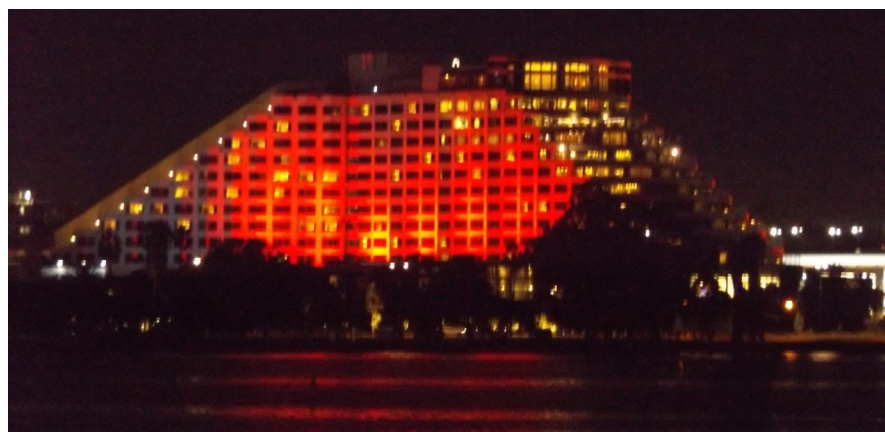
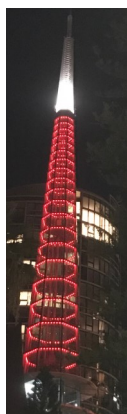
This landmark day also helped to illustrate the importance of the WFH Humanitarian Aid Program—an important endeavour for the WFH that provides a range of integrated care development training programs to ensure the local infrastructure and medical expertise are available to optimize and appropriately use donated products.

Over 70 landmarks in cities around the world “Lit it up Red” this year, we would like to thank the following organisations for their Support.

Thank you!

**Bell Tower Perth
Optus Stadium
Main Roads WA (Matagarup Bridge)**

**Crown Perth
Trafalgar Bridge**



19th Australian Conference on haemophilia, VWD & rare bleeding disorders



Novotel Manly, Sydney 10-12 October 2019

To be held in Sydney later this year, the 19th Australian Conference on haemophilia, VWD & rare bleeding disorders promises to bring together people with bleeding disorders, their families, health professionals, policy makers and industry from around Australia and across the ditch.

Once again there will be a diverse program on offer as well as abstracts and poster presentations. There will also be Men's, Women's and Youth Group activities to join in on.

Please see the conference brochure and registration form enclosed or for more information, visit the HFA Website

<https://www.haemophilia.org.au/get-involved/events/event-listing/19th-australian-conference-on-haemophilia-vwd-r>

2019 Conference Funding

Limited funding to attend the conference is available to HFWA members, please complete the Conference funding application form enclosed and return to HFWA by 14 July 2019.

Office Coordinator
Haemophilia Foundation WA Inc.
City West Lotteries House
2 Delhi Street
WEST PERTH WA 6005
office@hfwaw.org

HFA Ageing Project

HFA has received funding from the Australian Government Department of Health to investigate the needs of the bleeding disorders community around ageing and try out some solutions relating to education and peer support and has recruited Preetha Jayaram to lead the project and will be in contact with community members, HTC's and other stakeholders to consult about ageing issues.



With her diverse set of skills and background, Preetha is looking forward to taking on the Ageing project with HFA. She began her career as a social scientist and anthropologist conducting research into castes, tribes and rural development in Kerala State in India.

'After migrating to Australia in the early 1990s, I continued my research career working with Melbourne's local government community services departments on ageing projects,' said Preetha. 'This involved visiting and talking with many older people in the community – in one project we interviewed around 500 older residents!'

Preetha then moved on to curatorial work and digitising the indigenous collection at Museum Victoria. She also had the opportunity to undertake research and community consultations for the Stolen Generations organisation in Melbourne.

More recently, Preetha has followed her interest in education and has gained qualifications and expertise in education program design and content development for the Vocational Education and Training (VET) sector. She currently also works part-time as the Training and Compliance Manager for a vocational education provider in Melbourne.

'I love interacting with people and listening to their stories. I have a strong belief in using personal stories to understand and empower the community.'

Preetha enjoys music, art and meditation and values its therapeutic effects.

Preetha works on Monday, Tuesday and Wednesday and can be contacted at HFA office:

E: pjayaram@haemophilia.org.au

T: 03 9885 7800

Buzzle.com



As you get older
three things happen.
The first is
your memory goes,
and I can't remember
the other two.

— Sir Norman Wisdom

Extended Half Life Clotting Factor Products included in National Blood Arrangements

Inclusion of Extended Half Life Clotting Factor Products in National Blood Arrangements

The National Blood Authority (NBA) announced that they will include Extended Half-Life (EHL) factor VIII and factor IX products - treatments for haemophilia A and B - in the next national tender for clotting factors and related products. The tender is currently planned for 2019.

The Jurisdictional Blood Committee (JBC) recently approved the inclusion of EHL recombinant factor VIII and EHL factor IX products in the national arrangements for funding and supply of blood products managed by the NBA. The JBC decision was supported by a Medical Services Advisory Committee (MSAC) assessment of EHL recombinant factor VIII and factor IX products.

The NBA confirmed that the current arrangements for EHL clotting factor products will continue in the meantime. These arrangements provide temporary access to EHL products for approximately 200 haemophilia patients with high priority needs. Further information about these arrangements can be found at <https://www.blood.gov.au/plasma-and-recombinant-product-procurement>.

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>

Haemophilia Foundation Australia

HFWA Membership

HFWA Membership falls due on 30 June 2019

The HFWA membership period runs from 1 July 2019 to 30 June 2020. HFWA is committed to the promotion of Haemophilia and related bleeding disorders on a State, National and International level.

Being a member entitles you to:

- Membership to Haemophilia Foundation Australia.
- Receive the quarterly newsletter
- Access to peer support activities
- Access to library resources
- Subsidised Medic Alert emblem
- Shoe subsidies

The cost of membership is \$25.00, payment can be made over the phone or online.

Please see enclosed the 1019/20 membership form

Young Parent/Family Meeting

I recently had the privilege of spending the morning with fellow members of HFWA and Charlotte Bradley Penny (Social Worker) at Sticky Beaks Café in Kings Park.

It was lovely to share our stories, experiences, general thoughts and last but not least feelings. Some older members (with older children) that attended also provided beautiful insight and also articulated what we as mothers of young children with haemophilia experience in everyday lives, very well. Things like ED visits and operations for ports were some of the topics discussed. I always find our meetings helpful and informative and its great to be part of such a wonderful community.

The boys had lots of fun enjoying the surrounds and it was a beautiful morning for it too. Thanks Everyone ~ till next time.

Julene



Women's High Tea Report

On Sunday 14 April 2019, the HFWA women with inherited bleeding disorders group held a high tea at the beautiful Cottage Tea Rooms in The Swan Valley. One of the main topics of discussion was the upcoming conference in Manly Sydney. For details on how to register for the conference, visit <https://www.haemophilia.org.au/conferences/2019-conference>. Limited funding to attend is available from HFWA, please see the application form enclosed.



Men's Breakfast Report

On Sunday 14 April we had a Men's Breakfast at the Water Wall Restaurant at the Pagoda Hotel in Como. The breakfasts are always great way to catch up with other men in our community.



A wide range of topics were discussed:

- Travel insurance
- Dental services
- Aging
- World Hemophilia Day
- New treatments
- Services at Fiona Stanley Hospital
- Support network and other possible events for the Men's group
- Men's breakfast venue
- The Conference in Sydney

The Men's breakfasts are a great way to keep in touch with a diverse group of men and provide all with an opportunity to swap stories or just catch up

Gavin Finkelstein and Dale Spencer

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

1. 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.
2. 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.
3. a) Members will be invited to make application, (e.g. notice in newsletter) however; financial membership of HFWA shall not be a pre-requisite 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.
6. 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: _____

Age: _____

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

Shopping bags are still available.

To order your bags and arrange collection

email: office@hfw.org.au or
call: 9420 7294.



Jute Large Shopping Bag
42cm W x 33cm H

\$6.50



Red Shopping Bag
33cm W x 35cm H

\$3.00



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

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



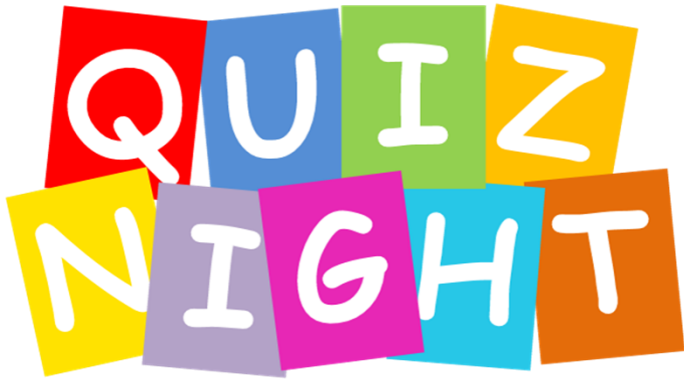
\$40.00

Assorted Colours

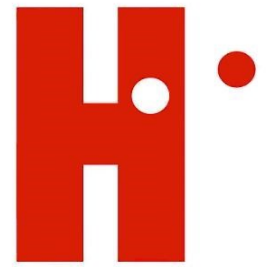
Helen's Melons, Emerald Green, Rose Gold, Silver and White.



**\$20.00
Each**



Haemophilia
Foundation
WA
Fundraiser



Don't forget to get your team ready for the HFWA Quiz Night!

The HFWA Quiz Night is happening in November. Not only will you have a great night but you will be supporting the HFWA community with proceeds going towards the 2020 Community camp.

Start swatting now for Quiz glory!



The new 2019|2020
Memberships are here

Go to:

<https://www.entertainmentbook.com.au/orderbooks/847b23>

To order your copy now!

19th AUSTRALIAN CONFERENCE
On haemophilia, VWD & rare bleeding disorders

CONFERENCE FUNDING APPLICATION FORM

To be completed by the applicant (or parent or guardian if under 18 years of age).

All Applications due by 14 July 2019

NAME:			
ADDRESS:			
		POST CODE:	
AGE:		TELEPHONE:	
EMAIL:			
AMOUNT REQUESTED (\$). (Breakdown required):	Flight Registration Accommodation Farewell Dinner Total	\$ \$ \$ \$ \$	_____ _____
Please give a brief description on how attending the Australian & New Zealand Conference would benefit you.			
If insufficient space, please attach a separate sheet.			
I make this application in good faith, having read and understand the attached guidelines and I shall accept and abide by the decision made by the Haemophilia Foundation Western Australia Inc. Management Committee, relating to this application.			
2019			
Signed Post to: Haemophilia Foundation WA Inc. City West Lotteries House 2 Delhi Street WEST PERTH WA 6005			Dated Email to: office@hfw.org

19th AUSTRALIAN CONFERENCE
On haemophilia, VWD & rare bleeding disorders

CONFERENCE FUNDING APPLICATION GUIDELINES

- Support funding for members to attend the National Haemophilia Conference may be provided by HFWA each year there is a conference.
- Funding may be provided at the discretion of the HFWA Management Committee.
- Financial members only may apply to receive assistance from this fund.
- Members should not see funding support as an automatic right.
- Assistance can be provided only if funds are available at the time of the request and all application criteria are met.
- Alternative avenues of funding assistance should be sought prior to requests being submitted to HFWA.
- Strict confidentiality is applied to all requests.
- Forms with the original application are stored securely at the HFWA office for accountability and auditing purposes only.
- HFWA will fund a maximum of Conference registration costs including farewell dinner, two night's accommodation and one economy return airfare.
- Previous applications for assistance will be taken into account.
- All applications to be made using the relevant form (copy attached), through the HFWA Committee members or Office Coordinator.
- If required, further information may be sought from HFWA Committee Members.
- Successful applicants are required to write an article about their experience at the conference for the HFWA newsletter.
- HFWA Management Committee will assess each application on its merit and its decision is final.
- Intending funding applicants/attendees must pay their expenses prior to reimbursement by HFWA
- Re-imbursement will be made to approved applicants once receipts have been provided. Discretion of the Management Committee can be applied at any time.

2019

**WHAT'S
ON?**



Sunday, 19 May 2019—Youth & Community Event

Sunday, 7 July 2019—Men's & Women's Breakfasts

Save the date

May 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