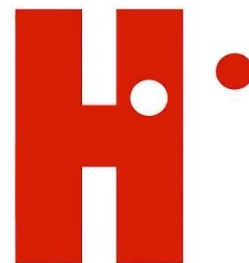


# Contact



**Newsletter of Haemophilia Foundation WA Inc.**

**July 2019**

## **May Youth/Community Event**



**HAEMOPHILIA FOUNDATION WA INC.**

City West Lotteries House, 2 Delhi Street, West Perth WA 6005  
P: 08 9420 7294 E: [office@hfw.org](mailto:office@hfw.org) W: [www.hfw.org](http://www.hfw.org)

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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](http://www.hfwa.org) 'Your Committee'.

**HFWA Office Coordinator**  
**Haemophilia Foundation WA Office**  
**Ph: (08) 9420 7294**  
**Email address: [office@hfwa.org](mailto:office@hfwa.org)**

## Cover picture

### Laser Tag participants May 2019

## 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

# 2019

Hi All

Things continue to roll on at HFWA with our Quiz Night fast approaching (see page 11), we are looking for donations for prizes and volunteers on the day to make it a memorable event. We have secured the ABC's Russell Woolf as our MC to make it a memorable evening for all those who attend.

The NBA has announced the tender for standard and extended half life treatment products, please go to the NBA website [www.blood.gov.au](http://www.blood.gov.au) for more information. It has taken a long time; let's hope we get a good result for all.

We have our regular Women's and Men's Breakfasts on Sunday 28 July (see page 13 for details); it would be great to see as many of you there as possible.

Don't forget the 19th Australian Conference on haemophilia, VWD & rare bleeding disorders is in Sydney from 10-12 October 2019. HFWA has a limited amount of funding available (please see pages 14 & 15) for details. HFWA would like to send as many people from Western Australia to attend as possible. It's an opportunity to meet new people and to hear the latest in what is going on with haemophilia and related bleeding disorders.

All the best,

Gavin

## Vale Phil Brenzi

In May the Haemophilia community lost one of its long-standing members in Phil Brenzi.

Phil served on the HFWA committee from 1996 to 2008. In his time on the committee Phil was integral in the organising of the 1999 conference in Fremantle, where his band also played at the conference dinner.

Phil also organised many community social events such as fishing trips and shooting at his local rifle club. We thank Phil for his contribution to the WA Haemophilia community and he will be sorely missed.



## Youth Community Event

It had come to be known as the “**Battle of Henley Brook**” ... and the legendary tales of the many valiant efforts from that glorious encounter on Sunday 19 May 2019 are still being talked about today.

On the banks of the Swan River twelve brave soldiers came together dressed in camouflage gear and face paint to wield machine guns and heavy laser rifles. Each one knew that they had a tough fight ahead of them if they were going to taste victory.

The hot midday sun beat down on the scorched, parched earth of the 20 acre Lasercorps battlefield. The dry grass and crusty soil was littered with ravaged wooden pallets, abandoned structures and the ghosts of those who had gone before them.

The Ferocious FlatCaps with their fearless leader Field Marshall Spencer (Dale) were to face off against the Brave BucketHats under the lolly-snake leadership of Brigadier Burgess (Nici).

These two small armies came together that day to battle for Honour, Glory, Valour and bragging rights. As they looked out over the combat zone each soldier silently wondered just how many of them would return from the conflict that day.

As each laser warrior launched themselves into the fight their cries thundered through the silence.

***“NO RETREAT - NO SURRENDER - HEY...WAIT FOR ME !!!”***

A pitched battle ensued. Young Corporal Jack, the newest FlatCap recruit, couldn't wait to get started and raced across the field using a scattershot approach. Team tactics were discussed. Bold moves were executed. Rapid laser fire was exchanged. Commando Cooper (alias “Captain Big Chungus”) was courageous in his efforts to defend basecamp until BucketHat reinforcements arrived.

Sergeants Shelby (alias “The Spitfire”) and Ebony-Rose (alias “The Scorpion”) bunkered down in the abandoned old bus and did an excellent job of providing cover.

Ben and Bri (alias “The Deadly Duo”) launched a swift pre-emptive strike on the BucketHats with their double firepower. It was a daring move that paid off. The FlatCaps had won the first strike of Battle Royale.

Major Brian (alias “The Smiling Assassin”) carried out his ambushes to the war cry of “*Take no Prisoners BucketHats*” and was seen launching missiles at random, successfully wiping out many strategic targets.

While Field Marshall Dale (alias “The Daring Destroyer”) stormed the barricades with the FlatCaps and captured the creek crossing placing the BucketHats under siege.



***Continued next page***



## Youth Community Event Continued....

### *From Previous Page*

Corporal Blaise (alias "The Super shot") was a dynamo shot from his FlatCap stronghold in the rusty old car and ensured that the ammo laser re-charge box was always close by.

With nerves of steel Lieutenant Willem (alias "The Sniper") inched his way towards the enemy picking off targets left and right as he launched a frontal assault on the FlatCaps.

Brigadier Burgess ensured her soldiers had sustenance and allocated an extra ration of lolly snakes for the troops. The sugar hit worked a treat and the BucketHats managed to Capture the Flag from the FlatCaps. Glory was short lived though before Private Brax (alias "The Valiant") boldly carried out the ultimate flanking manoeuvre and outwitted everybody.

Acts of heroism were encountered everywhere that day but all good contests must come to an end. Hot, weary, bruised and battered they trudged.....dragging their battle weary bodies up the hill for well-earned refreshments. Luckily everyone returned from the battlefield that day but the legendary stories of the bravery of those glorious twelve have now been written into the history books (or at least this newsletter) to be passed on down from one generation to the next.

### **Nici Burgess**



## PROBE for real-world evidence



***The real-world PROBE study is now available!***

What is the impact of haemophilia and treatment on Australians? How can we have access to high quality evidence about this?

With new treatments becoming available this kind of evidence is particularly important. We need to be able to explain what it's like to have haemophilia and the impact of different types of treatments. HFA's advocacy relies on credible data. Without this data we have not had enough strong evidence to use in our advocacy for new treatments.

The **PROBE (Patient Reported Outcomes Burdens and Experiences) study** is a great opportunity for you and others in our community to give this evidence.

### **What is PROBE?**

PROBE is a multi-national research study ([www.probestudy.org](http://www.probestudy.org)) which allows people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life. It compares their answers to other people in their community who do not have a bleeding disorder.

**You may have done the PROBE survey in the past. This was testing the survey.** In 2015 Australia joined more than 20 other national haemophilia organisations around the world to successfully test and validate the questionnaire. The international PROBE team is led by well-respected haemophilia organisation and academic investigators.

**This time the PROBE study is collecting real-world evidence.** Statistics from Australians who complete the questionnaire will be provided to HFA by the international team for us to use in our advocacy and planning for the future.

### **How can you help?**

You are invited to complete the questionnaire if you are **an adult (18 years+) who lives in Australia** and:

**Have haemophilia or carry the gene**  
**OR**  
**Do NOT have a bleeding disorder.**

You may also like to pass the survey on to your partner/wife/husband or other members of your family or interested friends.

We need a few hundred Australian participants for good quality results, so the more people who complete the survey, the better!

***Continued next page***

**Probe Study Continued****How to do the survey**

The questionnaire is available:

Online at <https://stage.mcmaster.plus/PROBE/>  
Or ask your local Foundation or HFA for a print survey pack

**What happens to your data?**

All responses are anonymous and confidential. They are combined as statistics and will not identify individuals. The survey is voluntary – it is up to you if you want to complete it and no one will know if you have or haven't.

**More information**

For more information about the **PROBE study in Australia**, visit [www.haemophilia.org.au/research](http://www.haemophilia.org.au/research)

Or contact Suzanne at HFA:  
E: [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au)  
T: 1800 807 173

## Bleeding Disorders Awareness Week 2019

***Challenging the status quo***

Bleeding Disorders Awareness Week is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a campaign and activities to raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia during the week of 13-19 October 2019.

This year the theme is Challenging the status quo.

What does challenging the status quo mean to you? Look out for the personal stories from the bleeding disorders community that we will publish during Awareness Week. We invite you to share these stories with other people you know: it's through sharing personal experiences that we can connect and increase understanding in the wider community.

**RED CAKE DAY**

Start thinking about hosting a Red Cake Day during the week. It is a great way to involve family, friends and workplaces to take part in a special event to help raise funds during the week.

HFA can post out promotional packs for your event or awareness packs for your event or awareness stand, such as stickers, balloons, tattoos, or colouring sheets. Orders will be open in August.

To go on the Bleeding Disorders Awareness Week/Red Cake Day mailing list, email [donate@haemophilia.org.au](mailto:donate@haemophilia.org.au) or keep an eye on the page: [www.haemophilia.org.au/BDAW](http://www.haemophilia.org.au/BDAW)





**The 19th Australian Conference on haemophilia, VWD & rare bleeding disorders** will be held at the Novotel Manly, **Sydney**, **10-12 October 2019**.

Our conferences bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.



### **PROGRAM**

Chaired by Dr Liane Khoo, Director, Royal Prince Alfred Hospital in Sydney, NSW, the program committee is developing a multidisciplinary program which will interest everyone.

### **Keynote speakers**

International expert on pharmacokinetics (PK) and measuring treatment outcomes in haemophilia, Prof Alfonso Lorio from the Department of Health Research Methods at McMaster University in Canada, will be presenting on his work and contributing to the discussion about where treatments are going in Australia. We will also have a plenary session with Dr Tim Sharp, AKA Dr Happy. Dr Sharp is an expert in human behaviour, in what makes people tick; but his focus is mostly on the promotion of positive psychology principles. His passion lies in helping individuals, teams and organisations to really thrive and flourish.

### **SHOULD I ATTEND?**

The Conference is a great opportunity for the bleeding disorders community and people working in the sector to hear the latest information and discuss current and emerging issues together. It is a niche conference, focused on the specific questions relevant to bleeding disorders, and caters for all delegates. We invite the following people to attend:

- People with haemophilia, von Willebrand disease or other bleeding disorders and their families - parents, siblings, partners – all ages welcome from young adults to seniors!
- Health professionals – doctors, nurses, physiotherapists, psychosocial workers and other health care providers;
- Treatment product producers, suppliers and service providers;
- Policy makers and government officials;
- Haemophilia Foundation volunteers and staff.

### **COMMUNITY FUNDING**

HFA has allocated funding to assist people living with a bleeding disorder, relatives/partners or carers to attend the Conference for expenses such as flight, registration, accommodation. Part funding applications are encouraged so we increase access and you will generally be expected to contribute towards your costs. Applications will be assessed on their merit – it is in your interests to provide full responses to the questions on the application form.

For an application form visit <https://tinyurl.com/HFA-conf-funding> or call HFA on 1800 807 173.

### **Applications close 31 July 2019.**

HFWA also has limited funding available for members to attend the conference, please complete the funding application form included in this newsletter and return to HFWA by 14 July 2019, or contact Mel in the office on 9420 7294 or [office@hfwf.org](mailto:office@hfwf.org) on details on how to apply.

### **MORE INFORMATION AND DETAILS**

- Visit [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences) and download the registration and Information brochure
- Or email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au).



## Future proofing

An important aspect of the health and wellbeing of bleeding disorders community members?

I took up the position of Project Officer at HFA in February 2019 and, as a first step in the project, have been looking into the needs of people with bleeding disorders in the future. This has involved consulting with community members, state and territory foundations, medical specialists, haemophilia nurses, psychosocial workers and physiotherapists to explore current issues and how to 'future proof' as people grow older.



*Getting Older* is a priority project of HFA. The project aims to identify, understand and respond to the range of needs people with bleeding disorders may have as they are getting older and help find appropriate solutions for them and their partner/family or friends/carers.

In the second stage of the project we will look at some solutions to enable people in the bleeding disorders community and their partner/family to manage their health and wellbeing into the future as they grow older. These will be taken from the recommendations in the needs assessment. To reach the community in this digital age, this will include online options for community members to inform themselves and connect with each other. This may involve, for example, expert information about exercise with arthritis or travelling as you get older. It will be important to give a voice to men and women – both people with bleeding disorders and partners/family or carers - so that they can share thoughts about what is needed and the strategies and services they have found useful. It may also involve strengthening current peer support groups.

I am looking forward to speaking with bleeding disorders community members and their partners/family around Australia to hear the issues they see around 'future proofing' their lives.

**If you are interested in sharing your thoughts about 'future proofing' and getting older with a bleeding disorder, please contact Preetha Jayaram at HFA to talk about your availability.**

**Partners and family also welcome.**

Phone: 1800 807 173

Email: [PJayaram@haemophilia.org.au](mailto:PJayaram@haemophilia.org.au)

*Preetha Jayaram*

Preetha Jayaram is the HFA Getting Older Project Officer



## **New phone counselling service for carers**

The Australian Government has recently launched a new support service for the estimated 2.7 million unpaid carers in Australia; this service is a free pilot program. The Carer Counselling Service provides six free phone counselling sessions with a trained professional counsellor over a few weeks to a few months for unpaid carers who are over 18 years and caring for a relative or friend.

An unpaid carer is defined as someone who provides free support to a family, friend or neighbour to help that person remain healthy and live as well as possible. Many carers will experience anxiety, stress, depression or low mood due to their ongoing carer role. The Australian Institute of Family Studies found that 51% of female carers and 30.7% of male carers have felt depressed for six months or more and twice as many carers have poorer physical health when compared to the general population.

This service will provide carers with a place to be able to receive free support and to provide them with counselling through telephone sessions from the comfort of their home. It will be available nationally and the operating hours are Monday to Friday 8am to 8pm (AEST time).

If you have any questions, please contact the Carer Gateway Counselling Service on 1800 227 301.

## **HFWA Membership**

HFWA Membership fell 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 2019/20 membership form

## **We need your help!**

We are desperately seeking people who can help with ideas, creating and assisting in the facilitation of HFWA family/ community camp 2020.

Currently our camp committee numbers are extremely low and the reality is that if we can't find more people to assist with this important event, it will have to be postponed until the following year.

Camps are such a critical component in creating a network of knowledge and support for all in the bleeding disorders community, not to mention the fun and lifelong friendships that are made.

If you are keen to help, please contact the office ASAP as a decision needs to be made soon if we can proceed for camp 2020.



## **Quiz Night—Save the Date!**

### **Haemophilia Quiz Night - Saturday 16<sup>th</sup> November 2019**

Those of you who have attended our past Quiz Nights will know that HFWA put on a great night, packed full of fun and great prizes. So, we are really excited to announce that we will be holding another Quiz Night once the weather warms up a bit. This year's event will be held at the fabulous Riverton Leisureplex complex on Saturday 16 November.

The months will fly by so start thinking about getting a table together. Tickets will go on sale soon and keep an eye out for the order form coming your way.

Our goal is to raise \$10 000 from the Quiz Night and this money will be used to run the family camp in March 2020.

We will also be looking for volunteers to help set up on the day or help in anyway and especially anyone who would like to donate prizes. If you can help please call the office on 9420 7294.

**So grab all your friends and family and get a table together for a great night.**





Shopping bags and nail polish gift packs are still available.

To order your bags and arrange collection  
email: [office@hfwa.org.au](mailto:office@hfwa.org.au) or  
call: 9420 7294.



 **entertainment.**

The new 2019|2020  
Memberships are here

Go to:

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

To order your copy now!

  
Haemophilia Foundation  
Men's

# Breakfast



SUNDAY 28 JULY | 8:30AM

RSVP BY 25 JULY: MELANIE 9420 7294 [OFFICE@HFWA.ORG](mailto:OFFICE@HFWA.ORG)  
GAVIN FINKELSTEIN 0415 978 031 [GAVFINKELSTEIN@GMAIL.COM](mailto:GAVFINKELSTEIN@GMAIL.COM)

THE

*Pagoda*

112 MELVILLE PARADE | COMO

## HFWA WOMENS *BREAKFAST*

Sunday 28 July 2019 @ 8am

RSVP by 25 July 2019 to Melanie on 9420 7294 or [office@hfwa.org](mailto:office@hfwa.org) or  
Cheryl Ellis on 0402 033 652 or [vice\\_president@hfwa.org](mailto:vice_president@hfwa.org)

International on the Water  
Hotel  
1 Epson Ave, Ascot

**19<sup>th</sup> 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: <a href="mailto:office@hfw.org">office@hfw.org</a>



**19<sup>th</sup> 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.

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**2019**

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**WHAT'S  
ON?**



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**Sunday, 28 July 2019—Men's & Women's Breakfasts**

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**Save the date**

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**Now 2019 - Entertainment Books Fundraiser—Page 12**

**28 July 2019—Men's & Women's Breakfasts—Page 13**

**19 September 2019—HFWA AGM—Watch this space!**

**10 - 12 October 2019 - 19th Australian and New Zealand  
Conference on Haemophilia and Rare Bleeding Disorders—  
Page 8**

**13-19 October 2019 - Bleeding Disorders Awareness Week—  
Page 7**

**Saturday 19 October 2019 - Bunning Sausage Sizzle**

**Saturday 16 November 2019 - HFWA Quiz Night—Page 11**