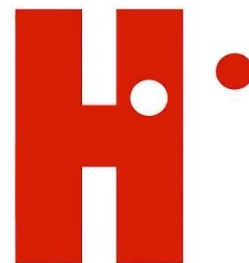


Contact



Newsletter of Haemophilia Foundation WA Inc.

September 2019

Join us at the next Sausage Sizzle



HAEMOPHILIA FOUNDATION WA INC.

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

Cover picture

Lots of fun at last year's sausage sizzle.

HFWA is grateful to Fuji Xerox for their ongoing support in printing the Contact Newsletter.

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

I hope everyone is enjoying spring and looking forward to some warmer weather coming up?

The year is ticking along nicely and we have a number of events coming up which will make the end of the year a very busy one. We recently held our AGM on the 19th of September with a guest speaker from WA Health Alliance to talk about "Our Health Record", it was a very interesting and informative talk. We were pleased to see an increased number of members attending the AGM this year and I hope everyone enjoyed the talk.

The 19th Australian Conference is coming up next month. We have a number of people from WA attending and I'm sure it will be a valuable experience for everyone involved. Bleeding Disorders Awareness Week follows on from the conference. If you are thinking about holding a Red Cake Day, please contact HFA for a promotional pack. The Bunnings Sausage Sizzle will be held on Saturday 19 October 2019, please contact Mel in the office on office@hfwf.org to volunteer some time to help us sell sausages or arrange a time to drop off cans of cool drink.

If you haven't done so already, please help us by completing PROBE study. The results from the study will help HFA to better understand current issues and for our future treatment advocacy, please see more details on page 6.

Unfortunately we were unable to get any volunteers to help with the community camp, so the committee have decided to cancel the 2020 camp.

The quiz night will be held on Saturday 16 November at Riverton Leisureplex, please secure your table by completing the form enclosed.

The annual end of year/Christmas party will be held at Adventure World, we hope that you will be able to join us to celebrate the end of the year. Please keep an eye out on the website and in future issues of the newsletter for more details.

Look forward to catching up with you soon.

Gavin

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 library resources
- Shoe subsidies
- Access to peer support activities
- Subsidised Medic Alert emblem

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

Please see enclosed the 2019/20 membership form

Men's Breakfast 28 July 2019

Once again the HFWA men's breakfast was held at the Pagoda Hotel restaurant. The venue is a firm favourite with the guys.

It's easy to access and seems pretty much a central location for all members to attend. Today's gathering was a little smaller than usual, with only seven "hangry" blokes giving the well-stocked buffet the once over.

With fuel in the tank, chat around the table was varied. Joint replacement, treatment centre services/comprehensive care plan, traveling with products, life after Hep C and the upcoming 19th Australian Conference. Those were just a few topics discussed between mouthfuls of food, all being washed down with coffee and juice.

As usual, the discussion at the men's breakfast doesn't always dwell on living with haemophilia: tig welding; football results; Optus Stadium seating; current working life and the transition into retirement were chatted about. Non haemophilia day to day life and life experiences/stories were also shared around the table.

Once the staff starting clearing tables around us, we all got the hint that it was time to leave.

If you have never attended a HFWA men's breakfast before, or it's been a while since your last one, keep an eye on the newsletter for the next brekkie.

They are always a good morning

David Bell

Women's Breakfast

The July women's breakfast was held this time at Ascot International Hotel on Epsom Avenue in Ascot. Many of us didn't even know it existed and after finding it, were quite surprised at how luxuriously adorned it was.

We enjoyed a full buffet breakfast, views of the Swan River and great conversation. Most of the things we talked about were bleeding disorder related, such as the upcoming conference in Sydney, the AGM, camp, looking after grandchildren and Home infusion, running back and forward to the doctor, nurse at home, diagnosis, bruising, Quiz night and the Christmas party.

Other things that we discussed were: caring for extended family members, allergies including food allergies, work-life balance, travel to work and working in the city.

Once again, it was a very enjoyable morning with great company, maybe another time we can all go for a bit of a stroll after to work off the breakfast (depending on where we go).

Keep an eye out in the newsletter and eNews for an invite to the next women's event on Sunday 3 November 2019.

Melanie

Bunnings Sausage Sizzle

Calling all volunteers and generous donors

Saturday 19 October 2019

Come and join us for a fun time at our annual Bunnings Sausage Sizzle. HFWA has been fundraising at **Bunnings Homebase in Subiaco** as part of Bleeding Disorders Awareness Week for a number of years now.

We would love you to come along for a couple of hours to help on the day (any time between 7.30 am and 4.00 pm).

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

Everyone always has a great time.

We are also looking for donations of canned soft drinks or bottles of water to sell on the day - lemon squash, Coke (any sort), Fanta, lemonade or water.

REMEMBER we are fundraising for Youth Events!

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

✂

.....

I

- Would like to volunteer at the Bunnings Sausage Sizzle between the hours of
- Would like to donate soft drink or water, quantity

My contact details are:

.....

✂

HFWA Family/Community Camp—CANCELLED

It is with great sadness that due to a lack of volunteers, the committee has had to make the difficult decision to cancel our community camp due to be held in March 2020.

If you have any feedback on this decision please contact the HFWA office on office@hfw.org.



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) 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

Or contact Suzanne at HFA:
E: 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 or keep an eye on the page: 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**.



Program

THURSDAY 10 OCTOBER 2019

Welcome & Exhibition Opening ~ Onsite

Come to see the exhibition and meet people before the conference. This social activity is free for all registered delegates.

FRIDAY 11 OCTOBER 2019

Plenary and concurrent streams scheduled all day from 8.30am – 5.00pm.

Remembrance Service ~ Onsite

A Remembrance Service is a very special time during our Conference to remember friends and family, and the people we have cared for in our community who have passed away. The service is non-religious and everyone is welcome. It will be held before the Conference Dinner.

Conference Dinner ~ Onsite

Come and join your fellow delegates for a relaxing and casual night. It's a great chance for you to talk, share and meet others. Dinner is available at a subsidised cost of \$50 per person – this includes food and beverages, so it's great value. Dinner tickets must be purchased in advance - no tickets will be available during the conference or on the night. Free seating on the night.

SATURDAY 12 OCTOBER 2019

Plenary and concurrent streams scheduled all day from 8.30am – 5.00pm.

Men's Breakfast ~ Onsite 7.00am - 8.20am

Women's Breakfast ~ Onsite 7.00am - 8.20am

Come along to participate in a panel session and share your ideas and experiences with other men or women! The cost for a subsidised breakfast ticket is \$30 per person for a hot plated breakfast. You must book and pay for your ticket in advance.

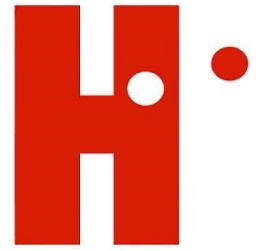
OTHER FUNCTIONS AND ACTIVITIES ASSOCIATED WITH THE CONFERENCE

The annual meetings of specialist health professionals' groups will be held on Thursday 10 October 2019:

- Australian Haemophilia Centre Directors' Organisation
- Australian Haemophilia Nurses Group
- Australian Haemophilia Social Workers' and Counsellors' Group
- Australian & New Zealand Physiotherapy Haemophilia Group
- ABDR Data Managers Group.



Haemophilia
Foundation
of WA
Fundraiser



Saturday 16 November 2019

Hosted by Russell Woolf



6.30 Arrival for a 7pm Start.

Venue
Bill Cole Function Centre
Riverton Leisureplex
67 Riley Road, Riverton

Tables of 8-10 Available \$15 per Ticket per Person
SILENT AUCTION ON THE NIGHT!

NO BYO DRINKS—FULLY LICENSED EVENT
PRE ORDER PIZZA AVAILABLE
(REFER TO BOOKING FORM)

BRING LOTS OF GOLD COINS

All funds raised will help the foundation with the running of our Youth Group activities and with the costs of sending people to the World Congress in Malaysia in 2020."

Any enquiries please contact HFWA on
08 9420 7294
Or
Cheryl on 0402 033 652
Jenny on 0410 100 237

Preserving our Services and the Foundation

In recent years HFWA has enjoyed a resurgence in community interest, thanks mainly to a small number of volunteers who have gone above and beyond to organise youth events, fantastic camps and fund-raisers like the Quiz Night. This effort was rewarded by great turnout at these events and for a number of years HFWA has been the envy of other Foundations in Australia who struggle to get engagement with their communities.

Last year the number of people on the HFWA Management Committee dropped to six, which is the lowest it has been for many years. Over the past 12 months, the committee has observed some worrying trends as we have tried to get events and activities up and running. In addition to this we are seeing services at our treatment centres being slowly eroded.

We are all busy people with family and work commitments; none of us are able to attend every single event and sometimes we have to miss appointments, but we need to remember that the services and events that we rely on and enjoy won't continue if they are not used.

HFWA Management Committee

HTC clinic attendance

I have heard that attendance numbers of the clinics at the Fiona Stanley Hospital (FSH) Haemophilia Treatment Centre (HTC) are down. We are already seeing a dilution of services at the HTCs, and we as a community need to be very mindful of supporting the system that supports us.

I am lucky or unlucky enough, to have lived through the different stages of haemophilia care that we, as a community have accessed over the years. The high level of care that we are fortunate enough to enjoy today is a result of hard work by HFWA committee members past and present, advocating on behalf of its members.

Support from key people within the health department and past and present staff members of the HTCs and hospitals (Fremantle Hospital, Royal Perth Hospital and Princess Margaret Hospital) were instrumental in establishing the foundations of the HTCs, and today the ongoing HTC care at FSH and Perth Children's Hospital (PCH) is a result of this combined effort. These historical changes in services and care and the evolution of treatment of haemophilia and related bleeding disorders, now enable us to all lead relatively normal lives.

As we are all aware, our life long chronic condition is very expensive to treat, and in this current time the health dollar is stretched very far over the wider community. If the finance people notice outpatient clinic numbers are declining, it won't take long for hospital budgets to be reviewed and cuts to be made, hence HTC services and care will be affected; I for one do not want to see this happen.

If you run into an older person with haemophilia whilst at the HTC or an HFWA event, ask them about their own life experience, the trials and tribulations of living with haemophilia.

The treatment, care and services we access today are worlds apart from what the older generation experienced many decades ago.

As the old saying goes – "if you don't use it you lose it" and I don't wish this to be the case, as the HTC and comprehensive care model is an important and valuable tool in my journey of life, living with severe haemophilia.

I am sure other members, especially the older generation, feel the same way?

David Bell
HFWA community member



Ambulance Services Public Consultation

To register your interest please contact info@hconc.org.au or (08) 9221 3422



- Consumer feedback survey
- Public consultations in:

Location	Date	Time
Perth	Friday 20 th September 2019	11am – 1pm
Broome	Tuesday 24 th September 2019	12pm – 2pm
Bunbury	Friday 4 th October 2019	12pm – 2pm

<https://www.hconc.org.au/projects/ambulance-services-project/>



HEALTH CONSUMERS'
COUNCIL



THE
BEHAVIOUR
CHANGE
COLLABORATIVE

Events and Workshops are held throughout the year.

Check out our website www.hconc.org.au to learn more.

ABN 87 841 350 116

2019 HFWA Annual General Meeting

This year's Annual General Meeting for HFWA was held on Thursday 19 September 2019 at City West Lotteries House. It was good to see attendee numbers up on recent years with 21 HFWA members in attendance.

We were fortunate to have Sean Matthews from the WA Primary Health Alliance as the guest speaker. Sean gave a presentation on the benefits of My Health Record and provided a good overview of how the system works, the type of personal health information that is stored, key security features and some very useful information on how to use the system. It was clear from the presentation that My Health Record may be a valuable resource for people living with haemophilia or a related bleeding disorder and we will follow up with more information in future newsletters.

After a question and answer session with Sean we moved onto the formal proceedings of the AGM. Listening to the reports from the President, Treasurer and Office Coordinator reminded me of just how much HFWA does each year; the events and fundraising activities, peer support and other valuable services. All done with limited funding and in the main by a small group of dedicated volunteers. The Foundation remains in a stable financial position with funding from the Health Department in place for the coming year.

I am also pleased to report that the Management Committee numbers for 2019/2020 have increased slightly to seven. All current committee members renominated for the coming year and we are very pleased to welcome Michelle Dinsdale back to the committee. Three vacancies still exist on the Management Committee so if you are interested in joining please contact Gavin, Cheryl or Mel in the office for more information. The committee meets monthly, usually on the third Tuesday in the early evening. Prior experience on committees or boards is not necessary, just a keenness to learn and a passion for helping out where you can.

We wrapped the evening up with some conversation over a drink and some tasty treats from Miss Maud's. Thank you to everyone who attended. For those who could not make it, the annual report will be available on the HFWA website soon, once the Financial Statements have been audited.

Shane Meotti
Secretary

Save the date

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—Page 5

3 November 2019 —Men's & Women's Breakfasts

Saturday 16 November 2019 - HFWA Quiz Night—Page 9