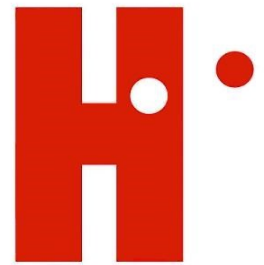


Contact



Newsletter of Haemophilia Foundation WA Inc.

November 2020



HAEMOPHILIA FOUNDATION WA INC.

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

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

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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

Paul Keogh

Michelle Dinsdale

Belinda Broughton

Melanie Gould

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

HFWA Office Coordinator

Haemophilia Foundation WA Office

Phone: (08) 9420 7294

Email: office@hfwa.org

Cover Pictures

CommBank Grant Re-Boot Day

PERTH CHILDREN'S HOSPITAL CONTACT DETAILS

Clinic H, Level 1 (Haematology/Oncology Outpatients: Ph: 6456 0170

Medical Staff: **Dr Tina Carter Ph: 6456 0170**

Nursing Staff: **Natalie Gamble-Williams and Stacey Hutchison**

(Mon - Thurs 8:00 am - 4:30 pm) Ph: 6456 0170 or 0466 318 286

After Hours: **(EMERGENCIES ONLY) Ph: 0410 717 816**

Social Worker: **Helena Reynolds (Mon - Thurs 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: **Helena Reynolds (Monday to Thursday, 8:00 am - 4:30 pm, adults and paediatrics, contact for appointment) Ph: 6152 652**

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

2020

Hi Everyone

Our activities at HFWA are getting back on track but with precautions being taken to avoid any possible health issues. Things change from day to day with WA's borders now gradually opening up to more people, so we have to be wary of any possible COVID-19 contact occurring, and observe social distancing and handwashing/sanitiser use.

HFWA held a successful reboot at Holey Moley in Cannington see page 5, and we are grateful to the Commonwealth Bank for their generous donation which funded the day. The balance will be used to partially fund the Community Camp which will hopefully take place in March 2021.

The AGM was held on Thursday 8 October and we welcome one new and one returning committee members to HFWA - Melanie Gould (Mel just can't get enough of us, don't know why ???) and Belinda Broughton, who returns after spending some time in Sydney. We look forward to their contribution. We also had a viewing of the film Bombardier Blood, which is a story of a man with severe Haemophilia B and his quest to climb the seven highest mountains on all seven continents, culminating in him conquering Mount Everest. It was an inspirational and moving film.

We have been requested by our funders from the Health Department to send out a survey to our members and community to get their thoughts on peer support, education, advocacy and other services that HFWA provides.

Please take 10 minutes to complete the survey by using the following link - www.surveymonkey.com/r/YZ2HMQ8 Your responses can be anonymous/confidential if you wish.

This year's HFWA Christmas Party is at Outback Splash - The Pavilion Area, 1635 Neaves Road, Bullsbrook, see page 4 for more details.

Your committee and I look forward to catching up with as many of you as possible at our Christmas Party and other HFWA events.

Wishing you a Merry Christmas (or whatever you celebrate!) and a Happy, Healthy 2021.

Gavin Finkelstein

Introducing Mel Gould

Hi, I'm Mel.

Most of you know me as I worked in the office for a number of years, then had a hiatus and then like a bad smell came back for a while. Well, you still can't get rid of me! and I have joined the Committee.

As most of you know, I have worked in the not-for-profit sector for a long time and hope to bring my knowledge with me. I also like to be involved in the community and I can't think of a better group of folk to give my time to. So I hope you are happy to have me, and I look forward to seeing you all at either the Christmas party or Camp next year.

Mel

Introducing Belinda Broughton

Hi everyone, my name is Belinda and I have severe factor 10 deficiency. I grew up in Kalgoorlie -Boulder with my parents and two brothers.

A few years ago, I joined the HFWA committee and then shortly after moved to Sydney for some time. Recently I moved back to Perth after realising how much I had missed my friends and family. Now that I am settled back in Perth again, I have decided to re-join the committee.

I am currently working at a dental practice in Burswood and love it. I work with a great team and enjoy what I am doing. I love to live an active lifestyle and I am always looking for new hobbies I can start up. Growing up in a country town did mean I did not have the support from other haemophiliacs to lean on. I had never actually met any other bleeders until I went to my first camp in Perth. I was lucky enough to meet some great people from camp which inspired me to do more for the bleeding community. I am really excited to keep the bleeding community going and give my support however I can. I look forward to see some old and new faces.

Thanks

You're invited to HFWA Christmas Party

Where: Outback Splash, 'The Pavilion'
1635 Neaves Road, Bullsbrook

When: Sunday 6 December - 10.30am

RSVP's: Closed - You can still come along and join in the fun!

Please bring along your picnic lunch and blankets or chairs

Food can be purchased at the kiosk (no BBQ's avail)

Soft drinks and water will be provided

Santa will appear between 12.00pm - 1.00pm

For those of you that had not RSVP'd by the due date but you would like Santa to have a gift for your children, please bring one along wrapped and labelled, to the value



HFWA Office Christmas Closure

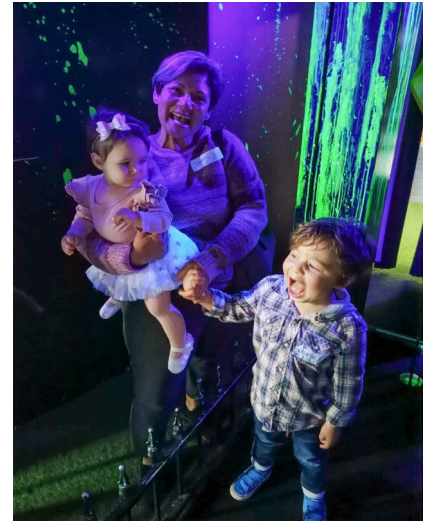
HFWA office will be closed from
Monday 21 December 2020 and re-opening on
Monday 4 January 2021



CommBank Grant Re-Boot Day at Holey Moley

Thank you to the generosity of CommBank for their grant to be able to bring some of our lucky members a wonderful day out at Holey Moley. This quirky mini golf with a twist was topped up with 10 pin bowling. The many smiles and laughter on the day said it all.

Thank you to Robin Dique for her wonderful contribution in helping to raise awareness of HFWA and to help make this grant happen.



Robyn Devenish - Saving Lives in Cambodia

This is a must read article about a remarkable woman with a passion to help others

'This is what God wants me to do'

Mandurah medical scientist Robyn Devenish has been saving lives in Cambodia for more than 10 years.

BY CLAIRE SADLER

IT WAS the day after Robyn Devenish decided to become Christian that she experienced her epiphany.

Robyn was working at Royal Perth Hospital as a senior medical officer at the time when she received an email from someone who needed help in a lab in Cambodia.

"I remember thinking this is what God wants me to do," says Robyn, the passionate volunteer scientist.

"I sent an email saying I am interested and they wrote back and said 'are you the answer to our prayers?'."

"I still get goosebumps about it."

Packing her bags in 2001, Robyn arrived in Cambodia thinking she would only be there for a year but little did she know she would continue to work there for more than 10 years.

"When I started to see the situation there I was absolutely horrified," she said.

"When I saw some of the labs and hospitals I actually wept because they were so awful and the poor lab staff were using all manual methods."

Cambodia was still struggling to recover from the Khmer Rouge regime that

decimated the country in the late 70s, targeting the educated for torture and execution.

"Their whole lab systems, doctors and hospitals were all destroyed," Robyn said.

"I went in 2001 and they still hadn't really recovered and they still haven't even today."

"There were lots of things wrong in the lab as far as quality and there were many lab tests that they weren't doing so a lot of patients were being wrongly diagnosed."

Robyn began to see there was no local knowledge of haematological disorders, with many children dying due to health issues such as thalassemia, and haemophilia.

To minimise misdiagnosis, she set up testing for bleeding disorders, trained the lab staff and doctors, instilled quality control in labs, raised over \$500,000 for lab upgrades, set up the Cambodia Haemophilia Association, and to top it off, saved hundreds of lives.

Despite saving so many lives, her very first case of treating haemophilia has stuck with her forever.

"Three months after I set up the testing for bleeding disorders a young boy came in with this massive knee the

size of a football," she said.

"The surgeon thought it was osteomyelitis and I had to almost have a punch up with him to say don't operate it could be haemophilia - we tested and sure enough it was."

"It's a genetic disorder that boys get and if they get cut they just won't stop bleeding so if they went through with the operation he would've died."

Now back in Mandurah due to international travel restrictions, Robyn continues to help the lab staff in Cambodia via email and has begun teaching young women STEM at Peel Bright Minds.

"I'm in email contact with a lot of the lab staff and they still send me pictures down the microscope that they need help on," she said.

For her never-ending list of volunteer work, Robyn was awarded a Medal of the Order of Australia (OAM) in June "for service to the international community of Cambodia".

She also recently received a STEM Hero Award from Peel Bright Minds to acknowledge her volunteer work not only in Cambodia but her efforts locally to make a difference in the field of STEM.



STEM HERO: Robyn Devenish has helped to save many lives in Cambodia by setting up testing for haematological disorders. Photo: Claire Sadler.



POSITIVE OUTCOME: Robyn Devenish began volunteering at Angkor Hospital for Children in 2001. Photo: Supplied.



DIAGNOSIS: Robyn's first case of treating haemophilia was a boy with crippling swelling in his knee. Photo: Supplied.

Hemlibra Treatment Update

We are pleased that all Australian governments have agreed to fund Hemlibra® and that it is now available under the national blood arrangements along with the suite of other treatment products on the National Blood Authority's National Product List.

Hemlibra® (also known as emicizumab) is a treatment that can reduce or prevent bleeding in people with severe or moderate haemophilia A with and without inhibitors. **Further information is available on the National Blood Authority website - [National supply arrangements for Hemlibra \(emicizumab\)](#)**

HFA has made a submission to the Australian Parliamentary Committee undertaking an inquiry into approval processes for new drugs and novel medical technologies in Australia. Our recommendations for changes to the assessment processes were based on recent experiences of processes that contributed to delays for access to extended half-life clotting factors and Hemlibra®.

With more new therapies for haemophilia likely to arrive in the next few years, it is an important time to consider ways to streamline the processes to evaluate new therapies for government funding so that these delays do not occur again in the future.

On the 25 September Gavin Finkelstein and our very own HFWA member Robin Dique were interviewed by both Channel 9 and Channel 10 and the following article was published in The West Australian on Hemlibra and this game changing treatment. See article below

DOSE OF OPTIMISM

Free access to 'game changer' blood drug

ANGELA POWNALL

Hundreds of Australians suffering from haemophilia A will get access to a "game-changing" treatment later this year after the Federal and State governments agreed to pay for the drug.

About 300 West Australians have the life-threatening blood clotting disorder and the funding of Hemlibra, or emicizumab, is expected to help 800

patients nationwide. Hemlibra, which costs \$675,000 to treat just one patient a year, is a lifesaving and life-changing preventive medication, Haemophilia Foundation WA president Gavin Finkelstein said.

"It is a unique product that is game changing. There's nothing like it available. That's why we were so keen to get hold of it," he said.

Mr Finkelstein said Hemlibra was different because it worked for the 30 per cent of haemophiliacs who have "inhibitors" that stop other treatments from working.

"This is a fantastic result for everyone. A lot of people's lives are going to be saved.

"They'll be able to get out and do

stuff, be productive in society," he said. Mr Finkelstein said the drug was available in 40 countries and the Haemophilia Foundation had been lobbying Australian governments to fund it.

People with haemophilia are at risk of life-threatening and severely disabling internal bleeding and joint damage because their blood does not clot.

Charlie Dique, four, developed haemophilia because his mother Robin is a genetic carrier of the condition. Mrs Dique, a nurse, said Charlie when a baby had nosebleeds and cuts that did not stop bleeding, so she and her husband asked for a clotting test when he was 14 months old, which led to his diagnosis.

Since then, their lives have revolved around ensuring he avoids any bleeding, particularly internally which cannot be easily picked up.

Mrs Dique said today's announcement "has filled me with optimism and excitement".



Robin Dique with Charlie who has haemophilia

World AIDS Day 2020



World AIDS Day is marked globally on 1 December.

The theme for World AIDS Day in 2020 is ***Now more than ever***. For the bleeding disorders community this is a profoundly meaningful message.

1 December is a day when we are mindful of the members of our community living with HIV and those with HIV who have passed away.

In the mid-1980s the bleeding disorders community in Australia and internationally was devastated when many people with bleeding disorders acquired HIV through their plasma-derived clotting factor treatment products. HFA's recent *Getting Older* report documented the ongoing impact of this epidemic on our community: the trauma and health challenges for those who were diagnosed with HIV and now live with the consequences, and the grief and sadness experienced by those who lost loved ones and friends to HIV. Often forgotten is the emotional impact on the health professionals at the Haemophilia Treatment Centres too, who had cared for their patients with HIV over their lifetime and knew them so well.

The *Getting Older* report recognised the very positive contributions people with bleeding disorders and HIV have made to our community: the inspiring optimism and generosity of individuals with HIV, in spite of all their experiences, speaking out and providing leadership and a way forward into the future.

Some of the people with HIV who participated in the *Getting Older* consultation also highlighted other issues that need addressing, including discrimination by health professionals in the wider health sector, based on an unfounded fear of transmission. This can result in barriers to testing and treatment and access to services.

'There needs to be a concerned education campaign for health professionals to educate them about the low risks of HIV infection when the patient is well suppressed.'

TAKING ACTION

On World AIDS Day we are encouraged to educate ourselves and others about HIV.

In Australia HIV infection is now usually well-managed with treatment. However, the *Getting Older* report reminded us how important it is to acknowledge the experiences of our community members with HIV and the impact these experiences have had on them. We also need to recognise the impact on those who love them and care for them: their partners, family, friends and carers.

Hearing their stories and learning about the impact of HIV on them in the past and now is an important part of acknowledgement in our community. Foundations are also conscious of making sure there is always a supportive environment at community events. Wearing a red ribbon on World AIDS Day can help to raise awareness and reduce discrimination by demonstrating solidarity with people with HIV.

World AIDS Day challenges us to take action – and by this action to ensure that people living with HIV can participate fully in the life of the community, feeling supported and free from judgement, stigma and discrimination.

HFWA - Containers for Change

We are very excited to bring you our latest fundraising venture. You can save the environment and help raise much needed funds for our HFWA community.



CONTAINERS
FOR CHANGE

HAEMOPHILIA FOUNDATION WA! We're all set.

We've joined the Containers for Change to make a real difference in our communities and to our environment.

Here's our Containers for Change scheme ID, which makes it even easier to return containers.

Scheme ID

C10338968

Save your scheme ID to your mobile

iPhone users



Android users



Save the Date!

2021 HFWA HAEMOLYMPICS

Community Camp for all the family

Fri 19 March - Sunday 21 March 21 - Community Camp

Swan Valley Adventure Centre

58 Yule Avenue, Middle Swan

www.swanvalleyadventurecentre.org



Men's Breakfast

Come along to the first men's breakfast of 2021 at a popular breakfast venue

Where: Straits Café Scarborough

When: Sunday 7 February 2021

Time: TBA

Save the date

Ladies High Tea

High Tea is always a classy way to end a weekend, so keep an eye on your inbox ladies for more information

Venue: TBA

When: Sunday
7 February 2021

Time: 2.00pm



Hows Family Christmas Lights fundraiser

HFWA are very fortunate to have the Hows family generously choose to fundraise for us this year at their annual Christmas lights display. They are located behind Jackadder Lake at 9 Oakwood Avenue, Woodlands

Viewings are from 6pm -11pm every night from 1 December to 31 December.

Please help to support our community, enjoy the festive spirit and go along to enjoy the Hows Family Christmas Lights



<https://www.facebook.com/Woodlands-Christmas-lights-9-Oakwood-Avenue-101301141366343/>

Entertainment Books

Entertainment Books are still available in digital format only and can be purchased via the the following link <https://www.entertainmentbook.com.au/orderbooks/847b23>

They now expire 12 months from the date of purchase and remember that for every purchase you make, HFWA will receive a donation. New goods and services are updated continually and it is a great idea for the upcoming school holidays.

HFWA membership

HFWA membership fell due on 30 June 2020 and the HFWA Membership period runs from 1 July 2020 to 30 June 2021. Please click the following link or enter it into your browser to access the membership form <https://www.hfwa.org/get-involved/memberships>.

HFWA is committed to the promotion of Haemophilia and related bleeding disorders on a state, national and international level and 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 and payment can be made by EFT, by phone on 9420 7294 or by credit card by copy and pasting the following secure link into your browser

<https://checkout.square.site/merchant/06461WB19EDA8/checkout/FA6HLJO6E6E55VN6ZZTDPDMK>

Bunnings Sausage Sizzle

Saturday 17 October 2020



We weren't too sure it was going to go ahead but the annual HFWA Bunnings Sausage Sizzle was held on the 17 October.

I arrived for my shift at 9am and was informed things would be running a bit differently this year due to COVID-19.

We had to direct people to the front table for service and we were only allowed a certain amount of people in the marquee at one time. We were also given the task of putting the sauce on everyone's hotdogs (which was the hardest part as I'm very particular with my sauce amounts).

With all restrictions aside it was a really great day, an awesome turnout and we sold out of hotdogs. A great effort by our fantastic volunteers.

Look forward to seeing you all again next year.

Dale Spencer

Expression of Interest - Polo and T-shirts

HFWA will be ordering new Polo and T-Shirts for any interested members and volunteers

Please fill out the following Expression of Interest. Cost to be advised.

I, would like to express my interest in purchasing polo / t-shirts for the following:

Name	Polo Shirt	T- Shirt	Ladies / Gents	Size



Our prestigious models brought to you exclusively by HFWA at Bunnings Sausage Sizzle



2020

WHAT'S ON?



Sunday 6 December 2020

Family Christmas Party - 10.30am

The Maze - Home of Outback Splash

1635 Neaves Road, Bullsbrook

www.outbacksplash.com.au

Save the date

Fri 19 March - Sunday 21 March 21 - Community Camp

Swan Valley Adventure Centre

58 Yule Avenue, Middle Swan

www.swanvalleyadventurecentre.org

Sunday 7 Feb 2021

Men's Breakfast - Straits Café Scarborough

Sunday 7 Feb 2021

Ladies High Tea - Venue and time TBC

(watch this space)

More information following in the coming weeks on the abovementioned events
Please contact Jenny on 9420 7294 or office@hfwa.org to RSVP to any of these events

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



I would like to order _____ Jute large bags

I would like to order _____ Red bags

Total \$ _____ (postage can be arranged at extra cost).

Please complete credit card details below or deposit the total with your Surname as your reference to:
Acct Name: **The Haemophilia Foundation of WA Inc.** BSB: **086 488** Acct No: **03 523 3031**

PLEASE NOTE THAT CREDIT CARD DETAILS WILL NOT BE RETAINED AFTER PROCESSING

Name: _____

Address: _____

Telephone: _____ Email: _____

Card Type:

☐ Visa ☐ MasterCard ☐ AMEX ☐ Diners

Card Number:

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Expiry Date:

		/		
--	--	---	--	--

Name on Card:

HFWA NAIL POLISH GIFT PACKS

A great Christmas Stocking filler!

Three bottle gift packs available.
Looking for that personalised gift with a real message for family
and friends? Look no further!

Gift Packs \$20

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 following colours:

I would like to order _____ Bottles of the following colours:

Total \$ _____ (postage can be arranged at extra cost.)

Please deposit the total with your Surname and "Polish" as your reference to:

Acct Name: **The Haemophilia Foundation of WA Inc.**

BSB: **086 488**

Acct No: **03 523 3031**

Phone the office: 08 94207294 to pay by credit card

Name: _____


Address: _____

Telephone: _____ Email: _____

HURRY STOCK IS LIMITED!



The HFWA
Management Committee
would like to extend
their best wishes
to all of our members
and their families



Have a very
Merry Christmas
and a safe and
Happy New Year