

CONTACT

Newsletter of Haemophilia Foundation WA Inc.

September 2022



Cover Picture: Photo taken from 2018 HFWA Camp by Lena Smith & Paul Keogh

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HAEMOPHILIA FOUNDATION WA INC.

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YOUR COMMITTEE

Gavin Finkelstein (President)	0415 978 031
Cheryl Ellis (Vice-President)	0402 033 652
Robert Butler (Treasurer)	
Paul Keogh (Secretary)	
Michelle Dinsdale	
Susie Couper	
Evyn Webster	

Profiles of committee members can be found on the website, at www.hfwa.org/yourcommittee

Office Coordinator—Ann-Maree Foran

HFWA Office—2 Delhi Street, West Perth

Phone

9420 7294

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office@hfwa.org

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**

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** and **Lara Olson**

Social Worker: **Helena Reynolds** (Mon and Thurs 9:00 am - 1:00 pm, 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

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President's Report

Hi all,

Now that winter is behind us all it is time to come out of hibernation and get things growing and back on track with HFWA.

We have held our AGM; hopefully as many of you as possible attended and we have our faithful, enthusiastic members re-joining the committee. It is possible to join the committee, or just come and observe what happens at committee meetings; contact me or Cheryl and we can give you some info.

It has been a tough period for HFWA, with the long-lasting impact of Covid on our activities and events that bring our community together, and the 'retirement' of two very important long term committee members.

I would like to extend a massive thank you to Shane Meotti for the many years that he has served the HFWA community on the committee. Shane was always willing to put his hand up to volunteer (himself and his family) for any community activities, has overseen our IT issues & implemented all the necessary IT "stuff" with a minimum of fuss and to the benefit of the operation of HFWA. He was also HFWA's delegate to the HFA Council for a number of years, plus always had a reasonable opinion or perspective of any issue we needed to deal with. Personally I have learnt from Shane, enjoyed his company and contribution to HFWA and his presence will be sorely missed. I wish him all the best in the future.

Dale Spencer has been part of the bleeding disorders community in WA & in Australia for many years. He has been an integral & highly-valued member of the HFWA, serving as a mentor, role model & organiser for HFWA's Youth subcommittee and the HFWA committee, and many of our community, including our younger members, know & love Dale.

On behalf of the bleeding disorders community of WA, I extend a big thank you to Shane & Dale for your years of much valued service to our community and we are better off for having you both as past committee members.

We welcome Ann-Maree Foran to HFWA as our new office coordinator. Some of you might already know Ann-Maree and we wish her all the best in her new role - please feel free to contact her to welcome her to HFWA.

It is now time for us to start having community activities; the first being our annual Bunnings Sausage Sizzle to be held at Bunnings, Subiaco on Sunday 16 October. We always need volunteers to work the barbie, sell the snags etc., so please contact Ann-Maree in the office and work out a time when you can come down and help out. It would be nice to see some new faces instead of always relying on the same people who are dragged into it every year. This is a fund raiser for your foundation and we all need to support it. We are also accepting donations of water & canned soft drinks to sell on the day. Have a look at page 14 for details.

We will be starting up Men's and Women's Breakfasts again soon, so please watch out for the adverts & invites.

Our Christmas Function will be held at Outback Splash on 27 November we will keep you posted

Gavin

Picture: Dom Dique celebrating his birthday at the recent AGM





WELL HELLOOO!

Hi Everyone,

My name is Ann-Maree Foran and I am the new Office Coordinator. For those of you who do not already know me, I have been part of the HFWA community for many years due to family involvement namely my sister, Cheryl and her two boys Taj and Ben!

I have been in hospitality as a Chef and cafe coordinator for over 20 years, so I have lots of experience with events and eating. I have been in hospitality administration in the more recent times so I have quite a bit of office experience which is brought me to this awesome opportunity in the HFWA office.

I love cooking, listening to music, swimming, going to the beach, camping and eating. I'm hoping to work on my kayaking (which means I have used it twice and want to get out more!)

I have a daughter, Victoria who is 10. She loves dancing and has been doing so since she was 5. She also loves basketball and is awesome on the fast breaks and screens.



We have a pet budgie named Johnson, who is extremely cheeky and talks a lot... I'm not sure where he gets that from?

He rides a mini skate board and plays soccer.

Please send in some of your family pet photos and a little description so we can pop them in the next newsletter. Maybe they help you to be active, or are great company ?





Thank you !

I'd like to thank Sean for the great job he has done holding the fort recently. He has been implementing a new database of all of our members and stakeholders of the HFWA. It's a mammoth task getting it all in order. I am learning how this will work for us and we are constantly coming upon new ideas, tricks and uses for the database. We ask for your patience if we happen to request information you may have already provided.

I'd love to hear from you, please give me a call or an email to catch up. We have a wealth of information in our office for families and individuals in the community.

We can't wait to get our in person events going again really soon. Stay tuned while I get the events on the website up to date

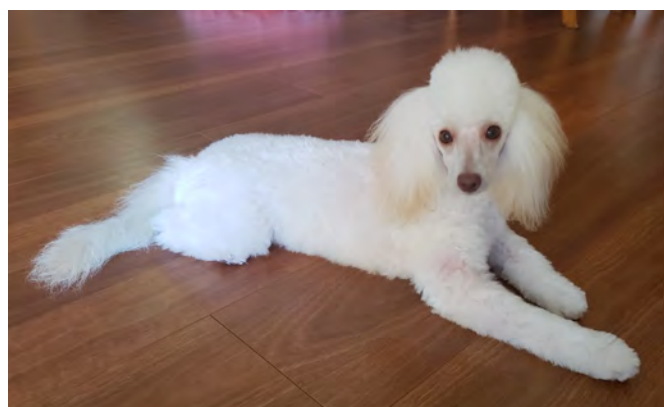
I'm in the office part time. But keep an eye on our inbox.

Thank you,
Ann-Maree



HFWA Pals

Hi, my name is ANGEL I am a Parti Poodle. My humans are the Burtons. I enjoy dressing up. This is me helping the Easter bunny. I am 3 years old and when I see the two legged walkers I like to show that I can walk on two legs also, it's easy. I don't bother showing the other doggos this as they normally get a bit jealous. So you could say I'm a bit quirky but really I'm just a fun loving creature of this earth. I love my humans and they love me so.





World Hepatitis Day 2022

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World Hepatitis Day is marked globally on 28 July. This is part of a worldwide campaign to eliminate viral hepatitis by 2030. In 2022 the theme is **hep can't wait**, reminding us that we need to be proactive in our efforts.

Hepatitis C has had a profound effect on our community. In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of bloodborne viruses from plasma-derived clotting factor products in

HEP CAN'T WAIT!

Australia is now considered to be extremely low.

But many people in our community live on with the consequences of those early infections.

TAKING ACTION

Highly effective hep C treatments are available in Australia. They are easy to take – one tablet a day, not injections - with cure rates above 95% and few if any side effects.

WHO IS AT RISK?

If you had clotting factor or a blood transfusion before 1993, you could be at risk for hepatitis C.

Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured – but some might not even know they have hep C. You may have had very few treatments in your lifetime and never thought you would be at risk for hep C. If this is you, don't wait. Talk to your doctor about being tested – find out if you have hep C. Testing and treatment is simple. Hep C can be cured.

**WORLD
HEPATITIS DAY**
28TH JULY 2022

#HepCantWait

#WorldHepatitisDay

Hepatitis Info line: 1800 437 222
worldhepatitisday.org.au





WERE YOU CURED OF HEP C?

Did you have liver damage or cirrhosis? Has your liver recovered from hep C? Don't wait to find out.

Call your hepatitis doctor or your GP to check your liver test results. Find out whether you need ongoing follow-up with a liver specialist.

REMEMBER

If you had cirrhosis or extensive scarring before being treated and cured of hep C, you still need to have a liver ultrasound scan every 6 months long-term.

KEEP YOUR LIVER HEALTHY

Have a balanced diet, maintain a healthy weight, and avoid or minimise alcohol intake.

Sadly, some people with bleeding disorders and hep C have very advanced liver disease caused by long term infection. Close liaison between hepatitis or liver specialists and Haemophilia Treatment Centres is very important for care and treatment. Research is continuing into new and improved hep C treatments and management of advanced liver disease.

For more information, visit :

www.world.hepatitisday.org.au

or the HFA World Hepatitis Day page –
www.haemophilia.org.au/world-hep-day

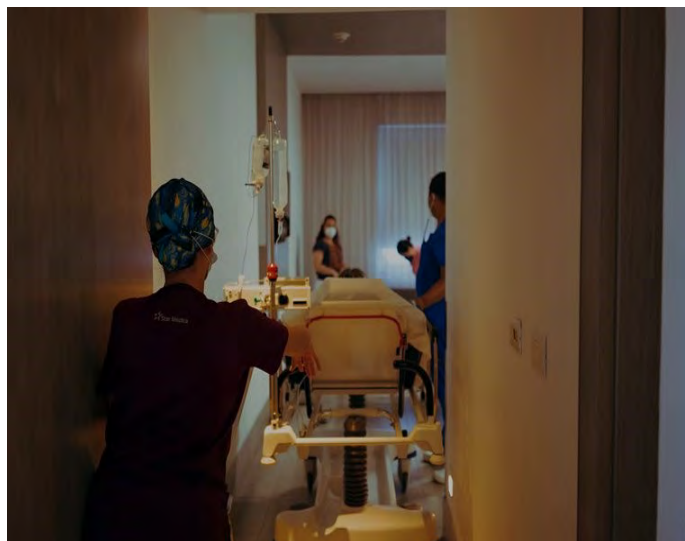


Click here to read some stories of Hep C carriers

www.haemophilia.org.au/about-bleeding-disorders/living-with-a-bleeding-disorder/personal-stories/hepatitis-c/clearing-hep-c-as-a-child-johns-story

Or

www.haemophilia.org.au/about-bleeding-disorders/living-with-a-bleeding-disorder/personal-stories/hepatitis-c/clearing/turning-liver-health-around-after-hep-c-jake-s-s





HFWA Pals continued from pg 5.

My name is Loki and I love my humans, most especially the smallest human Finnick. We love hanging on the couch watching Bluey and especially when my bro hugs me . Sometimes he tries to go for a ride on my back. I'm very gentle with Finnick, and he is getting better with being gentle with me Mum tells us both to not hurt each other. It's ok he's my best buddy and I love to sing for him, can you see us below?



Hi I'm Shelby, I'm a black kelpie and I have moved in with the Ellis Family when I was 12 weeks old. My old place wasn't nice and I needed rescuing.

My mum is Cheryl she feeds me and is nice but my favourite is Darren.....I am 10 months old and I am a kelpie cross (I get cross when I am hungry or miss my walks) I love long walks at the park I love chasing the ball and returning it near my family. I also love swimming in the big water at my house and doing zoomies on the nice, new soft new couch I share with my humans. See me with my puppy school certificate (above) and me when I was little walking in mums yummy garden (left).



River Cruise

Save the date! HFWA will be hosting a river cruise on the 19th of November! This event will take place on a (hopefully) pleasant spring's day. Planning has begun for this event. So, leave the kids at home, hop aboard the SS HFWA for a relaxing, enjoyable evening. We'll be floating down the Swan River, enjoying the twilight and having fun.

It'll be one of our first big social events for the year, besides the AGM.



It's a great chance to reconnect to the community, to get involved and see other people. If you're in need of letting your hair down, more information will be coming out in future issues of the newsletter, so keep your eyes out for that!

If you'd like to register your entry early on, feel free to contact us at office@hfw.org and let us know you're keen!





Bleeding Disorders Awareness Month

OCTOBER 2022

OCTOBER 2022

WHAT IS A BLEEDING DISORDER?

Haemophilia

- A rare genetic bleeding disorder where the blood doesn't clot properly
- Caused by an alteration in the gene making clotting factor VIII (8) or IX (9)
- Usually inherited, but 1/3 of people have no previous family history
- A lifelong condition and can be life-threatening without treatment
- Treatment can help prevent repeated bleeding into muscles and joints, which causes arthritis and joint problems
- Most people diagnosed with haemophilia are male
- Women and men can have the genetic alteration causing haemophilia and pass it on to their children
- 20-30% of females who carry the gene alteration have bleeding problems and may have haemophilia, usually mild.

How common?

- In Australia there are more than 6,600 people diagnosed with haemophilia, von Willebrand disease or other related inherited bleeding disorders.

Von Willebrand disease (VWD)

- An inherited bleeding disorder
- Occurs when people do not have enough of a protein called von Willebrand factor in their blood or it does not work properly
- Most people with VWD have mild symptoms but some people have a more severe form. With all forms of VWD there can be bleeding problems and some people bleed quite often
- Many people are not aware they have the disorder and are currently undiagnosed
- Both men and women can have VWD and pass it on to their children.

Other Bleeding Disorders

- Other bleeding disorders include rare clotting factor deficiencies and inherited platelet disorders
- Factor XI deficiency is the most common of the rare bleeding disorders, estimated at 1 in 100,000 people, and is the third most common bleeding disorder to affect women after von Willebrand disease and haemophilia.

1800 807 173
www.haemophilia.org.au



HAEMOPHILIA FOUNDATION AUSTRALIA



Bleeding Disorders Awareness Month

OCTOBER 2022

As you may know, this year in October we will have a whole month to raise awareness about bleeding disorders.

The 2022 theme for Bleeding Disorders Awareness Month is **ONE COMMUNITY, MANY FACES**. Each week we have different topics and will meet community members from all ages and stages of life to hear their stories.

ACTIVITIES AND EVENTS – BOTH VIRTUAL AND FACE 2 FACE

We will launch our calendar at the end of September. To be advised about events, register for our E-news www.haemophilia.org.au/enews or keep an eye on our website and social media platforms.

PROMOTIONAL ITEMS

Promotional items orders are now open. Order the free goods to use for your school, workplace or family/friend event. We have balloons, pens, Fling Things (like a frisbee), colouring-in sheets, information posters and lots more.

Put your order in at

www.haemophilia.org.au/BDAMorder



HOW CAN YOU BE PART OF THE WEEK?

- Order promotional items for your event, information stalls and your child's school/child care
- Run a virtual or face-to-face fundraising event
- Host a red cake day
- Share information on your social networks
- Share your story - <https://tinyurl.com/HFA-story>
- Children and their friends can take part in the colouring-in competition or a Scavenger Hunt
- Take part in HFA and Foundation activities (Calendar coming soon)

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For more information, contact

Natashia Coco

MB: 0403 538 109

E: ncoco@haemophilia.org.au
.....



Red Scavenger Hunt 2022

What can you find **RED** inside and outside – see if you can find all 9! Add a picture in the boxes or simply tick.

Tree	Playground	Picnic
Food	Insect	Bench chair
A path	Book	Something you haven't seen before

Ask your parent or guardian to share your answers on HFA Facebook

www.facebook.com/HaemophiliaFoundationAustralia or email them to hfaust@haemophilia.org.au



WHATS ON

**BLEEDING DISORDERS AWARENESS MONTH:
OCTOBER**

**SAUSAGE SIZZLE: SUNDAY 16 OCTOBER
BUNNINGS HOMEBASE**

**MENS AND WOMANS BREAKFASTS: COMING
SOON**

RIVER CRUISE: SATURDAY 19 NOVEMBER

**END OF YEAR EVENT: SUNDAY 27 NOVEMBER
OUTBACK SPLASH**



Bunnings Sausage Sizzle

Calling all volunteers and generous donors

Sunday 16th October 2022



YIPPEE, it is on this year!

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 so sign up early to get your preferred time - don't miss out!

Everyone always has a great time! And what a great fun way to mix with your peers.

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@hfwa.org with the contribution you can make for YOUR HFWA



CONTACT

September 2022

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

To order your bags and arrange collection

Jute Large Shopping Bag



Red Shopping Bag



Email your order for the shopping bags and / or nail polish directly to the HFWA office at office@hfw.org with your name, address and phone number or phone 9420 7294 and we will advise when your order can be collected - or we will dispatch your order promptly by mail (postage can be arranged at extra cost)

For fast and secure payment, follow the secure Square credit card payment link below or simply scan the QR code to go straight to the Square checkout

<https://checkout.square.site/merchant/06461WB19EDA8/checkout/R74ZARTGOWNVOO6YVONMBHMX>

HFWA NAIL POLISH GIFT PACKS VERY LAST TIME

Three bottle gift packs available.

Gift Packs \$20

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



Assorted Colours \$10 each

Helen's Melons, Emerald Green (almost gone), White, Top Coat & Rose Gold



For fast and secure payment, please follow the secure Square credit card payment link below or simply scan the QR code to go straight to the Square checkout below for your Nail Polish purchase

<https://checkout.square.site/merchant/06461WB19EDA8/checkout/V55VON3QLYYU3PUWTEB65RA>



We are fundraising with
 **Entertainment**

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PLUS, a **FREE upgrade to Multi City** when you buy a
Single City – **SAVE \$50!**

SUPPORT US & BUY NOW

*T&Cs apply



Say hello to savings & more

Get your Membership today & enjoy hundreds
of offers on dining, shopping, travel & more.

SUPPORT US & BUY NOW

Say hello to giving

Buy today and **20% of the purchase** goes
directly to our fundraising cause.



Entertainment

Support us today:

<https://www.entbook.com.au/847b23>

When you return your containers to Containers for Change, you're not just keeping them out of landfill and saving the planet - you're also having a direct, visible impact on your local community. And you're helping out your Haemophilia Foundation at the same time when you use the Scheme ID above to donate. A big thank you to our members of the community that have donated.

Scheme ID
C10338968



ELIGIBLE CONTAINERS



Most glass, plastic, aluminium, steel and
paper-based cartons between 150mL and 3L.



INELIGIBLE CONTAINERS



Containers not commonly found in litter, including all
plain milk, flavoured milks 1L and above, pure juice
drinks, wine and spirit bottles, cordials.