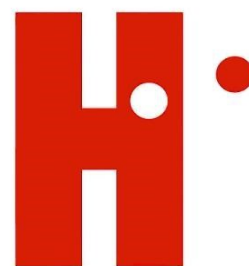


Contact



Newsletter of Haemophilia Foundation WA Inc.

February 2022



Happy New Year to all of you! HFWA Management Committee extends their gratitude to all members and supporters and it is shaping up that there may be some more challenges ahead in the coming year and we would like you to all stay safe and well.

Stock images sourced from pixabay.com unless otherwise noted

HAEMOPHILIA FOUNDATION WA INC.

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**HFWA is grateful to Fuji Film Australia for their ongoing support in printing
the Contact Newsletter**

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Your 2021/2022 Committee

Gavin Finkelstein (President) 0415 978 031
 Cheryl Ellis (Vice President) 0402 033 652
 Robert Butler (Treasurer) 9381 3386
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 Susie Couper susie.couper@outlook.com
 Shane Meotti
 Dale Spencer
 Evyn Webster

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

HFWA Interim Office Coordinator - Sean Robertson
Haemophilia Foundation WA Office
Phone: (08) 9420 7294
Email: office@hfwa.org

Cover Picture

Valentine's Day & Back To School

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 8:30 am - 4:30 pm) Ph: 6456 0170 or 0466 318 286
 After Hours: **(EMERGENCIES ONLY) Ph: 0410 717 816**
 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** 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

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

2022

Hi All

I hope everyone is well and managing given all current restrictions.

I would like to welcome Sean to the role of Office Coordinator. Jenny unfortunately had to resign due to ill health. We thank Jenny for her time at HFWA and wish all the best for the future

Clinics still go on, whether your appointment is by phone, tele-health or in person. If you are not available for your clinic appointment, please do the polite and right thing and ring advising you are unable to attend your appointment.

Due to the ongoing restrictions faced by HFWA, we are not holding any face to face community activities. However, we are looking to hold a couple of online events such as movie nights, trivia nights, sports watch parties and such, to keep people engaged and in touch with each other.

We will be inviting you all along, so please support your foundation. The more people that attend these events, the more enjoyable they will be and the more the community will benefit.

If you are struggling to cope with everything that is going on at the moment feel free to contact the Social Worker Helena Reynolds 61526527, or contact Cheryl or myself for a chat.

We always welcome suggestions for activities, whether they are virtual or physical. Email Sean at office@hfwa.org with all your ideas.

We look forward to engaging virtually soon.

Regards

Gavin Finkelstein

HFWA Community Christmas Party 2021

This year our Community Christmas Party was held at Adventure World in Bibra Lake. It was a blazing hot day, making the water and thrill rides a welcome reprieve. From the dizzying loops of the Abyss to the cool waters of the Lagoon, a good time was had by all.

The next two pages include some photographs of the visit from Santa, who gave gifts to the delighted kids gathered for the party, as well as a photo with Gotham's greatest hero.

Once again our members and their families had a wonderful time and I would like to thank those of you that were able to join us on this very successful day. Plans are currently underway for next year's Christmas party—we are hoping to hold it at Outback Splash in Bullsbrook, as we did in 2020. This is part of an ongoing plan to alternate between hosting events north and south of the river.



HFWA Christmas Party At Adventure World



HFWA Christmas Party At Adventure World



Rare Diseases Day - 28 February 2022



Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease.

Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse— but united in purpose.

Rare Disease Day is observed every year on 28 February (or 29 in leap years)—the rarest day of the year.

Rare Disease Day was set up and is coordinated by EURORDIS and 65+ national alliance patient organisation partners. Rare Disease Day provides an energy and focal point that enables rare diseases advocacy work to progress on the local, national and international levels.

Though Rare Disease Day is patient-led, everyone, including individuals, families, caregivers, healthcare professionals, researchers, clinicians, policy makers, industry representatives and the general public, can participate in raising awareness and taking action today for this vulnerable population who require immediate and urgent attention.

By Sharing your colours via social media, events, illuminating buildings, monuments and homes, by sharing experiences online and with friends, by calling on policy makers and shining the light on people living with a rare disease, collectively we aim to change and improve lives of the 300 million people worldwide.



RAREDISEASEDAY.ORG

World Haemophilia Day 2022

17 APRIL 2022

Every year on 17 April World Haemophilia Day is recognised worldwide to increase awareness of Haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

World Haemophilia Day was started in 1989 by the World Federation of Haemophilia (WFH), which chose 17 April as the day to bring the community together in honour of WFH founder Frank Schnabel's birthday.

This year the theme is *Access for All*. The World Federation of Haemophilia, with the support of volunteers from around the world, does remarkable work with developing countries with their GAP and Twinning Programs and Cornerstone Initiative. HFA is currently connected with the Myanmar Haemophilia Patient Association as a part of the WFH Twinning Program.

Did you know: WFH estimates that over 75% of people living with haemophilia worldwide have not yet been identified and diagnosed.

Access For All

HFA and HFWA are both WFH member organisations, and many Australian volunteers have been involved with WFH programs. HFA has supported many programs over the years and participated in the WFH Twinning Program and various committees that work to achieve the objectives of WFH.

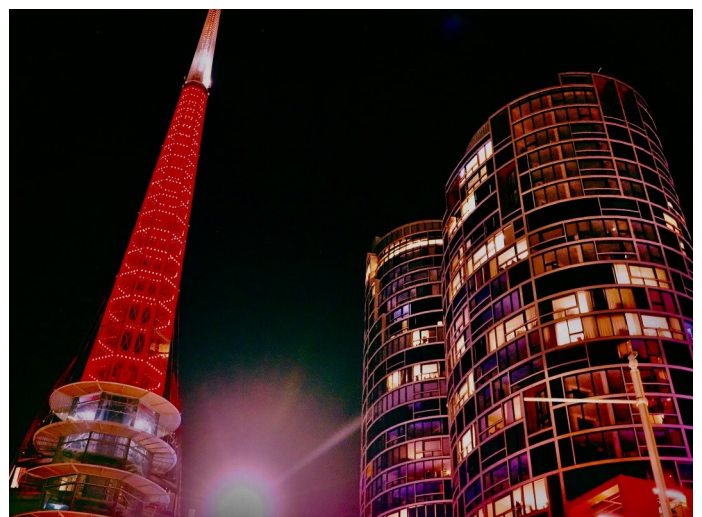
We are grateful that our community has access to high quality treatment but we recognise that many other parts of the world do not have access to diagnosis, treatment and care. Together as Australians, let's take this opportunity to recognise this special day and put our support behind the worldwide effort for Access for All.

Light It up Red

We have many locations and landmarks over Australia Lighting up Red in support of the day. These locations will be listed on HFA website. Keep an eye out and share photos on HFA social media platforms. HFA will have some virtual activities available at <https://www.haemophilia.org.au/WHD>

For more information, virtual activities and Light It Up Red Landmarks visit

<https://www.haemophilia.org.au/WHD>



The Bell Tower, lit up red last year. Photo By Leon Ewing.

More Than Love Languages

With Valentines Day just behind us, love is well and truly in the air—but how do we show it? According to Gary Chapman's book *The Five Love Languages*, there's not just one way to show your affection and appreciation to someone, and everyone reacts differently. Some people work best with verbal affection and complements. For others, small and thoughtful gifts work best. Some people just enjoy spending quality time together, where you focus your attention. Sometimes, doing mundane stuff like washing the dishes or cleaning the house makes them feel appreciated. Other times, physical intimacy is what's needed.

This theory doesn't just apply to romantic partners though. It's a great way for parents to show their appreciation of their kids (or for kids to show their appreciation of parents). It's definitely something worth considering, to see how it might help you. What do you enjoy most?

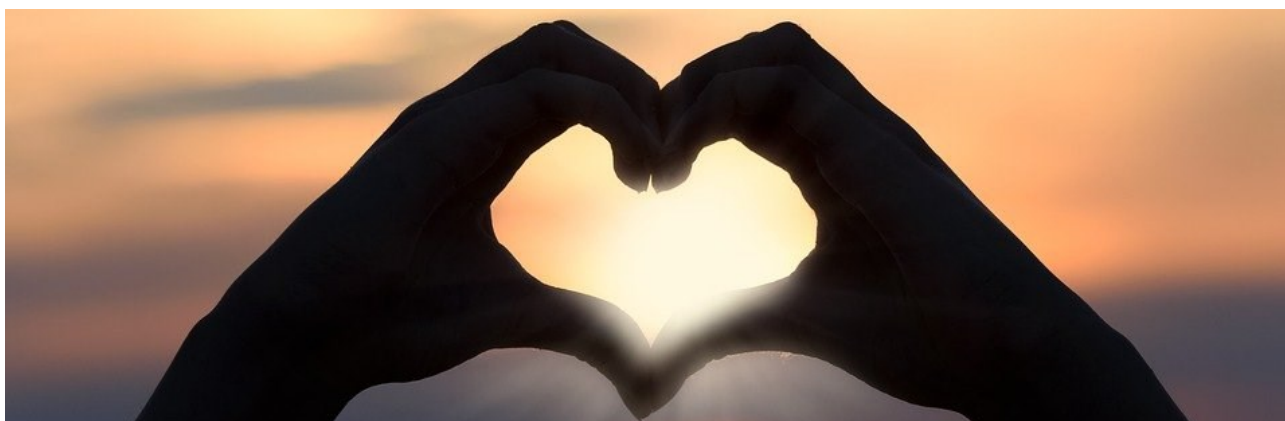
Australian of the Year

Dylan Alcott

Dylan Alcott was named Australian of the Year 2022 and what a wonderful ambassador he is for people with disabilities. Being the first person with a disability in the history of the awards, this is a milestone worth celebrating.

Dylan will bring something to the table that will impact and benefit the disability sector like no-one has before him and it will be incredibly positive for exposure and awareness.

Dylan is a record-tying seven-time winner of the Australian Open Tennis Championship, has won eight other Grand Slams, and is a two-time Paralympic gold medalist. In 2021, he made history by becoming the third person to complete a Golden Slam in a calendar year, by winning all four Grand Slams and Olympic gold in one year.



Australian Conference and World Congress Updates

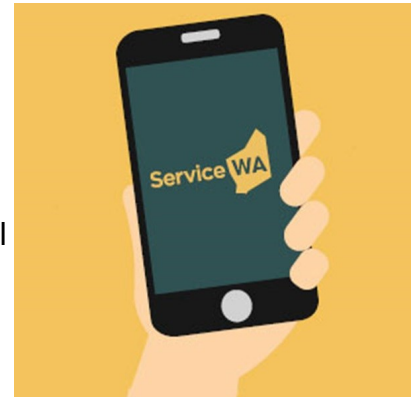
The Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders was held virtually in October last year, but it's not too late to benefit from it. HFA has made all of the sessions, virtual exhibition boosts and ePosters available on demand until April. This is a great opportunity to learn new information and gain new perspectives, or to rewatch a session you already saw. I highly recommend checking it out at <https://www.haemophilia.org.au/events-and-conferences/conferences/2021-conference>

The World Congress is also coming up and is scheduled to open on May 8. Due to the ongoing COVID situation, the decision has been made to utilise a novel hybrid approach, with a mixture of in-person sessions in Montreal and virtual sessions held on the internet. While our members will not be attending physically, we are all looking forward to the valuable online elements of the Congress. This is an event which has shown a lot of new perspectives to our members, and is always a highlight of the year to those involved.

Your Health Matters - COVID Updates

One-stop ServiceWA App Launched

The ServiceWA app allows people to show proof of vaccination, check in at businesses and venues with SafeWA and access their G2G Pass for interstate travel - all in one convenient place. Although the app is somewhat time-consuming to set up, it will make day-to-day life easier with your vaccination confirmation, SafeWA check-in and G2G Pass all in one place. This is especially useful with the new requirement to present proof of vaccination in order to dine in at restaurants.



WA Border Allows More Exemptions

Based on the latest health advice, WA's Safe Transition Plan has been updated with new hard border settings from Saturday, February 5, 2022. The updated plan means the full border opening will be delayed given the full impacts of Omicron in Australia are still unknown. This delay provides more time for Western Australians to receive a third vaccination, which has been shown to decrease the impacts and spread of Omicron. Although the border is still closed, the new settings provide expanded exemptions for those who have recently lived in WA and intend to permanently reside within the state, those coming to see family members and those who have recently travelled interstate to see family members. Currently, the border is set to re-open on March 3.

Free Rapid Antigen Tests For Concession Cards

From January 24, holders of Pensioner, Commonwealth Seniors, DVA, Health Care and Low Income Cards can obtain up to 10 free Rapid Antigen Tests from pharmacies. These tests are intended for personal use; if a test is required due to isolation or quarantine requirements, one can be accessed directly from a hospital.

Third Dose Timelines Moved Forward

The TGA has announced that, from the start of February, eligibility for the third dose of COVID-19 vaccines begins three months from the date of vaccination. This allows people to be further protected against Omicron, lessening the spread and reducing the likelihood of severe health outcomes. Since December 22, those who are subject to a vaccination mandate due to their sector of employment have been required to get a third dose within one month of becoming eligible. In addition, those aged 16 and 17 became eligible for third doses from February 3.



International Border Re-opens

Australia has maintained a closed border for much of the pandemic, but that has finally changed. Individuals are now able to enter the country without quarantining if they are fully vaccinated. This is great news for the tourism industry, plus anyone with family abroad.

What have we been doing?

Strategic Planning Day - March 2022

Phase 2 of the HFWA Strategic Planning is now being held in March with our very motivating facilitators Paul Leighton and Ashley Cooper. Phase 1 was used to brainstorm and Paul and Ashley's exceptional organisation skills kept us all on track and on our toes.

We were able to target some important areas that will be our focus of attention in Phase 2 to ensure we keep running the foundation up to it's full potential to help and assist all of our valuable members and their families. We are planning away in the background so keep watching this space for more information.



Database Renewal Project

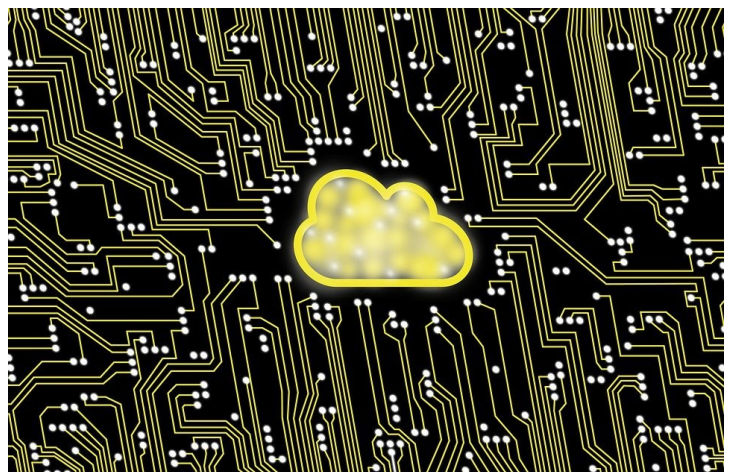
The HFWA Membership Database was created for the Foundation back in 2005. It has served us well over many of years but it is now in desperate need of attention. 17 years on, it is no longer fit for purpose and the platform it is built on is no longer fully supported by its developers.

We were very lucky to have Sean Robertson apply his techie talents early last year and provide detailed analysis and recommendations for improvements to the database. Armed with this, we procured the services of ONGC, a Microsoft partner that specialises in IT solutions for the not for profit sector. Late last year the team at ONGC commenced work and over the past 2 months have been working with us to identify our requirements and build a prototype system that meets the current day needs of HFWA.

While this sort of work is largely invisible to our members and the wider bleeding disorder community, it is important that we are transparent and communicate on these matters. Ensuring the security and privacy of membership data is a critical responsibility of the HFWA Management Committee and this was a key factor in both the decision to upgrade the database and in selecting a solution provider. The cost of this work is not insignificant. Fortunately, the Foundation is in a sound financial position, and making such improvements to our systems will save money and provide better outcomes for the community in the future. It also demonstrates to our funders that the HFWA has the appropriate governance in place.

Having a revamped system will make the task of communicating to members and organising Peer Group events much simpler and we are looking forward to more of both in the not too distant future. The new system might mean that your membership forms will look a little different, as we will be tracking new aspects of your experiences and needs.

The Management Committee are also very pleased that Sean has agreed to assist us in the office while we find a replacement for Jenny. Sean is already off and running and giving some much overdue love to the HFWA Office IT.



Sean's Top School Tips

School can be tough and disorganised, but it doesn't have to be. There are plenty of ways to make everything easier, both as a parent and as a student. Here's some of my personal favourites!

1. Find a way to track your assessments. It doesn't matter if you use a physical calendar, something on your phone or a giant sheet of paper... knowing when your assessments are will help you make sure you don't submit an assessment late. If you find that you don't benefit from one organisation tool, swap to another one! There's nothing wrong with experimenting to find what works.
2. It's better to finish an assessment a day early than a day late. Give yourself extra time in case something takes longer than expected, or you have to do something else. It's more work now, but you will thank yourself later.
3. Work is important, but breaks are too. Sitting in front of a computer for three hours and just trying to study won't be effective. Make sure to take *short* breaks to stand up and stretch, and grab some water. A good balance is five minutes of break out of every 50-60 minutes. While you are working, also follow the 20-20-20 method for eyestrain, and look at something 20 metres away for 20 seconds every 20 minutes. Water is crucial too, stay decently hydrated.
4. Make sure you sleep. As tempting as it may be to stay up late doing school work (or not doing school work), you'll be much more effective and you'll learn better if you sleep. Plus, you will be happier too. Trust me on that one.
5. Libraries are awesome, and so are librarians. Want something fun to read or help finding information you can't quite find? Check out your school's library, or your local one! You never know what you will find.
6. Your teachers aren't *that* scary, they usually love to teach. If there's an assessment type you struggle with or a concept you don't understand? Ask them, or one of the other teachers of the subject. They're there to help you. There are plenty of ways to ask too. You can ask during class, you can ask after class, or you can even send an email.
7. Your mind won't work at its best unless your body does too. Make sure to be physically active when you are trying to be mentally active. Go out for a run or walk, ride a bike or throw a ball. Getting your blood pumping will get your mental juices flowing.
8. Sometimes, not working is as important as working. Giving ideas time to sink in will help you remember them later. Spending time away from a project can help you look at it with fresh eyes, adding new ideas or fixing mistakes you missed. This is part of why it's good to start and finish assessments early, so you *don't* have to do everything all at once at the end, with no breaks and time away.
9. There are lots of ways to study. Maybe music helps you, maybe it doesn't. Maybe coloured pens or mind maps help you, maybe they don't. Experiment, try new things and give it a go, see what works for you. Everyone studies differently, and that's a part of life.



Bushfire Emergency Plans

Do you have a plan?

Western Australia is at the height of its bushfire season again and there have been several occurrences that have been brought under control by our brave and dedicated firefighters. We have been fortunate to date that no lives or properties have been lost but the loss to our wildlife and bushland is always devastating and will take many years to recover. To avoid loss in our community of homes, wildlife and bushland, those living in the rural community need a plan.

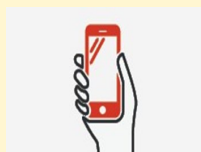


Even if you live in an urban or suburban area, it is still useful to have a plan. Placing identification and irreplaceable keepsakes together in an easy-to-take package will allow you to easily evacuate and take the most important items.

The present situation is dire for so many. If you don't have an emergency plan, we encourage you to visit the DFES website on the link below.

<https://www.dfes.wa.gov.au/bushfire/prepare/>

While there are arsonists in our midst there will always be a time for you to stay vigilant.



DOWNLOAD THE APP

You can access your bushfire plan anytime even without an internet connection.

To those of you who are on the front line, who put themselves in the face of danger in sometimes catastrophic and extreme conditions, THANK YOU! These very brave people may be saving your home while their own is lost to fire.

If these events happen to you, stay alert, be aware and above all else stay safe.



New HFWA Virtual Events

HFWA is proud to announce a new virtual event initiative, as mentioned in the president's report. We are currently in the planning phase, but we plan to run movie nights, game nights and more! These are a great chance to remain socially active and be connected with the community in these trying times, and are easy, low-pressure opportunities for fun - just put on some comfortable clothes, grab some popcorn and a drink, and enjoy the show!

We currently plan on hosting a variety of events for the Men's Group, the Women's group and the Youth group, to replace the face-to-face events we are unable to hold. The first event will be a movie night for the Youth group, and will probably be hosted at some point in March. The Men's and Women's events are likely to be held in late March or April, depending on availability and interest. We are still deciding on the frequency of future events, and it will largely depend on interest and attendance.

If you (or your kids) are interested, email the office to let Sean know at office@hfwawa.org and we will send information on potential movies, dates, platform and such. If you have any suggestions and opinions, we would love to hear those too. Everything from fun activities to awesome movies, we would love to have your ideas. We are especially keen for expressions of interest and thoughts for the youth event, as that will be held first.



Introducing Sean Robertson

Hi, my name is Sean! I am currently working as the interim office coordinator, after Jenny Hough has stepped down due to ill health. I am the son of Susie Couper, and my family has been closely involved with the foundation since my younger brother was diagnosed with Severe von Willebrand Disease. I am currently studying Computer Science at Murdoch, and I am looking forward to bringing some new ideas to the Foundation, such as better ways to use technology and some really cool youth-focused events.

Growing up, the Foundation was able to have a really positive impact on me as a sibling of someone with a severe bleeding disorder. It helped me to accept and manage the risk of my brother's condition, but also to realise that it isn't the end of the world. The memories I have from HFWA events are some of my fondest, from community camps to Christmas events and sausage sizzles, and it's a great opportunity to give back to a community which has helped me so much. I'd highly recommend being as involved as possible, to anyone going through primary and high school. The experience of being involved in a community like this is invaluable.

I feel that young adults are one of the hardest demographics to represent and consider on the committee. When children are young, it's normal for parents to be involved in the activities and hobbies, to know what their kids enjoy. As they get older, children naturally become more and more independent, finding their own hobbies and organising their own activities. This is a part of life, but it has tended to make it difficult for the committee to arrange activities targeting this age group. Getting young adults involved with the committee is difficult however, between the lack of lived experience and the stresses of secondary and further education. This is why I am so excited to give a new perspective, to help the Foundation recognise and respond to the challenges and needs of others like me. I believe that the Foundation can do a lot of good, and I am looking forward to helping it to do so.

Another benefit of my fresh perspective is my familiarity with the digital space. I am going to run some virtual peer support events during the ongoing pandemic measures, as a way to protect the community against the challenges and isolation which can be created by the lack of events. I actually spent substantial portions of 2020 in Melbourne, which means I am intimately familiar with the toll imposed by these sorts of measures, why they are needed and how to handle them. I am hoping to maintain some level of involvement for a decent amount of time, both as office coordinator and by continuing to run virtual events into the future, so watch this space. If we manage to return to physical events, I will also be looking forward to acting as a welcoming, familiar face at those.



2022

WHAT'S ON?



Rare Diseases Day - 28 February 2022

World Haemophilia Day - 17 April 2022

WFH 2022 World Congress - 8 - 11 May 2022

Bleeding Disorders Awareness Month - Oct 2022

Save the Date

Men and Women's Peer Support events
Postponed until further notice
(see President's Report)

River Cruise
Postponed until further notice

Virtual Events
Coming Soon!
Contact office@hfwa.org for details

Fundraising

We are fundraising with
 **Entertainment**

Hello 2022. Hello Savings. HelloFresh!

Buy an Entertainment Membership & get
up to \$120 off* your first six HelloFresh boxes.

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**

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



EMPTYES DAY 29 JAN

DONATE YOUR 10¢ CONTAINERS
TO US THIS SUMMER



Scheme ID
C10338968

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.

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



Email your order for the shopping bags and / or nail polish directly to the HFWA office at office@hfwa.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>

or deposit the total of your order with your Surname as your reference to:

Acct Name: **The Haemophilia Foundation of WA Inc.** BSB: **086 488** Acct No: **03 523 3031**

HFWA NAIL POLISH GIFT PACKS

Three bottle gift packs available.
Looking for that personalised gift for a friend or to spoil yourself? Look no further!

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>