

CONTACT

Newsletter of Haemophillia Foundation WA Inc.

May 2022



Cover Picture: Optus Stadium lit up for World Haemophillia Day

This Easter, landmarks all over Perth lit up for World Haemophilia Day!

Haemophilia Day images taken by Leon Ewing, IG@sonnenmasse; Stock images sourced from pixabay.com unless otherwise noted

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

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Nursing Staff: **Sandra Lochore** and **Lara Olson**

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Entrance to the Cancer Centre is on the outside of the building
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Community Spotlight

A new feature now is the Community Spotlight! In each issue of the newsletter, we will present an interview with a member of the community highlighting matters such as new treatments, changes in experience, and life with bleeding disorders.

The first spotlight will be coming up in the next newsletter, so make sure to check in to see that. Want to see your name in lights? Feel free to send an email to us at office@hfwf.org for details and to register your interest! We are particularly seeking people who have tried new treatments and have opinions of those, or people who have managed a bleeding disorder over a long timespan.

President's Report

Hi Folks

I hope all of you are well and have avoided catching Covid in the latest wave. Even though restrictions have been eased numbers are still rising.

HFWA will monitor the situation so that when it is appropriate to recommence community activities and events we will do so

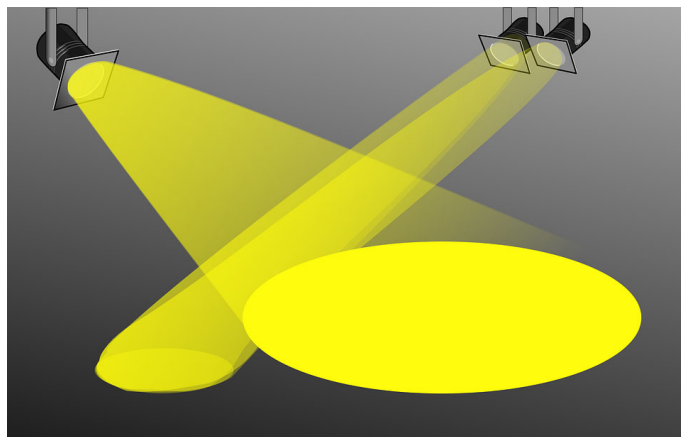
We have just had our second strategic planning meeting and we will provide a more detailed report on the outcome of that in upcoming editions of the Newsletter.

The World Federation of Haemophilia Congress held in Montreal in person and virtually has just wound up and there has certainly been lots of good information and research which has come from it.

Watch out for the HFWA AGM in September and feel free to come along.

Looking forward to catching up with you when we recommence foundation activities,

Gavin



A photo from the 2019 Australian Congress, the last major in--person event.



What Have We Been Doing?

Lots of work in the background here at HFWA! The AGM will be held in September and will be featuring a special panel discussion. Keep your eyes peeled for more in the next issue.

We have also just held a strategic planning meeting, which will allow us to continue benefitting the community in the most effective way possible, now and into the future. There are several new and exciting initiatives we expect to run as a result of this planning, so we definitely recommend watching this space.

Unfortunately, the youth events announced in the previous newsletter didn't eventuate. Turns out it's hard to get teenagers to do things, who would've guessed? It's still not too late to register interest in that, though—feel free to email the office with expressions of interest for the youth events.

Finally, membership renewals will be due this July, and renewal forms will be provided with the next newsletter. These might look a little different to what you are used to, to go with the new member database we have implemented to allow for better planning.



The NEWSletter

You may have already noticed, but the newsletter has a new look! HFWA had been using the same format for over a decade, and we figured it was high time for a change. The new layout is designed to be modern and eye-catching, with more colour spread throughout and more pictures as well. It's also been designed with accessibility in mind, ensuring higher contrast throughout the newsletter for greyscale printing and also to improve accessibility for colourblind people.



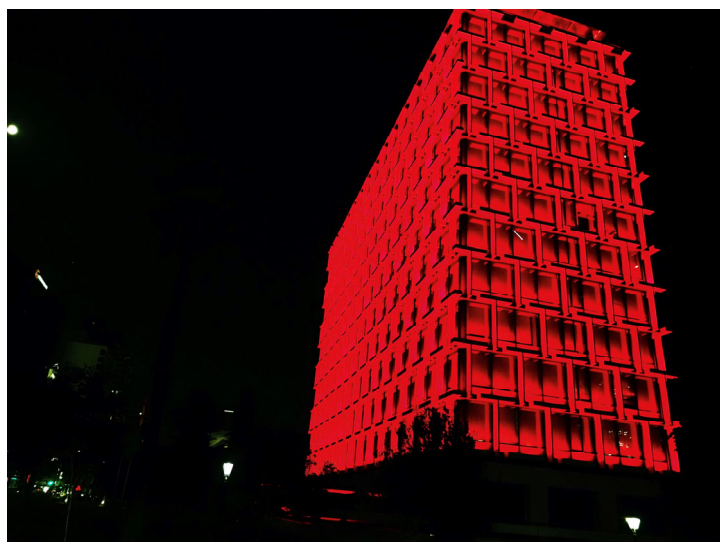
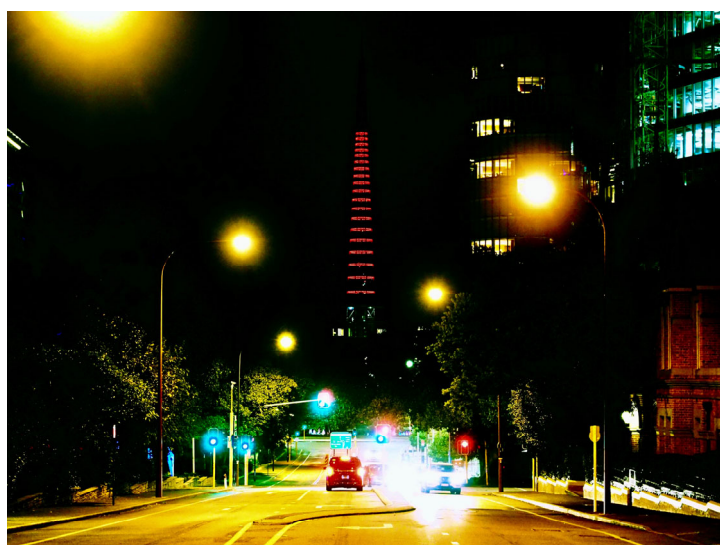
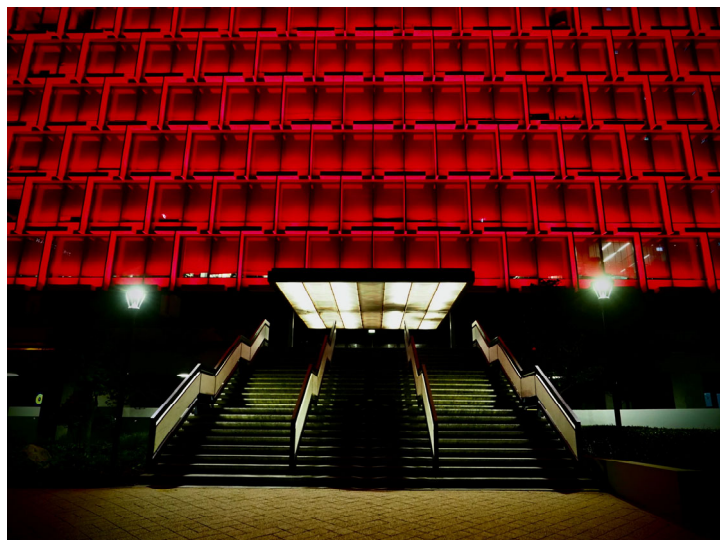


World Haemophilia Day: Access For All

This April, landmarks all over Perth lit up red to celebrate World Haemophilia Day. We are immensely grateful to the team at the Bell Tower, Council House, Main Roads and Optus Stadium for their assistance this year. Elsewhere, landmarks such as Niagara Falls and the CN Tower were lit up as well.

This Year's theme was "Access For All", which is a very relevant cause here in Australia. While we do have strong and robust access to treatment here in Australia, it has taken a lot of advocacy and work to get this. People in many other countries are far less fortunate, and do not enjoy the same quality of treatment.

However, there is still a gulf between the quality of treatment for Haemophilia and rarer bleeding disorders. While gene therapy and Hemlibra provide new and exciting avenues for those with Haemophilia, there has been far slower progress with other disorders such as Von Willebrand disease, platelet function disorders and deficiencies of other clotting factors. The theme of Access For All is important and relevant here not in spite of our high quality treatment, but because of it.





World Federation Congress 2022

The WFH 2022 Congress has used a unique hybrid model, with some sessions being held physically and some sessions being held virtually. Many of our members have had huge benefits from attending the conferences in the past; while we did not send any members physically, we have eagerly participated in the virtual elements. There were workshops and talks on a wide variety of topics, such as dental care, mental health, diagnosis, and more.



One of our members, Susie Couper, has been involved behind the scenes shaping some of the content for this congress. As part of the Women and Girls with Bleeding Disorders Committee, she has worked to shed light on previously hidden experiences. This work includes helping to shape sessions around the differences in laboratory testing for women and girls, the ways different cultures interact with bleeding disorders for women and girls, and the differences in the impact of Von Willebrand's Disease.

While the sessions were held late at night here in Perth, the hybrid model of this congress allowed those of us here in Perth to watch the sessions at a much nicer time. In addition to these sessions, there were discussions from various medical professionals on topics such as new treatment options and the future of treatment. If you want to get involved in the congress, it's not too late! Registrations are open even after the congress, and the virtual sessions will be available on demand up to 60 days after this very valuable event.



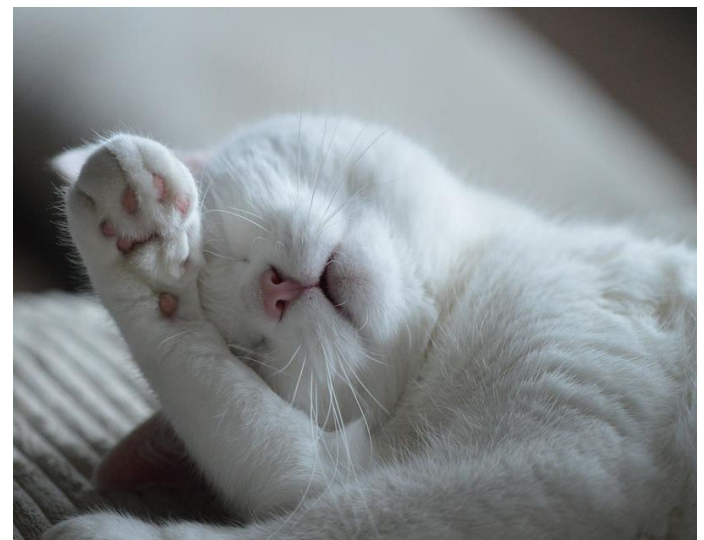
*Images, top to bottom:
Downtown Montreal, Montreal Skyline, Biosphere*



Health Corner: Sleep Time

In times of work-from-home, homework, exams and stress, it can be all too easy for our sleep to be disrupted. What's the harm in a little more time awake, or an extra hour of sleep? Turns out it can be quite substantial. Maintaining regular, restful sleep is important for our mental and physical health. Here's some tips for better sleep!

- Avoid having caffeine later on in the day. The effects of Caffeine can linger on for up to 6 hours, and it can take up to 10 hours for it to be fully eliminated from the body. A coffee at 4 PM might still be with you at 1 AM!
- Try to minimise the exposure to bright lights from screens and devices. Bright lights signal to the body that it should stay awake and alert, regardless of colour. If you can't put down your phone, at least turn the screen down. Just filtering out blue light isn't enough.
- Set a regular bedtime. Your body works in rhythms. It's easier to fall asleep if you go to sleep at the same time every day, as this will help to reinforce your rhythm.
- Wake up at a regular time. Your body's rhythms work the other way around as well. You'll find it easier to wake up and get to sleep if you have a regular time on both ends.
- Use your body and your mind during the day, but not too close to bed. Being physically and mentally active during the day has been shown to help with sleep, but doing it right before bed will only keep you up.





Lightyear Family Movie Night

HFWA is proud to announce a family movie night! We will be attending a screening of Lightyear. The idea of the movie night is to provide a community event, giving an easy opportunity for people to meet up and stay connected. It will be a fun, light-hearted night for all, to meet new people and stay connected. This event will be heavily subsidized by the foundation, but there will be a nominal fee. We highly recommend registering your interest and booking early.



Lightyear © 2022 Disney-Pixar

More Virtual Events!

While the teenagers may not have been interested in the previous virtual events, that doesn't mean we are giving up! Our next two events will be a movie night for the existing women's group, and an AFL watching night for everyone. The events will be free to enter, although we do recommend grabbing some popcorn or drinks. Want to be involved? Send an email to office@hfwa.org with your expression of interest, availability and any movie ideas!



What is a virtual movie night?

COVID restrictions may have been eased, but there's still no place like home. Virtual events are a nice, simple, low-pressure way to stay connected and active in the community. For these ones, one person will show the video over Zoom, displaying it for everyone to watch.

It's a good chance for everyone to gather around and all watch the same thing, as if we are together, all from the comfort of our own homes. Put on some comfy clothes, get a warm drink, settle in and have fun!





New Resource For Women & Girls

HFA has published a new education resource, ***Haemophilia testing in women and girls: your questions answered***. It's a comprehensive booklet about genetic testing and factor level testing in haemophilia for women, girls and parents of girls. There are often many questions and things to think about when checking to see if a woman or girl is affected by haemophilia.

- What is involved in genetic and factor level tests?
 - Who should have them?



- At what stage in their life?
- How is haemophilia passed on in a family – and what if there is no family history?
- Why do some women and girls have bleeding symptoms or haemophilia and others do not?

HFA developed the booklet to answer these and other questions in collaboration with women and parents in our community, HTC's and genetics and legal experts. It includes infographics, tables and personal stories.

Download the booklet from the HFA website [here!](#)



If you would like a print copy, email HFA at hfaust@haemophilia.org.au or call 0398857800 to ask them to post you a copy.

Thanks to everyone who contributed to the development of this resource, and a special mention of Jane, Sharri and Michelle for sharing their personal stories.

We invite you to take a look at the resource and pass it onto anyone you think would find it helpful—and look out for the short and simple version which is coming soon!



(Photos sourced from Haemophilia Testing booklet)



UPCOMING EVENTS

LIGHTYEAR FAMILY MOVIE NIGHT: JUNE

MEMBERSHIP RENEWAL: JULY

AGM: SEPTEMBER

VIRTUAL MOVIE NIGHTS: SOON

CONTACT

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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

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HFWA NAIL POLISH GIFT PACKS

Three bottle gift packs available.

Gift Packs \$20

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



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



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