

CONTACT

Newsletter of Haemophilia Foundation WA Inc.

December 2023



Cover Pictures: BDAM Morning Tea, Charlie D & The Bell Tower and BDAM custom brownies.

HFWA Management Committee extends their gratitude to all members and supporters for 2023 and we would like you to all stay safe and well over the upcoming break and into 2024.

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HAEMOPHILIA FOUNDATION WA INC.

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HFWA proudly acknowledges our Patrons,

**His Excellency The Honourable Chris Dawson AC
APM**

**Governor of Western Australia
and Mrs Darrilyn Dawson**



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

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

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

Social Worker: **Sarah Franz** (Three days per week, contact for appointment) Ph: 3456 0413



FIONA STANLEY HOSPITAL CONTACT DETAILS

Clerk Front Desk: **08 6152 6542**

Medical Staff: **Dr Stephanie P'ng** and **Dr Dominic Pepperell**

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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
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President's Report

Hi All,

It was great to see so many people attend our Community Christmas party at Adventure World, it was certainly hot enough for all to enjoy the delights of the water and the activities available. We had the obligatory visit from Santa which thrilled the younger kids and Ben!

The office will be closed from 21 December until 8 January. You can always contact me if necessary.

Our attendance at PCH clinics have been going really well. It's great to reconnect with others we have not seen for a while.

Please ensure you take the time to complete the PROBE study (whether you have a bleeding disorder or not); details are on page 13, it is a very useful study that is used in Australia and overseas to help people with bleeding disorders.

Also, it is essential that everyone who uses any treatment products records this usage on MYABDR, information is identified and used for research and budgeting purposes - your treatment center knows how much products you use but it is your responsibility whilst getting free products that you record your usage accordingly.

I wish everyone a Happy Christmas/ Channukah or whatever you celebrate and a happy and healthy 2024.

Regards,
Gavin



HFWA Christmas Party at Adventure World on 25 November 2023. From left to right: Cheryl (Vice President), Ann-Maree (Office Coordinator), Paul (Committee Member), Darren (Committee Member) Gavin (President) Susie (Committee Member). Front: Father Christmas (the jolly man in red) and his elf Darcy



Bleeding Disorders Awareness Month: October 2023

The bleeding disorders awareness month (BDAM) morning tea was such an informative and interesting event!

The Vice President of the foundation, Cheryl, was so down to earth and enlightening, the time she spent engaging with the crowd and sharing her wealth of knowledge was so great. I learnt about the advocacy work being done for people with mild haemophilia (our grandson is mild), as well as the bleeding disorders community as a whole and also highlights from the latest conference. As a grandparent of two grandsons with haemophilia, events like this are definitely a great way to connect to the community and have those important discussions.

Penny Benson

We had a fantastic turn out to the BDAM morning tea held at City West Lotteries House (CWLH) on Wednesday 18 October. Members and many of the tenants and their guests joined us to learn about bleeding disorders and what the HFWA does.



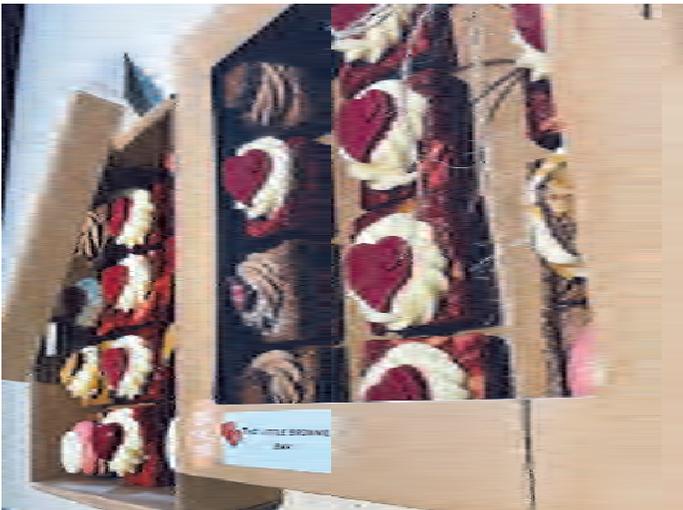
I'd like to extend a big thank you to Robin, Penny, Beryl and Cheryl for bringing goodies along, and Nicky and Fiona from CWLH for donating some amazing catering for our guests.

Suzie from The Little Brownie Bar for donating the delicious and beautiful array of brownies specially styled for #BDAM2023.

Contact them to place an order, you wont regret it!

thelittlebrowniebar@gmail.com

Ann-Maree Foran : Office Coordinator





Bleeding Disorders Awareness Month

In the Month of October one of our member's daycare centre helped raise awareness of bleeding disorders. Ally would like to share some pictures from the bake sale Finnicks daycare (Leapstart Jandakot) did this year again for bleeding disorder awareness month.



They went all-out and decided to combine it with a Halloween theme too! The kids helped bake and decorate! Thanks for sharing, Ally, and thank you to Leapstart Jandakot. Congratulations on the birth of your new baby, Valerie, I bet Finnicks is excited.



New Haemophilia booklet

The new HFA **Haemophilia** booklet is now available. Much has changed with new haemophilia treatments and the 2023 edition has been revised completely.

It is a great introductory resource about haemophilia that is very useful for new families and educating others – for example, extended family, schools, employers and health professionals who are new to haemophilia. It covers:

- what causes haemophilia
- diagrams of genetic inheritance and how bleeding occurs in haemophilia
- diagnosis
- treatment (including new treatments)
- carrying the gene alteration
- family planning and pregnancy
- tips on living well.

Thank you to all of the community members and health professional experts who contributed to its development.

Accessing Haemophilia 2023

Download it from the HFA website -

<https://tinyurl.com/HFA-haemophilia>

ask HFA to post you a free print copy –

hfaust@haemophilia.org.au





ABDR :

“The ABDR tells the story of a patient, their bleeds and their treatment over their lifetime. “

Do you keep your MyABDR up to date?

The [Australian Bleeding Disorders Registry \(ABDR\)](#) is the system used by HTC's around Australia for the clinical care of their patients. It is much more than a simple registry of diagnosis, with data about a patient's bleeds, treatments and the treatment plan, results of tests and other measures, hospital admissions and related clinical interventions such as surgery, and information about treatment outcomes. It also includes details about ordering, supply and use of treatment products for each individual patient.

In these days of home treatment, it is important to know what is going on outside the hospital. Since 2014, people with bleeding disorders or parents/caregivers have been able to use the MyABDR app on their mobile device or their computer to contribute data about their or their child's bleeds and treatment, along with a record of treatment stock they are managing at home.

The ABDR has evolved enormously since it was first established in 1988. Originally it was an Access database funded by Haemophilia Foundation Australia which was updated using spreadsheets provided by each HTC. In 2008, funding was provided by the NBA, and the ABDR became a national and very complex internet-based database. The role of the Data Manager was developed to ensure that accurate ongoing information was recorded nationwide and to co-ordinate the protocols for entering data into the ABDR.

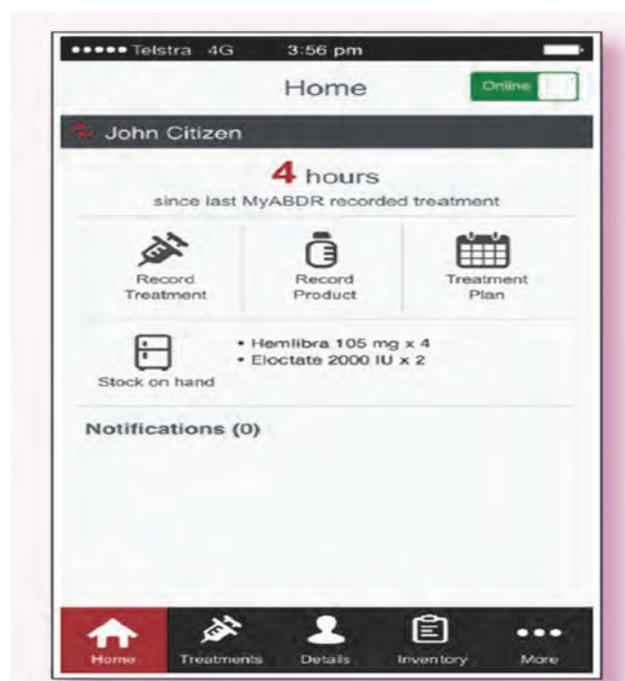
The contributions patients and parents make in MyABDR are an essential part of the ABDR patient history. In these days of personalised treatment where people with haemophilia treat at home, the data on when and how much product they used in treatment and details of bleeding episodes play an important role in developing a treatment plan that works best for the individual.

With the MyABDR app, the patient can record quickly on their phone and can keep a record not only of details of treatments but bleeds as well – including the part of the body, so that they can see patterns emerging

[Taking care of your ABDR data - Haemophilia Foundation Australia](#)

The above is an extract from the HFA article featured in the JUNE newsletter 2023. The full article can be found in the link above. You can seek assistance from the local data manager Marina Goruppi located at the HTC in Fiona Stanley Hospital.

Below: Sample image of MyABDR app





World AIDS Day: 1 December

World AIDS Day is marked globally on 1 December to raise awareness about HIV and eliminate stigma and discrimination. In 2023 the national theme for World AIDS Day is **Inclusion, Respect. Equity.**

Part of our everyday life as a community is being mindful of our community members living with

HIV, of demonstrating our support for them and honouring lives lost over the past 40 years. Wearing a red ribbon on World AIDS Day is one way of showing your support.

Much has changed since HIV was first identified in the mid-1980s. Today in Australia people living with HIV can get medication that allows them to live a healthy, long life, suppressing their viral load so they have no risk of transmitting the infection to a sexual partner. There are also medications to prevent HIV infection if exposed to the virus.

HIV IN THE BLEEDING DISORDERS COMMUNITY

HIV is a very important part of our community's history. In the mid-1980s some adults and children with bleeding disorders acquired HIV from their clotting factor treatment products. Some lost their lives to HIV while others live with HIV today. Treatment product safety is now greatly improved and the risk of bloodborne infection from products derived from blood is extremely low. Nevertheless, the impact of HIV has been profound, not only the people who acquired HIV but those close to them, those who have cared for them and the community generally.

The HIV experience drew on the resilience that was already a strong element among people with bleeding disorders and led to a resolve to respond as a community, taking on effective advocacy around safer treatments and providing support.

INCLUSION, RESPECT. EQUITY.

This year's theme is a timely invitation to consider what **Inclusion, Respect. Equity.** means to us.

We are grateful to some of our community members living with HIV who generously shared their thoughts.

Neil

I've been very open about my HIV status for years now and I've been humbled by the respect shown to me by everyone I've told. Being free to answer questions and break down any fears has only helped my inclusion in social circles.

Mike

When I see the word 'inclusion', I think of how the bleeding disorders community and the HTCs have come together to deal with HIV. (continued on next page)

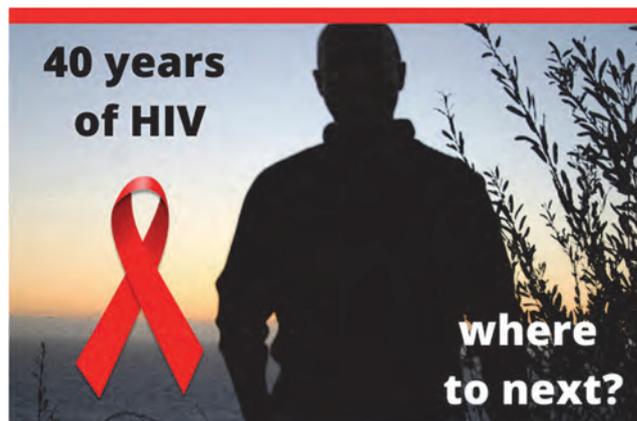


Haemophilia when I was growing up in the 1950s, 60s and 70s was life threatening and I required many treatments.

The 1980s was a catastrophic period. HIV caused a lot of devastation and worry to me and my wife personally. It also brought a lot of families together, and it was this support that helped us to survive this period in our lives where so much was unknown.

We were very fortunate to have great team of doctors, nurses and a psychologist who were very understanding and supportive, and we would not have survived this time without the tireless work from HFA.

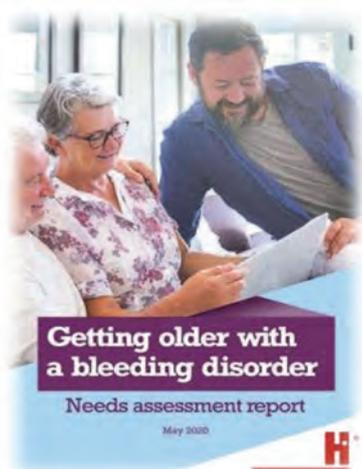
READ MORE: Read **40 years of HIV – where to next?** for reflections from our affected



community about their experiences and thoughts about the future - <https://tinyurl.com/HFA-40-years-HIV>

Visit www.worldaidsday.org.au for more information about World AIDS Day in Australia.

In Australia HIV infection is now usually well-managed with treatment, but while some people with bleeding disorders and HIV are going well, others have more complex needs. HFA has outlined ways of addressing this in our [Getting Older report recommendations](#). If you would like to read and understand more, we encourage you to read the sections on bloodborne viruses in our [Getting Older report](#). (browse the full report - bloodborne viruses feature in several sections. We recognise the very positive contributions people with bleeding disorders and HIV continue to make in our community, in spite of all their experiences: the inspiring optimism and generosity of individuals with HIV, not only providing support to their peers with HIV, but empathy, leadership and a way forward into the future for the whole community.





Medic Alert

Are You a Member of MedicAlert? It Could Save Your Life...

Do you or your loved ones have a serious medical condition? Are you worried that you or they may not get the care required care when it is needed? The MedicAlert instant access QR Code service, backed up by the 24/7 Emergency Information hotline, shares your vital information directly to those who need it, for swift and accurate treatment when seconds count.

For over 50 years, the MedicAlert Foundation has given Australians with hidden health conditions peace of mind that they will communicate for them in everyday and emergency situations. As part of a worldwide network of MedicAlert affiliates, their network helps protect and save lives across the globe. MedicAlert's Emergency Information Service is accessible from anywhere in the world, 24/7, giving you peace of mind at home and when you travel.

There is a \$52 annual service fee, which is a small price to pay for the peace of mind that



comes with the knowledge that you & your loved can easily advocate for your & their own health.

The MedicAlert Foundation is a registered National Disability Insurance Scheme (NDIS) provider for participants that have a Consumables or Assisted Technology package included. Whether you are self-managing, have a NDIS fund manager or go directly through NDIS, MedicAlert can assist you.

Department of Veterans' Affairs (DVA) Gold Card holders may apply for their MedicAlert Membership to be covered. Please contact MedicAlert for more information.

[Click for the application form to join MedicAlert.](#)

Or head to the MedicAlert website for more information - <https://www.medicalert.org.au/>

HFWA offers members a subsidy for MedicAlert emblems & bracelets; [email the office](#) for more information, or check out the application form [here](#).

Cheryl Ellis (content from MedicAlert website)





HFWA Christmas Party:

Saturday 25 November saw the HFWA have their annual family Christmas event, it was held south of the River at Adventure World.

Wowee wasn't it a hot one, 39 degrees after a week long heatwave.

We had a great turn out of 42 people made up of 10 families with 14 kids and young adults. We all had a great day in our reserved area behind the Dragons Kingdom in a beautifully shady and cool area. Thank you to everyone who was able to make it. Now hear it out of the mouths of babes.....

Hi my name is Austin Tull. I am 7 years old and I went to adventure world with my family for the HFWA Christmas party. I really enjoyed playing in the water, especially the Wahoo speed slides because they went so fast and the water sprayed me. Other highlights were the water mountain mat slides and the rocky mountain rapids. Thank you to Father Christmas for giving me a present and the HFWA team for organising the day. *Austin Tull*



I really enjoyed the day it was so much fun and I loved the present that I made it about 2 hours ago it looked so good I loved it thanks for organising it.

Sayuri Moir



My name is Lewis and I am 10 years old. We went to Adventure World for the HFWA Christmas Party. My favourite activities from the day were the roller coaster, water slides and tube rides. They were fast and refreshing with the warm weather. Thanks for providing the lollies and drinks. The Christmas baubles were very cool and I look forward to putting them on my Christmas tree. We were very lucky to have a visit from Santa and got a fun present which I like. Thank you for putting on a fun day. *Lewis Tull*





HFWA Christmas Party contd..



Charlie, Madeleine & Freddie (below) loved the kids pool, the kiddie rides, they and their parents, Robin and Dom along with Grandie's Steve and Penny love the HFWA community. Seeing Hoho and Elf Darcy was a highlight . *Dique Family*



Finnick (right) loved Meeting Santa, helping with the presents and playing with the bubbles that were blowing. He enjoyed looking at all the rides and taking in the excitement of the surrounds. This was Finns second HFWA Christmas party.





Grit, Romi, Rubi and Bradley said that it is always great to catch up with everyone. They enjoy spending time with the HFWA team. They had a great day out but not the long queues. Overall the day was enjoyable and fun! *Andre family*



I had a good Chat with Santa who told me a lot of his secrets. He said there is no naughty list, and Rudolph is his favourite reindeer. I like how he gave me a present and pronounced my name correctly.



Ben and Brianna enjoyed the sunny weather. They went on the Goliath ride and then had a fun line ride waiting for their cooling frozen coke at the Kahuna Café. *Ben Ellis*



I liked today, it was a lot more entertaining than Outback Splash. I just enjoyed it overall and it wasn't too hot. *Liam*



Nice to see the young families here and it was a great spot. Nice and shady. *Neil Venn (Pop)*



I enjoyed going on the Kraken and lots of Awesome rides. *Phoenix Keogh*

My favourite ride was the Kraken and loved hanging out with my family *Aurora Keogh*



I had a bubble gum Ice cream and we swam in the big pool, I liked the little pool. The Pokemon cards, I LOVED them from Santa they are powerful cards. I give today 10/10. *Lucas*



The skull pool, I really liked that one, we went into it twice. I love dogs and I loved Santa's dog book that he gave me it was the best because I love dogs especially Border Collie dogs they are my favourite. *Isabella*





Did you know?

PROBE

Patient Reported Outcomes Burdens and Experiences Study

We need people without bleeding disorders to participate in PROBE, too!



💡 The 2023 PROBE Australia Study provides valuable data on the health and treatment experiences of people with haemophilia vs without a bleeding disorder.

Learn more: tinyurl.com/probe-study

@haemophiliafoundationaustralia

HOW TO DO THE SURVEY

The questionnaire is available:

Web version at myprobe.org

Or download the **myPROBE app** from Apple Store or Google Play (Android)

Or ask **your local Foundation** or HFA for a **print survey pack**

FOR MORE INFORMATION

Visit www.haemophilia.org.au/probe-study Or contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au T: 1800 807 173





Head to Health – connecting people to mental health support

Head to Health is a free Australian Government initiative that helps people to access the mental health and wellbeing services that are right for them. It comprises the Head to Health digital platform www.headtohealth.gov.au, the Head to Health Phone Service (1800 595 212) and a network of Head to Health sites (currently Midland, Gosnells, Mirrabooka and Armadale). Head to Health site locations can be found on their website.

Head to Health connects people with the help and support they need to access treatment and keep mentally healthy. It makes it easier to navigate and choose the most suitable care options, whether that's face-to-face, via phone or online.

It also makes it easier for GPs and other health professionals to support the mental health of the people they look after, and those who support them, through improving access to, and coordination of, mental health services in their local community.



Bleeding Disorders Resources at Perth Childrens Hospital: Clinic H

You may have noticed a new resource stand when attending Coag clinic at PCH; this has been donated to the HTC team for distributing the many resources on bleeding disorders. You can find a wide range of up-to-date books, pamphlets and more to take home. The resources available include Female Factors, Haemophilia Testing for Women & Girls, HFWA newsletters, Haemophilia booklet, Telling Others About Bleeding Disorders, and many more.

This stand was donated by the HFWA and set up by committee members who have been attending the clinics recently to meet new families.





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

email: office@hfwa.org.au or call: 9420 7294.

Jute Shopping Bag \$6.50

Red Shopping Bag \$3



Email your order for the shopping bags 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, simply scan the QR code (above) to go straight to the Square checkout 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**



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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.

[Containers for Change WA App](#)