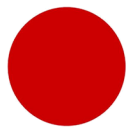


the
FACTOR



Haemophilia Foundation
Queensland

**SUMMER
EDITION**

Issue 77



DECEMBER 2023

HFQ MEMBER MAGAZINE

FROM THE PRESIDENT



I would like to introduce myself as the new President of HFQ, and thank outgoing President Shannon Gracey for stepping in as interim President in March this year.

I would also like to welcome former HFQ Manager Graham Norton back into the fold as the new Vice President, Chris Fullelove as the new Treasurer, Bernadette Staunton as a new board member, and welcome back the familiar faces on the board, including our tireless Secretary Tony Ciottariello.

It's also important to acknowledge the substantial contribution made by outgoing office holders; former Vice President Robert Weatherall, who served in that position since 2017, and Adam Lish, who has served as Treasurer since 2017, and previous to that was Vice President for four years.

While they may have left their 'formal' positions, I know Robbie and Adam will continue to contribute to the community in the years to come.

We have a wonderful program of activities planned for 2024, which includes another amazing winter function, regional outreach programs and continuing our fantastic support groups.

But of course while these activities are important, the core of the HFQ is to provide support and representation to anyone affected by haemophilia and other bleeding disorders and their families across Queensland. Myself, along with the board and Lauren and Sam in the HFQ office, are committed to ensuring HFQ continues to provide this support and representation. We exist for you, so don't hesitate to reach out to us.

Finally, a little bit about me.

I have been a HFQ board member since 2021, but my family connection to HFQ goes back over 40 years through my parents, John and Carol Wandmaker, who were instrumental in reinvigorating the then dormant HFQ in the late 1970's and early 1980's.

Indeed, as small child I was dragged along to many HFQ meetings, and as a teenager I attended the first two family camps in the late 1980's.

Speaking of family camps, the upcoming camp to be held at Sandstone Point Resort in March 2024 is already sold out, with over 140 people planning to attend. The 2023 camp, the first to be held at Sandstone Point, was a huge success, and I look forward to meeting many of you there next year.

Until then, thank you for the opportunity to lead the HFQ.

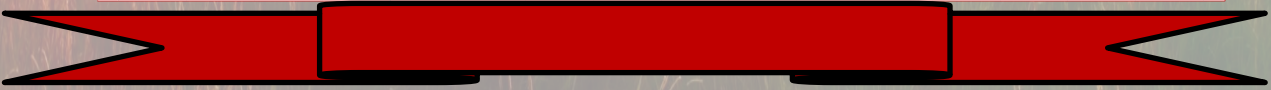
A handwritten signature in blue ink that reads "Shannon".

Shannon Wandmaker
President HFQ
president@hfq.org.au



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ABOUT HFQ

Haemophilia Foundation Queensland Inc. (HFQ) provides representation, health promotion, education and support for people in Queensland affected by inherited bleeding disorders. The Foundation receives a grant from Qld Health and employs a part time manager and an administration officer. It is guided by a Board of Directors which meets monthly.

We can be contacted on mobile 0419 706 056; or via email (info@hfq.org.au) or post at PO Box 30, Nundah, Qld 4012.

HFQ provides financial members with support and benefits, including subsidies on:

-  **Medic Alert bracelets (50% discount)**
-  **Electric Shavers (up to \$75 off)**
-  **Supportive footwear (75% off)**

HFQ Management Committee

President	...	Mr Shannon Wandmaker
Vice President	...	Mr Graham Norton
Secretary	...	Mr Tony Ciottariello
Treasurer	...	Mr Chris Fullelove
Members	...	Mrs Belinda Waddell
		Mr Charles Eddy
		Mr Adam Lish
		Mr Robbie Weatherall
		Ms Leah Emery
		Ms Bernadette Staunton

HFQ Delegate to HFA

Mr Adam Lish

Acknowledgements

HFQ is grateful for the support of our patron: Her Excellency the Honourable Dr Jeannette Young AC PSM Governor of Queensland.

HFQ programs and services are funded by the Queensland Government.

HFQ is also grateful for the support it has received from the Prescott Family Foundation.

Internet

Find us on the web at www.hfq.org.au or at our Facebook page at www.facebook.com/HFQLD

QLD HAEMOPHILIA STATE CENTRES

CHILDREN'S CLINIC

PAEDIATRIC CLINIC STAFF (QCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown – Haematologist
 Dr Nathan Morgan – Haemophilia Fellow
 Joanna McCosker – Nurse Practitioner
 Tamara Shannen / Salena Griffin – Clinical Nurse
 Claire Bennett (Mon, Tues, Wed) - Physiotherapist
 Elise Mosey (Thurs, Fri) – Physiotherapist
 Tiara Tan - Psychologist (Mon 1/2 day, Wed, Thurs)
 Lara Nicholson—Social Worker (Mon, Tues, Wed)

Contacting the Clinic - Please call the Haemophilia mobile for urgent enquiries on 0438 792 063 (office hours 8 – 4pm).

For all non-clinical/non-urgent enquires please email QCH-Haemophilia@health.qld.gov.au

After hours— call switch and ask to speak with on-call haematology consultant or present to the emergency department

Appointments — Outpatient Bookings Office on 1300 762 831 or email QCH-Outpatients@health.qld.gov.au

Your health care team does not make these bookings or any changes to your appointments. Referrals can be sent to the Referral Centre Fax Number 1300 407 281

Haemophilia Outpatient Clinic — Dr Simon Brown — held in 3c outpatients Level 3, Thursday afternoons 1.00 – 3.30pm

Haemophilia Carrier Clinic – as needed Thursdays 1pm – 3.30pm

ADULT CLINIC

ADULT CLINIC STAFF (RBWH)

Switch: 07-3646 8111

Dr Jane Mason - Haematologist	3646-8111
Dr Sally Campbell - Haematologist	3646-8111
Haemophilia Registrar	3646-8111
Beryl Zeissink - Clinical Nurse Consultant	3646-5727
Alex Klever - Clinical Nurse Consultant	3646-5727
After Hours - Page Haematologist	3646-8111
Natalie Karlovic - Physiotherapist	3646-8135
Joanne Bidgood—Social Worker	3646-8111

Contacting the Clinic Please telephone in the first instance. Appointments 3646-7752 or 3646-7751

For all non-clinical/non-urgent enquires please email RBWH-Haemophilia@health.qld.gov.au

Haemophilia and Genetic Clinic — Dr Jane Mason — Wednesdays 1.30pm New Patients Thursdays 8 - 9.30am

Haemophilia/Orthopaedic Clinic — Dr Jane Mason and Dr Brett Halliday — 9am every four weeks

OUTREACH CLINICS

Gold Coast Hospital, Toowoomba General Hospital, Nambour Hospital, Cairns Base Hospital & Townsville Hospitals: For queries email CHQ-Haemaphilia@health.qld.gov.au at QCH

What's On?

DECEMBER 2023 - MARCH 2024



1ST DEC

World Aids Day

7 TH DEC

Bunnings Rothwell Community Event
6pm to 8pm

10TH DEC

Mens Group Christmas Lunch
Norman Hotel

25TH DEC

Merry Christmas to our Community

22 DEC - 2 JAN

HFQ Office Closed

NO EVENTS IN JANUARY

7 TH FEB

Men's Group Lunch
Easts Leagues Club

18TH FEB

Women's Lunch
Venue TBA

20TH FEB

HFQ Board Meeting
Online

14TH MAR

Toowoomba Outreach Clinic
Toowoomba Hospital

22ND - 24TH MAR

Community Camp
Sandstone Point Resort

19TH MAR

HFQ Board Meeting
Grange Library

YOU'RE INVITED TO

Men's Support Group (OBES) Christmas Lunch

10 | at 12 PM
December | Norman Hotel
102 Ipswich Rd,
Woolloongabba

RSVPs are essential on 0419 706 056 by 2/12/23

Getting to know.....

Joanne Bidgood has recently joined the Haemophilia Centre team at the RBWH as the Social Worker. We thought it was the perfect opportunity to introduce her to our community. Be sure to say hello if you spot her at your next clinic visit!

Tell us a bit about yourself. Where were you born, what hobbies do you have outside of work?

I was born in Adelaide but have lived in Brisbane for the last 20 years.

My hobbies are walking, swimming, reading books and I love all sport, particularly cricket!

What drew you to social work as a career choice?

I initially thought I wanted to be a teacher and whilst completing my teaching degree I undertook volunteer work at a hospice in Adelaide. One of the hospice staff was a Social Worker and it was after meeting her and hearing about the work she did that I realised Social Work was the career for me.



Can you tell us a bit about a typical day working as a social worker?

I currently hold several Queensland Health jobs so my day always look a bit different depending on which role I am sitting in. My days generally involve coming in and checking emails / responding to any urgent matters, attending MDT's, receiving referrals

and prioritising work. It may involve providing emotional support to patients and families, helping with service navigation, advocacy work, providing information, networking with relevant agencies. Providing training and education.

What have been the highlights of your career?

I lived in London for 10 years and was able to work as a Social Worker in a range of settings, including Child Protection, Adoption and Fostering, Family Support work. I immensely enjoyed working in such a large and culturally diverse city.

Joanne Bidgood



What accomplishment are you most proud of?

Apart from being a mum of 2 boys, I have to say it would be the satisfaction of doing a job that I find personally and professionally rewarding.

What have been the challenges?

Alongside my role in the Haemophilia Centre, I work in the Bereavement space. It can be very challenging to work in the grief and loss space at times, but it is also an area that I feel very passionate about.

What is one piece of advice you would give to families facing a diagnosis of a bleeding disorder?

I have learnt over the years that people and families are incredibly resourceful and are the experts in their own life. I am constantly amazed at the level of resilience people show despite adversity.

If you could possess one super power, what would it be?

I would love to be able to fly. It just looks fun!



The ducks enjoying the duck pond at the end of Jo's property.

80's Trivia Night



On Saturday 14th October, HFQ hosted it's inaugural fundraising trivia night at Arana Leagues Club.

We went back to a time of leg warmers, neon and big hair to throw an 80's themed extravaganza. The event was attended by over 140 people and everyone had the best night.

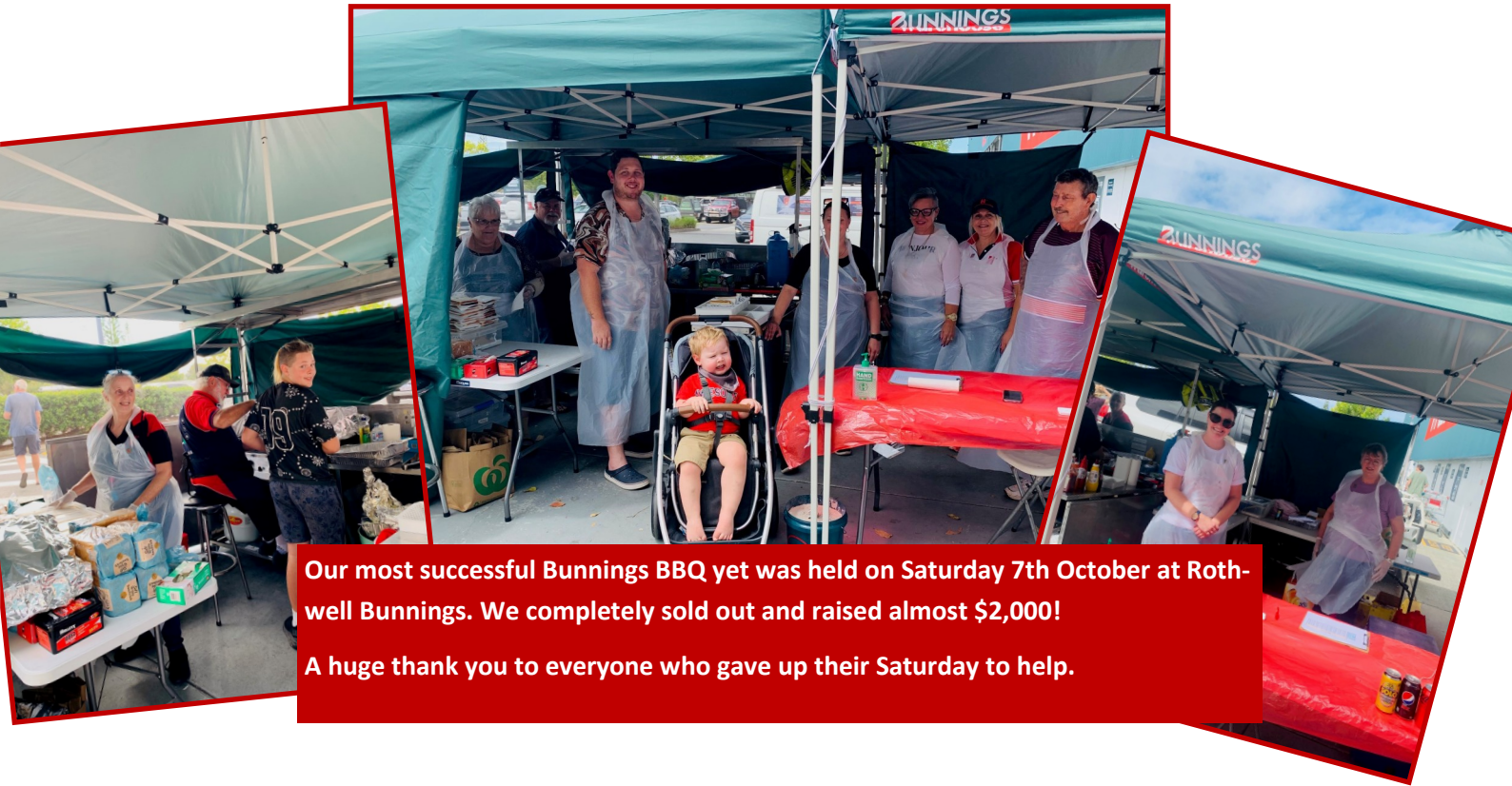
In addition to a fun night for the general community and our members, we also drew our fundraising raffle and the night also raised over \$4,000! This will go towards our events in 2024 so stay tuned for some exciting announcements in coming months.

The night would not have been possible without our wonderful sponsors; Vanguard Health, Greeny's Plumbing Solutions & Cr Vicky Howard. A special thanks also needs to go to John & Narelle Bardsley who volunteered their trivia hosting skills to run the evening for us.

The HFQ team are already getting stuck into planning the next trivia



BDAM Round Up

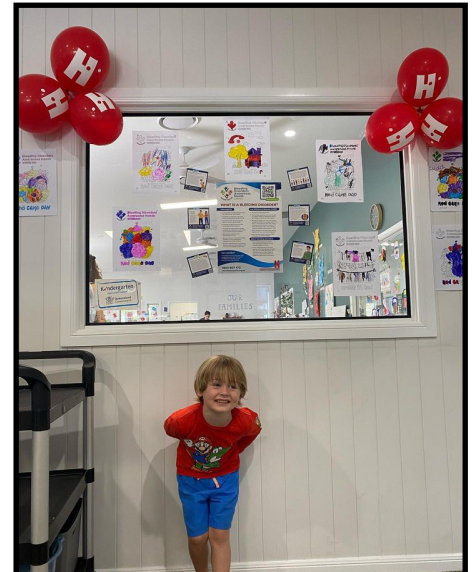


Our most successful Bunnings BBQ yet was held on Saturday 7th October at Rothwell Bunnings. We completely sold out and raised almost \$2,000! A huge thank you to everyone who gave up their Saturday to help.

We were hosted again this year for a reception at Government House to kick off Bleeding Disorders Awareness Month. This year it was held on Tuesday 5th October and was a 'Thank You GP's' event to thank those who help our community members. The Honourable Dr Janette Young presented Tony with his HFA Volunteer Award with Natasha Coco from HFA. Everyone even got a delicious BDAM cookie to take home!



Fundraising Champions!



Huge thanks to Tommy Bowdler (and his mum Lisa) who organised not one, but TWO fund and awareness raising stands during BDAM. Thank you to Mother Duck Kallangur and Dolphins Fitness & Aquatic Centre at Redcliffe. Awesome work Tommy & Lisa!

Murphy planned a BDAM display at his kindy to raise awareness. Great work Murphy!



The wonderful psychsocial team at QCH put on a free cupcake stall in the foyer to raise awareness for BDAM. They also had a display of the excellent HFA resources and activity sheets.

Thank you QCH team!

Courageous Conversations

8 year old Lachie Eddy - son of board members Shannon and Charles has a chat to his dad about having mild haemophilia.

Tell us about your haemophilia?

I have mild haemophilia A. I was diagnosed when I was born. Mum has haemophilia as well, so they knew I might have it.

Have you ever had any problems with bleeding?

Yes. I have had tummy bleeds, joint bleeds, a few knocks to the head and some pretty crazy bleeding in my gums and teeth. The tummy bleeds I had when I was little were really bad. Cause I'm only mild I have to go to the hospital every time something happens and get factor.

Do you remember much about your tummy bleeds?

I don't remember too much because I was pretty little. I know that it was pretty bad. Mum and Dad said that it got really serious and I was in intensive care a couple of times. Dr Simon said that even though I'm mild I bleed like a severe. I remember it being really hard to give me the factor and blood transfusions.



What is living with haemophilia like for you now?

It's mostly alright, but I do think about it a fair bit. I try to be careful, and there's some stuff I don't do. I know I can't really play rough sports, so I have to find other things to do at school when my friends are playing football and soccer. I still have some problems though.

Like what?

I was trying to jump over a bench with my friend at school and I slipped and smacked my face on the bench.

What happened?

I had a lot of blood and felt woozy. I went to the office and they called mum and dad. They came straight away and went straight to the hospital to get some factor. I had to go to the dentist to see how bad it was. I had a crack in a tooth and my gums were pretty messed up.

Then a week later I woke up in the middle of the night with blood all through my mouth and all over my pillow. I had to go straight to hospital for some more factor.

Are you worried about having to go into the hospital to get factor if you hurt yourself?

Very very very.



Lachie's Journey with Mild Haemophilia

What is it that worries you?

Because it hurts a little when I get the factor, but I know that I have to get it. I hate the numbing cream too, so I've stopped having it now.

What's something you wish everyone knew about having haemophilia?

That sometimes I have to be careful, and if I get hurt, or someone hurts me, that it can be bad and I'd have to go to hospital.

Do you think HFQ is important?

Yes, a whole lot. If HFQ wasn't here people wouldn't know about haemophilia and we wouldn't be able to help people. I really love it when the Story Bridge and other places in the city get lit up red so I can tell my friends about it.

What's your favourite HFQ activity?

The HFQ camp. There's events, and we get to go away and stay in cool places. I also get to see some friends I made who have haemophilia too.



A note from Charles:

Lachie is extremely resilient and has been through quite a bit. We are super proud of how he takes everything in his stride and remains positive.

Even though Lachie is clinically mild, he has had some really extreme and serious bleeding. Some recent tests have suggested that he might actually be more on the borderline between mild and moderate, and this is something we are looking into. When Lachie first had his gastro bleeding, everyone thought there's no way it could be as bad as it was.

It's really important to recognise that everyone experiences haemophilia differently, so don't hesitate to reach out to our awesome HTC's if you have any concerns.





HFQ Community Camp for 2024 is now officially **SOLD OUT!**

We have opened a waiting list so if you missed out this time, please contact us on info@hfq.org.au and we will add your name to the waiting list should anyone attending cancel. We are also keeping in touch with Sandstone Point Resort to snap up any extra villas that become available between now and March.

Thank you so much for your support of our Community Camp. We can't wait to go even bigger and better next year.

A GENE THERAPY Experience

Hundreds of years after haemophilia was first discovered, a new medication that was successfully tested on a Fort Collins man could be an answer for those living with Hemophilia A. Andrew Schulz, a 36-year-old in northern Colorado, was one of 112 participants in a trial for Roctavian, a medication that recently secured FDA approval.

Schulz was born with haemophilia, a disorder that prevented his blood from clotting. Since his youth he has been giving himself injections to help combat the symptoms of the disorder. "I've estimated 3,000 shots I've given myself," Schulz told CBS News Colorado's Dillon Thomas.

Schulz, like many others living with haemophilia, was raised taking many precautions when it came to protecting his physical health. Doctors limited his ability to participate in physical activities and sports that could cause bruising or bleeding. "If I would get bumped I would just keep bruising," Schulz said. "I had ankle problems, I couldn't run a mile and things like that."

For decades Schulz had to carry medications with him, injections that would help him avoid bleeding and bruising. He said it was a burden to have to carry the medications on flights, and to have to take the shots before going to events like concerts.

However, he recently heard about a trial taking place in St. Louis. A medical company was testing a medicine called "Roctavian," a single infusion gene therapy that was believed to help stop most of the symptoms of Hemophilia A.

Schulz signed up for the trial and was given the one time infusion.

"It essentially cured me of haemophilia," Schulz said. "I went from this cadence of a shot three times a week, traveling with needles, to no shots."

It has been years since Schulz participated in the trial. Like most others in the research, he has been able to move on with life without needing his regular medications. "My whole lifestyle has shifted because of that," Schulz said. "For 30-something years of my life I realized I had a negative outlook on my health."



Thanks to trial participants like Schulz, the FDA has now approved the medication and the first and only gene therapy to combat Hemophilia A.

Because he was a participant in the trial, the medication and treatment was free. Schulz said he was hopeful that others would have insurance that could help them receive the same

level of care without breaking their banks.

Schulz said his life has dramatically changed since receiving the infusion. "I started hiking, building up my muscle and reclaiming this body," Schulz said.

Schulz is now able to be more active with his wife and three children, and is moving on with a healthier life free of concerns from his haemophilia.

"That was just amazing. I just was breaking through ceilings I thought were always going to be there," Schulz said.

Article adapted for size. Original source: ["Essentially cured," Fort Collins man with Hemophilia A successfully tests lifechanging medication - CBS Colorado \(cbsnews.com\)](https://www.cbsnews.com/news/essentially-cured-fort-collins-man-hemophilia-a-successfully-tests-lifechanging-medication/)

2024, here we come!

In 2023, the HFQ Board and staffing went through some big changes so we wanted to spend the year connecting with our members and really listening to what they want and need from us as an organisation.

We have heard all of your feedback and wanted to give you a little sneak peek into what we are planning for the new year. We always welcome feedback and suggestions on the best ways we can serve you as our community, so please do not hesitate to call, email, or message us on our socials to let us know how we can improve, or share any great ideas you have for events!

We are booking in many regional outreach clinic visits, a Toowoomba event in September, another great winter event in June and many exciting things planned for Bleeding Disorders Awareness Month, as well as a Community Christmas Party in November!

**Welcome to our
New HFQ Board**

TONY CIOTTARIELLO
SECRETARY

ADAM LISH

BELINDA WADDELL

SHANNON WANDMAKER
PRESIDENT

ROBERT WEATHERALL

CHARLES EDDY

LEAH EMERY

SHANNON GRACEY

CHRIS FULLELOVE
TREASURER

BERNADETTE STAUNTON

GRAHAM NORTON
VICE PRESIDENT

H Haemophilia
Foundation
Queensland

Did you know?



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



FREE

Join your local Bunnings Christmas Family Event

7th December 6pm to 8pm

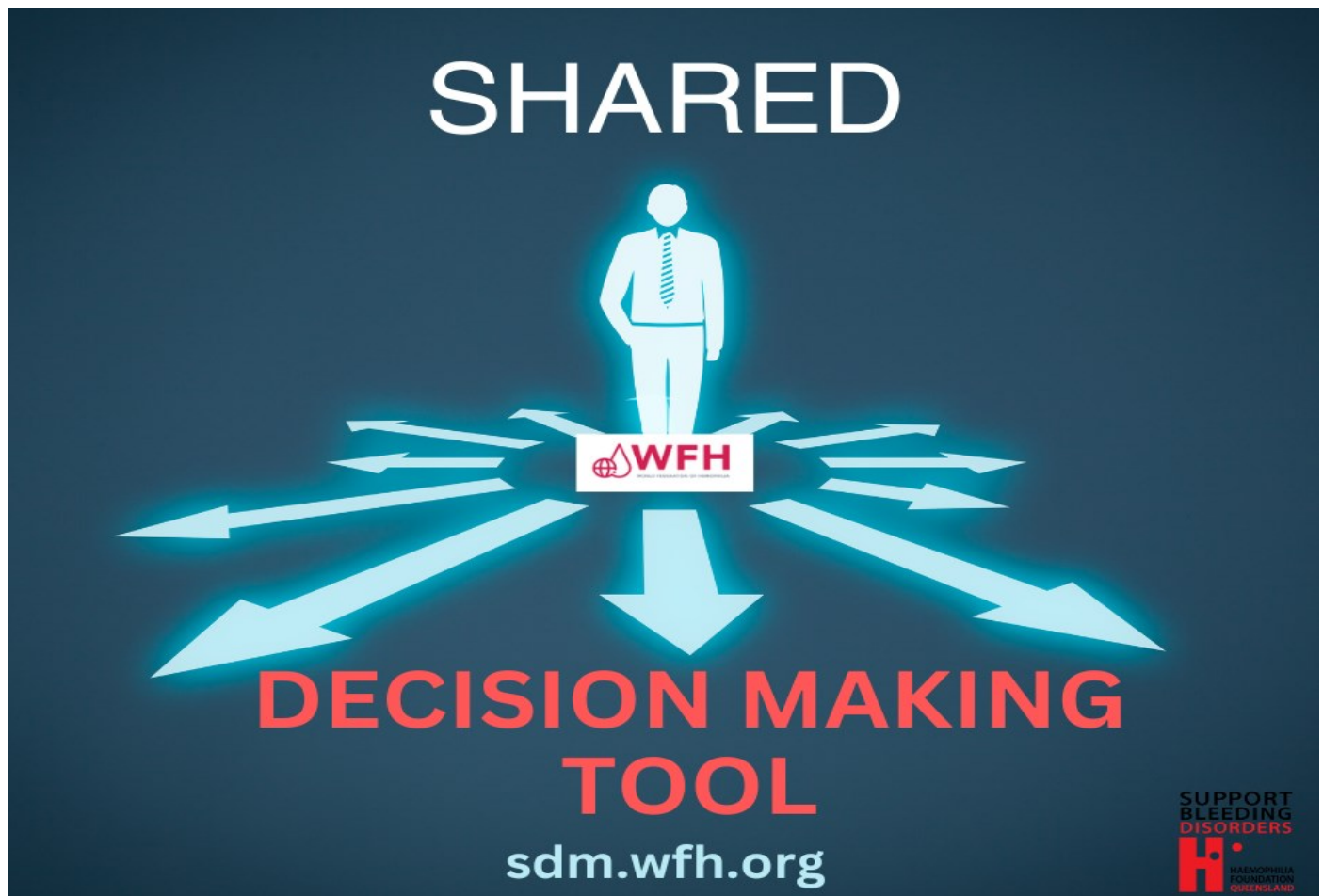


BUNNINGS ROTHWELL
Cnr Anzac Ave and Bremner Road
Rothwell 4022

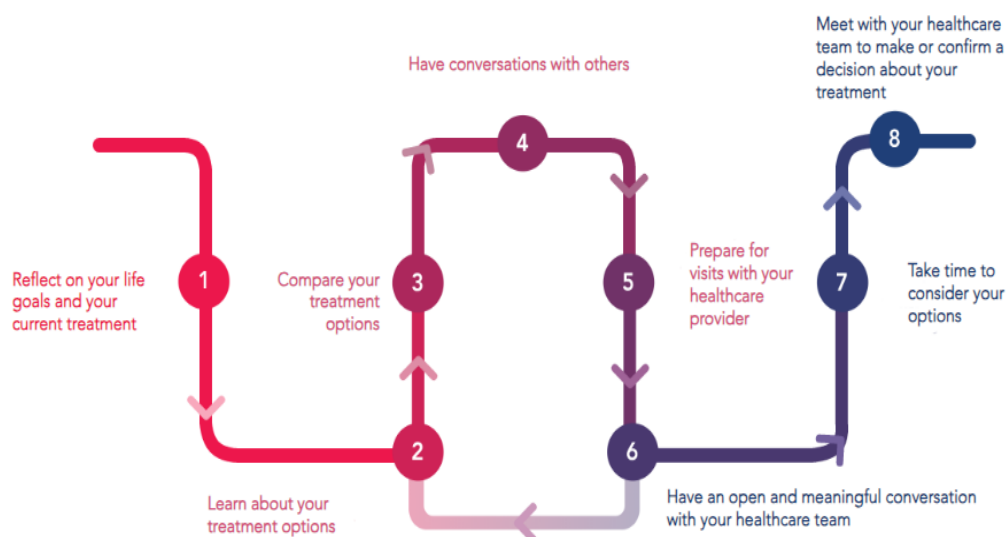
DON'T miss it!

Sausage Sizzle, Games, Craft Tables, Hot Rods, Santa visit, Live Music, Wildlife Unleashed, Face Painting, Giveaways & More!





This tool was designed to guide and support people with hemophilia A or B and/or their caregivers in gathering information so that they can have more meaningful and collaborative conversations with their healthcare team. After using this SDM tool and talking with your healthcare team, you may decide to remain on your current treatment, modify your current treatment, change to a new treatment, or continue learning about your options. The tool can be found at www.sdm.wfh.org





Happy Holidays

*WISHING ALL OF OUR WONDERFUL
MEMBERS A VERY MERRY HOLIDAY
SEASON FILLED WITH LOVE,
LAUGHTER AND TOO MUCH FOOD!*

***FROM LAUREN, SAMANTHA
& THE HFQ BOARD***



What is PROBE?

What is the impact of haemophilia on Australians? What has changed since new treatments became available? What about people with mild haemophilia and women?

HFA has joined with the international **PROBE (Patient Reported Outcomes Burdens and Experiences)** study team (www.probestudy.org) in a multi-national and well-respected research study to provide strong and credible data about this for our advocacy.

The study compares the answers of people with haemophilia and who carry the gene to other people in their community who do not have a bleeding disorder.

You may have done the PROBE survey in 2019. This is a new round of the survey.



The 2023 round will compare results now to 2019, which was before new treatments were widely available in Australia.

How Can You Help?

You are invited to complete the questionnaire if you are **an adult (18 years+) who lives in Australia** and:

have haemophilia or carry the gene OR do NOT have a bleeding disorder.

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

Choose **Country-Australia** and **Language-English** and **CONTINUE**. The web and app surveys automatically save answers as you go so you can come back later.

What Happens To Your Data?

The survey is voluntary. All responses are anonymous and confidential. They are combined for statistical data and will not identify

individuals. You may have seen the 2019 data in the HFA Getting Older report.

More Information:

For more information about the **PROBE Australia study**, visit www.haemophilia.org.au/research

Or contact Suzanne at HFA:

E: socallaghan@haemophilia.org.au

T: 1800 807 173



**WE
WANT
YOU!**

Want to be featured in our magazine?

**We want to make the H Factor more about
our wonderful members.**

**Do you write poetry? Create beautiful
artwork? Recently travelled somewhere
amazing? Have a fabulous recipe?
We would love to celebrate our members in
our magazine.**

**Send it to us at info@hfq.org.au with the subject line
'Magazine Contribution'**

About The H' Factor

The 'H' Factor is published four times each year by HFQ by the HFQ manager. We occasionally send important information and updates on local and relevant events for people affected by bleeding disorders to subscribers of our email list. If you would like to be on the HFQ Email List, please register your interest by sending through an email with the subject title The 'H' Factor email list' to info@hfq.org.au. You can be removed from the list at anytime.

Disclaimer: All articles, advice and information included herein are written by various individuals who volunteer their input. While the 'H' Factor magazine puts every effort into providing honest and accurate information and where possible, reference to research articles are made to validate content, it cannot be held liable for any errors or inaccuracies in published articles. The views expressed in this newsletter are not necessarily the opinions of the Editor, nor HFQ, their associates or supporters. Original contributions and letters are welcomed and encouraged, but publication of contributions will be at the discretion of the Editor. Articles in the 'H' Factor cannot be reproduced without permission.

Lauren Green

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