the H FACTOR

Haemophilia Foundation Queensland

WINTER EDITION

Issue 75

JUNE 2023

HFQ MEMBER MAGAZINE

FROM THE PRESIDENT

Hello Everyone.

I would like to introduce myself as the new President of HFQ.

As many of you are aware, David Stephenson recently made the difficult decision to step down from the President's role after many years at the helm. Firstly, I would like to thank David for his dedication and tireless work for the bleeding disorders community and also wish him well in his retirement. I am grateful for the chance to continue his great work and provide support to our amazing community.

I am really excited to step into the President's role. I have been a member of the board for the past 5 years and have life long experience in dealing with bleeding disorders. My grandfather unfortunately passed away from bleeding issues just before prophylaxis treatment became available for Haemophilia A. My mother as well as myself and my eldest son all have Haemophilia A.

Along with providing support to all of our members, I am extremely passionate about women with bleeding disorders as well as helping newly diagnosed families and anyone with a family history navigating the sometimes daunting process of starting a family.

I feel privileged to be a part of such a supportive and inclusive community. We have had some amazing events recently, notably our community camp, which based on your feedback will now be moving to an annual event! If you would like to volunteer or have any ideas for future events, fundraising opportunities, or ways to bring our community together then get in touch with Lauren and Sam - we are always happy to hear from you!

It has been amazing to be part of such a cohesive and dedicated group of staff, volunteers and board members through the recent changes and I am so excited for our future with new events, fundraising and opportunities for connection all over Queensland in the pipeline.

I can't wait to see you all in the not too distant future!

Shannon Gracey
President HFQ
president@hfq.org.au

Inside this Issue:

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	... ...	Ms Shannon Gracey
Vice President	...	Mr Robert Weatherall
Secretary	... ...	Mr Tony Ciottariello
Treasurer	... ...	Mr Adam Lish
Members	... ...	Mrs Belinda Waddell
		Mr Charles Eddy
		Dr Jodie Caris
		Mr Shannon Wandmaker
		Mr Chris Fullelove
		Ms Leah Emery

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 (Thur, 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
(Page Dr's through switch)	
Haemophilia Registrar	3646-8111
(ask to page Haemophilia Registrar on 42177)	
Beryl Zeissink - Clinical Nurse Consultant	3646-5727
Alex Connolly - Clinical Nurse (Part time)	3646-5727
After Hours - Page Haematologist	3646-8111
Liam Ball - Physiotherapist	3646-8135
Vacant - Senior Social Worker	

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?

MAKE IT YOUR EVENT

June - August 2023

Some of the HFQ programs and activities already planned

Please call the office for other events, more information or to RSVP

JUNE

Men's Monthly Lunch
Wednesday 7th June
Old Fernvale Bakery Café

HFQ Board Meeting
Tuesday 20th June

JULY

Joint Men's & Women's Event
Wednesday 5th July
Captain Burke Park

HFQ Family Winter Event
Sunday 16th July
Lone Pine Koala Sanctuary

HFQ Board Meeting
Tuesday 18th July

AUGUST

Men's Monthly Lunch
Wednesday 2nd August
Broncos Leagues Club

Women's Lunch
Sunday 6th August
Hamilton Hotel

Brisbane EKKA Public Holiday
Wednesday 16th August

HFQ Board Meeting
Tuesday 15th August

HFA Conference 2023
Thursday 24th—Saturday 26th August
Pullman on the Park, Melbourne

COMMUNITY FUNDING

The Conference is coming up soon and HFQ would love to see you there. If you require financial assistance to attend please let us now. We have allocated funding to help you attend. Please complete and submit your application asap. Go to our website or call us on 0419 706 056.

Getting to know...

Any of you who have been around the Treatment Centre at Royal Brisbane Women's Hospital in the last few years, would be very familiar with the warm smiling face that is the subject of our latest profile; Dr Jane Mason.

Dr Mason was kind enough to give up some of her very precious spare time to answer a few of our questions so we can all get to know her a little better outside of the clinical setting.

Jane is well known for her dedication to the bleeding disorders community and is always going above and beyond to provide the highest level of care, including being an integral part of the process of getting gene therapy trials in Queensland for Queensland patients, and even teaching herself to self-infuse with saline so she could better understand what her patients were going through!

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

A: *I was born and raised in Brisbane. I grew up in Gumdale (Southside) and loved running around the family acreage and paddling an inflatable raft in our (pretty murky) creek.*

I was a very keen gymnast as a child/ teenager and still follow the sport now. It definitely gets more difficult to do tricks with age though….I can only just manage a handstand now! My life outside work revolves around my young family. I have 4-year-old twins and a 1-year-old baby – all boys! I can tell you it is quite grounding hearing from the 4-year-olds about all the things I'm doing wrong each day….

Q: What drew you to medicine as a career choice?

A: *I was always very keen on science at school and liked the idea of combining this interest in a job where you got to meet lots of interesting people and hear their stories. Growing up and seeing my parents worry about money, I also really wanted to do something with relative career stability.*

Q: What have been the highlights of your career?

A: *A major highlight has been taking part in the journey of gene therapy from a pipe dream to reality. We have taken part and will continue to take part in gene therapy dosing studies in haemophilia A and B in QLD. There were considerable logistic / accreditation hurdles we faced to set this up but were determined that eligible QLD patients shouldn't have to travel to Sydney or Melbourne to participate in these studies. There is obviously more work to be done to better understand why people respond differently and this therapy is not yet suitable for everyone - but it gives me great hope for the future.*

Q: What have been the challenges?

A: *I'd have to say the balancing act is the main challenge! I have quite a few hats career wise, as well as having oversight of the Adults HTC, I also work in the RBWH laboratory and as a Paediatric Haematologist at the QLD Children's Hospital. Our HTC is very active in research to try and further the bleeding disorders field, but research activities are generally not well resourced in public medicine, so a lot tends to be done in our own time.*

Q: Who was the biggest influence in your career?

A: *I have a few, it is hard to name just one. Obviously locally Dr John Rowell taught me a great deal about Haemophilia care and his commitment to the community was inspiring. Internationally I look up to Haemophilia treaters Dr Paula James and Dr Flora Peyvandi.*

...Dr Jane Mason

Q: What have been the biggest changes you have seen in your time working with people with haemophilia?

A: *I think access to less frequent prophylaxis options that give people the ability to participate in life and physical activity without fear of bleeds. Improved access to longer lasting (extended half-life) factor products was a good step that enabled many of our patients to achieve better protection with fewer needles. More recently access to new non-factor therapies (Hemlibra) has been a game changer for people with moderate or severe Haemophilia A. Someone once said to me about being on Hemlibra: "It's like Haemophilia now only occupies a tiny part of my back brain….rather than weighing heavily on my mind all the time. I no longer fear waking up with a bleed". That definitely resonates with us at the HTC. With improved prophylaxis options we are seeing very few significant bleeds compared to the past.*

Q: What advice would you give to patients ageing with haemophilia?

A: *Find yourself a good GP that you connect with! Advances in haemophilia therapy mean that in general your life-expectancy is the same as your peers who don't have haemophilia. All those things (eg high cholesterol, high blood pressure, diabetes) that can crop up as we age can and do happen to people with haemophilia and it's essential to make sure your GP is in your corner with regard to routine health screening/ preventative measures. I would encourage everyone ageing with a bleeding disorder to stay active as much as possible – strong muscles help protect joints. I would also encourage anyone over the age of 50 with haemophilia to have a bone mineral density scan done through their GP. There is some emerging evidence that people with haemophilia may be at risk for earlier onset osteoporosis (low bone density) and it is important to pick this up early if present as there are treatment options to help strengthen bones.*

Q: What accomplishment are you most proud of?

A: *I'm quite proud of the "Hub and Spoke" model of haemophilia care that exists in QLD and the expansion of our telehealth service. Geographically QLD is quite huge and it is important that patients living rurally/ remotely/ regionally don't get left behind. We have identified a number of regional Haematologists that have a special interest in bleeding disorders that are willing to collaborate with us at the HTC to deliver some haemophilia care locally. This means that some procedures/ surgeries can be safely undertaken closer to home, with the local Haematologist on the ground/ appropriate factor support pre-arranged and the HTC touching base by phone each day. For many patients this is much better than upheaving their life to stay in Brisbane for surgery and recovery. The expansion of our telehealth service means that we can link into a patient virtually in their own home (using their smartphone or laptop). We have reconnected with remote patients that hadn't been seen by the service for many years. The use of telehealth has particularly been useful for our physiotherapist, who uses it frequently to assess and follow up progress after bleeds.*

Q: What drew you to haematology specifically?

A: *I loved the "bedside to lab bench" aspect of it. It is very rewarding to see a patient in clinic and then head to the lab to look at their blood film or interpret their complex coagulation testing myself.*

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

A: *Hmmm that is a tricky one! I would love the ability to be in two places at once! Or to slow down time. The balancing act of work and home life is always challenging. My kids ask me hopefully every day "Is it the weekend Mummy?" as they know they hardly get to see me on weekdays.*

On behalf of everyone in the bleeding disorders community, HFQ would like to thank Dr Mason for her years of service and dedication.

HFQ hosted it's Community Camp on the weekend of 10th—12th March. This was our first year at a new venue, Sandstone Point Big4 Resort. The new venue was met with overwhelmingly positive response from the community and was our highest attendance ever with 110 people in attending over the weekend!

We have already booked in for Community Camp 2024. Registrations will open in September 2023, so keep your eyes peeled for more information in our coming magazines and on social media.

Bleeding Damage Common in Paediatric Haemophilia DESPITE PROPHYLAXIS

Although prophylaxis is the gold standard of treatment for children with Haemophilia, a new report highlights the need to vigilantly monitor patients for signs of "hidden" joint damage.

The ankles are an area of particular concern, according to the authors of a new study published in *Thrombosis Research*.

Haemophilic arthropathy is the most common complication of haemophilia, wrote the study authors. In many cases, arthropathy leads to disability and diminished quality of life.

Primary prophylactic infusion of coagulation factor is used to prevent joint bleeding and bone damage. However, despite prophylaxis, some patients still develop joint damage, suggesting that subclinical bleeding is relatively common.

"It usually manifests as joint discomfort, which disappears with the new dose of replacement factor," they wrote.

Previous research shows that MRI can detect joint damage in children without a known history of joint bleeding. The problem, the authors said, is that MRI is not routinely used in daily clinical practice.

They wanted to better understand the problem of hidden joint damage in children and to analyse whether certain age groups or certain joints were more prone to damage. They recruited 106 patients with severe haemophilia who were taking prophylaxis and who were between the ages of 2 and 18 years. Eighty-eight percent of the participants had haemophilia A; the rest had haemophilia B. The investigators evaluated the participants' joints and conducted follow-up examinations at their clinic.

Primary prophylaxis is defined as regularly scheduled prophylaxis designed to prevent bleeding. Secondary prophylaxis is administered after a patient has experienced joint bleeding.

In the study, 59 participants were on secondary prophylaxis, while 47 participants were taking primary prophylaxis.

Of 636 joints evaluated, about a quarter (163 joints) had at least 1 joint bleed. The most frequent site of joint bleeding was the ankle (48.5%), followed by the elbow (27.6%) and the knee (23.9%).

In terms of joint damage, the investigators found it occurred more frequently in patients on secondary prophylaxis. While just 21.3% of participants on primary prophylaxis had joint damage, 72.9% of participants on secondary prophylaxis had joint damage. Joint damage was defined in the study as having a Hemophilia Early Arthropathy Detection with Ultrasound score of at least 1. On the other hand, the investigators said people on primary prophylaxis had a greater number of damaged joints at older ages. Participants 11 years and older had a greater frequency and degree of arthropathy. They said cartilage was most frequently involved in joint damage, followed by synovitis and bone damage.

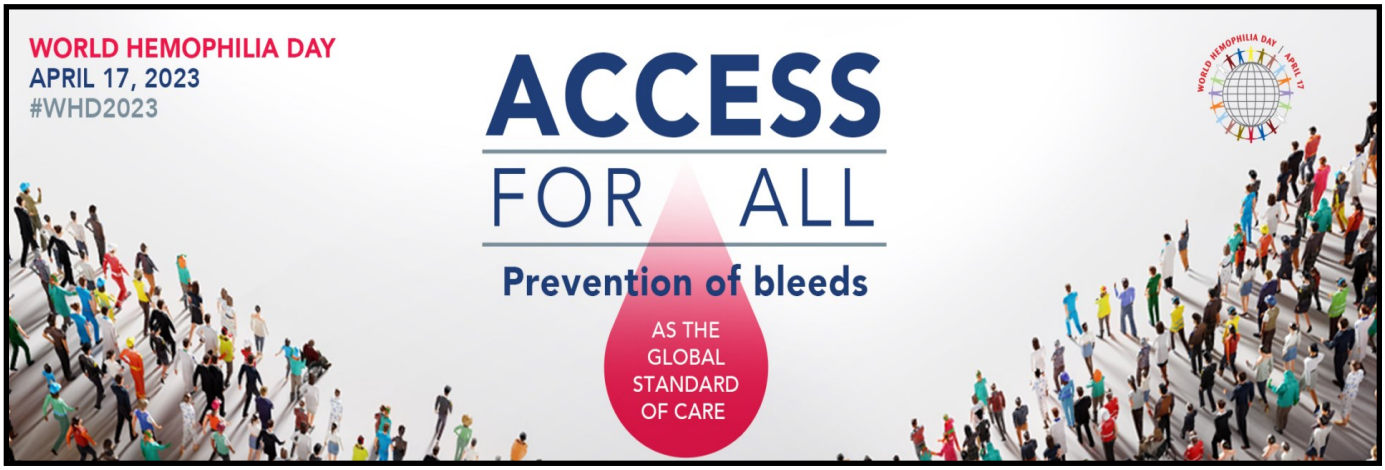
The investigators said their study shows that although prophylaxis is the best treatment for children with haemophilia, it does not prevent joint bleeding, symptomatic or otherwise.

"The routine evaluation of joint health is relevant, particularly of the ankle," they concluded.

They added, however, that their research aligns with previous studies suggesting ultrasound is a reliable method by which to detect early signs of arthropathy.

Reference

Daffunchio C, Galatro G, Faurlin V, Neme D, Caviglia H. The hidden joint in children with haemophilia on prophylaxis. Thromb Res. 2023;226:86-92. doi:10.1016/j.thromres.2023.04.012 *Article sourced from htpps://www.ajmc.com/view/bleeding-damage-commin-inpediatric-hemophilia-despite-pophylaxis*



This year, to celebrate World Haemophilia Day 2023, HFQ organized for a record number of landmarks to 'Light It Up Red' in Queensland.

We've included some pictures of the landmarks sporting their beautiful red glow to help raise awareness for those living with bleeding disorders.

Bleeding disorders & Endometriosis

Endometriosis and bleeding disorders are two distinct medical conditions that have been independently studied for years. However, recent research has brought to light a fascinating connection between these seemingly unrelated conditions.

Shared Mechanisms:

Endometriosis is a chronic condition where the tissue lining the uterus, known as the endometrium, grows outside the uterus, causing pain, inflammation, and infertility. Bleeding disorders, on the other hand, encompass a range of conditions characterized by impaired blood clotting, excessive bleeding, or both. While their primary mechanisms differ, studies have uncovered shared pathways that contribute to the interplay between these two conditions. One prominent connection lies in the impairment of blood coagulation. Endometriosis lesions release pro-inflammatory molecules, which can disrupt the clotting process and result in prolonged and excessive bleeding during menstruation. Simultaneously, bleeding disorders, such as von Willebrand disease or platelet function disorders, can exacerbate the abnormal bleeding experienced by women with endometriosis. The combined effect of these conditions can further perpetuate inflammation and the formation of endometriotic lesions.

Implications and Challenges:

The link between bleeding disorders and endometriosis carries several implications for affected individuals. Firstly, women with undiagnosed or poorly managed bleeding disorders may experience heightened pain and excessive bleeding during menstruation, potentially masking the underlying presence of endometriosis. This can lead to delayed diagnosis, inadequate treatment, and a prolonged period of suffering.

Additionally, the coexistence of these conditions can pose challenges during surgical interventions, as abnormal bleeding and impaired clotting may complicate procedures, necessitating specialized management strategies. It is crucial for healthcare providers to be aware of this association, ensuring comprehensive preoperative assessments and the involvement of multidisciplinary teams for optimal patient outcomes.

Early Diagnosis and Comprehensive Management:

Recognizing the interplay between bleeding disorders and endometriosis is paramount for timely and accurate diagnosis. Women with suspected or confirmed endometriosis should undergo a thorough evaluation of their bleeding history, including inquiries about excessive or prolonged bleeding, easy bruising, or a family history of bleeding disorders. Laboratory testing, such as coagulation profiles and platelet function assays, can aid in identifying underlying bleeding disorders.

Comprehensive management should involve a collaborative approach between gynecologists, hematologists, and other specialists, tailored to the individual's needs. Treatment options may include hormonal therapies to control endometriosis symptoms and decrease excessive bleeding, as well as the use of hemostatic agents or clotting factor replacement for individuals with confirmed bleeding disorders.

Additionally, patient education and support are vital to empower individuals with knowledge about their conditions and promote self-care practices.

HFQ Winter Event 2023

Come join us for a fun day filled with animals, nature and community.

HFQ is hosting it's annual winter event. This years' it will be hosted at **Lone Pine Koala Sanctuary** on *Sunday 16th July 2023*, starting at 9:15am.

Attendance includes entry to the park, lunch and the 'touch a koala' experience.

Minimum numbers are required for this event to proceed.

Please RSVP for a ticket by texting HFQ on 0419 706 056 and advising the names and number of family members attending.

Please let us know of any dietary requirements.

HFQ Men's Lunches

Are you a man affected with a bleeding disorder? Are you a father of a child with haemophilia? Are you the partner of a woman with a bleeding disorder? Do you find yourself wishing you had a mate to chat to who really understands what it's like to be in your shoes?

Then the HFQ Men's Lunches (otherwise known as OBEs) might just be the place for you! Open to men of **all ages** who lives are affected by a bleeding disorder.

If you are interested in joining our men for a monthly catch up, give the office a call on 0419 706 056.

Welcoming our newest board members.

Interview by Charles Eddy

It's been a time of change on the HFQ board with the retirement of our previous president David Stephenson and his wife Leanne's decision to step down as well. I want to take the opportunity to thank them again for all their years of service and dedication to the community. They will be missed.

We are extremely lucky to welcome two new board members, Chris Fullelove and Leah Emery, and look forward to their amazing contributions to the board and the community in the future. I asked them a few questions to help the community get to know them a little better.

Chris Fullelove

1. Tell us a little bit about yourself.

Not sure what to say here, so a random assortment of facts:

- I'm a father of 2 young boys (3 yrs and 18 months)
- I've lived in SEQ pretty much my whole life
- I'm an Electrical Engineer by training and have a strong interest in technology generally
- I enjoy cycling, although young kids have meant I'm not doing quite as much as I used to!

2. What was your introduction to bleeding disorders?

My first introduction to bleeding disorders was when I met my future wife Rosy and her brother James Rogers. I learned a bit about Haemophilia A and how that affected James, and how Rosy was also a "symptomatic carrier" (as it was described at the time). I also heard about the fun they had at youth camps when they were younger!

When we were having our first child, we knew that there was a risk that they could have Haemophilia and the considerations for Rosy as someone with mild Haemophilia. So I got to learn more directly about what that meant as a husband and father. The antenatal support from the team at the Royal Brisbane hospital was great and I think we were super prepared and informed leading up to the birth. When our first child was born, he was confirmed to have severe Haemophilia A and so it began!

He managed to get a bleed in his hand on day 1 so we got to meet the QCH team who came to visit us at the Royal. Then we had a spanner thrown in the works when it was discovered that he had coarctation of the aorta and required surgery right away. So, before we got to take him home, off we went to QCH where he successfully underwent surgery. The final hurdle was the presentation of an inhibitor, reducing the effect of the Factor VIII medication during recovery - not exactly ideal after heart surgery! It was certainly a character-building experience (I think we added a few grey hairs to the QCH Haematology team too!) but I am happy to say that so far the rest has been smooth sailing (relatively speaking!)

3. What made you want to join the HFQ board?

I had heard how important and valuable the HFQ events and support have been to the community since hearing about the youth camps from Rosy. Having attended the most recent Community Camp, I got to experience some of that myself and it was great! Not long ago I completed some training for work around organisational governance. This, combined with a desire to contribute more to the community, and the recent positive experience with the camp, prompted me to see whether I might be able to contribute by joining the Board.

4. Have you attended many HFQ functions? Do you have a favourite event?

I haven't attended as many as I would have liked so far, but the Community Camp is certainly my favourite.

5. What do you think the future looks like for the bleeding disorders community?

I'm still learning, but from what I've seen things look bright. With advancements in available medical treatments and a strong community for support, it's incredible the quality of life that is possible now compared with decades past. Imagine what it's going to look like 10 years from now!

Chris & Leah!

Leah Emery

1. Tell us a little bit about yourself.

I am the mother of two obligate carrier daughters, including one who has severe haemophilia A. I am also an art and cheese obsessive and have recently been indulging in self-care for my family by amassing multiple kittens in a short space of time.

2. What was your introduction to bleeding disorders?

My daughters' father has severe haemophilia A and I had to educate myself very quickly to understand all the challenging things that were going on for him in the pre-Hemlibra days. I went out of my way to seek as much genetic counselling as I could when pregnant (most of which was hideously inaccurate and I knew far more thanks to family experience than the counsellors who consulted outdated textbooks in front of me). When I got my daughter's severe haemophilia A diagnosis and had to advocate for her with anyone outside of our wonderful children's HTC who were usually dismissive, I started to be an annoying online troll, (politely) correcting forum posts and articles that argued against treatment for females with bleeding disorders, mostly in the wee hours of the morning, for fun!

3. What made you want to join the HFQ board?

I've been rabbiting on about it for years, but had spent too much time in hospital to make a commitment. Now, thanks to Hemlibra and Lauren's encouragement, I'm finally living the dream! The board is fuelled by such great, engaged people, it's been wonderful thus far.

4. Have you attended many HFQ functions? Do you have a favourite event?

Again, now that we have access to Hemlibra, we're able to be more social and attend more events in our favourite community! My daughters and I love the women's brunches, but love catching up with the wider community too.

5. What do you think the future looks like for the bleeding disorders community?

There's still so far to go, even in our own backyard, of fighting for appropriate treatment and support for our females with bleeding disorders. Carriers (many of whom would be eligible for a haemophilia diagnosis) experience restricted joint mobility as they age thanks to untreated issues throughout their lives, so I would love to see more support for them along the way. So many improvements have already been evident in our lifetime, and hopefully this will continue.

I would also love to acknowledge that that many of us have access to long acting factor, Hemlibra and gene therapy which has improved quality of life dramatically, but much of the developing world is still relying on very limited options like plasma on-demand and hopefully we can share our privilege with some of these communities in the future.

Thank you Fundraisers

A massive shout out to Josh Fisher from MR Real Estate Rockhampton for organising and holding a Fundraising Golf Day in April for Haemophilia Foundation Queensland. What a massive effort!

Thank you to Josh, Mr Real Estate Rockhampton, Rockhampton Golf Club, all sponsors and too everyone who attended this event and donated to the bleeding disorders community.

Another thank you needs to go Phil Hill from Fitness Compound who has challenged himself to do 100 burpees every day of 2023, which is no easy feat in itself, but he has also already raised over $1,000 for HFQ and will be continuing this fundraiser for the remainder of the year.

A mammoth effort already and the haemophilia community is very grateful!

My Aged Care

As you get older, living independently in your own home can become more difficult. If you're finding it harder to do the things you used to, you can ask for some help at home.
Asking for help doesn't mean losing your independence; it's quite the opposite. Getting a little help with daily activities means you can stay independent in your own home for longer. In fact, a little support can lead to a much better life.

Help at home looks different for different people. It may mean getting help with shopping and cooking. Or it could be receiving personal care to bath, dress, and get in and out of bed. It may even mean getting modifications to improve your safety and movement around the house.
Getting some help at home can enable you to continue to live independently in your own home for as long as possible.

What help is available?
Knowing if there's something that might help with your situation is one of the key questions most people have when thinking about whether to apply for aged care services.

How does it work?
The Australian Government subsidises the cost of home support services that you can receive in the comfort of your own home. What you need to pay depends on your services and in some cases, your financial situation.

How do I access these services?
Depending on your care needs, services can be accessed through the Commonwealth Home Support Programme or a Home Care Package. An assessment process determines what program is more suitable for you.

What if I'm not ready to look for services?
You might still be exploring your options and not need or feel ready to look for aged care services yet. Healthy ageing—working to maintain your physical and mental wellbeing as you grow older—can help you further delay your need for services.
The My Aged Care website provides information and access to online tools to help guide you in staying fit, well, and independent for longer.

What is healthy ageing?
Healthy ageing is about maintaining the ability to do the things that make you happy and fulfilled as you get older. Staying physically and mentally well can slow the impacts of ageing; it can also delay your need for aged care services.
You may experience some health and mobility challenges as you age. But there are things you can do to maintain your abilities before difficulties arise. Simple changes to your home, the use of different assistive devices, connecting with different community groups, volunteering, travel, and trying physical and wellbeing therapies are a few examples.

For more information, check out *https://www.myagedcare.gov.au/help-at-home*

High Use of Antidepressants, Anxiety & Pain Medication

Individuals with haemophilia consistently have a higher use of pain, depression, and anxiety medications compared with control populations, regardless of age, sex, or factor consumption.

This is according to recent data published in *Research and Practice in Thrombosis and Haemostasis*.

These findings underscore the need for improved bleed protection and haemophilia care for those with all severities of the disease, including mild haemophilia, the authors wrote.

To better understand treatment patterns of prescribed pain, antidepressant, and antianxiety medications, the researchers compared individuals with haemophilia with matched controls in 4 Nordic countries: Denmark, Sweden, Norway, and Finland.

Data were gleaned from the MIND study, which analysed longitudinal individual-level data from 2007 to 2017. Haemophilia can be classified as mild, moderate, or severe depending on the level of clotting factor in patients' blood.

A total of 3246 patients with haemophilia were included in the analysis, representing 30,184 person-years. The higher use of medication for pain, depression, and anxiety was most accentuated in the moderate to high factor consumption group and among men with low factor consumption, data showed.

The results also showed women, including carriers, who usually represent a milder phenotype, had an accentuated use of pain, depression, and anxiety medications. The 7 drug types included in the analysis were opioids, nonopioids, nonsteroidal anti-inflammatory drugs, steroids, neuroleptics, antidepressants, and antiepileptics.

"A higher opioid use was observed across all age groups: 4- to 6-fold higher in the moderate to high factor consumption group and 2- to 4-fold higher in the low factor consumption group," the authors added.

A total of 886 patients from Denmark were included in the study, in addition to 288 from Finland, 522 from Norway, and 1550 from Sweden. Just over 14,000 control participants were also assessed.

Seen Among Patients with Haemophilia

Not only did patients with haemophilia in the 4 countries have a higher use of pain drugs, they also had a longer duration compared with matched controls.

Results showed a higher use of antidepressant, antianxiety, neuroleptics, and antiepileptic drugs in many subgroups of haemophilia, a finding that may be due to the fact these drugs are prescribed as adjuvants to pain medication.

"The higher proportion of opioid use observed across all ages in our data highlights the need for person-centred approaches to pain and haemophilia management," the researchers wrote, noting patients with haemophilia are at an increased risk of opioid dependency. "Even when adjusting for inhibitors and joint complications, there was a remaining higher likelihood of use and volume of use of pain medications associated with" those with haemophilia than controls.

Previous studies have highlighted associations between pain, functional impairment, depression, and anxiety among individuals with haemophilia.

Although the prevention of bleeds has long served as a primary objective in haemophilia care, authors stress the importance of focusing on awareness of pain, depression, and anxiety in patients with haemophilia, even among women and men with low, no, or irregular factor consumption.

The dataset used in the analysis did not have information on laboratory values that allowed for the classification of disease severity. Instead, researchers relied on observed filled prescriptions for factor concentrates, marking a limitation to the study.

"In summary, our data show that [patients with haemophilia] use more pain, depression, and anxiety drugs compared with population controls," the authors concluded. "The increased use of these drugs is a sign of possible insufficient treatment and follow-up of haemophilia, irrespective of sex and haemophilia severity, even in those with a milder haemophilia phenotype."

Reference

Carlsson KS, Winding B, Astermark J, et al. High use of pain, depression, and anxiety drugs in hemophilia: more than 3000 people with hemophilia in an 11-year Nordic registry study. Res Pract Thromb Haemost. Published online January 30, 2023. doi:10.1016/j.rpth.2023.100061
Article source: https://www.ajmc.com/view/high-use-of-antidepressants-anxiety-pain-meds-seen-among-patients-with-hemophilia

If you are struggling with anxiety or depression, there are many organisations able to help, which we have listed below. Alternatively, you can speak to your GP.

Beyond Blue— 1300 224 636
Lifeline—13 11 14
MensLine Australia—1300 78 99 78
13Yard (for First Nations People) - 13 92 76

Health Updates

Long Term Effects of Hemophilia B Gene Therapy

Preventive treatment with Hemlibra (emicizuma b) appears to be safe and helps keep bleeding under control in babies who have severe haemophilia A.
The number of bleeds was "zeroed out" in nearly half of the babies, and most had zero bleeds requiring treatment.
That's according to interim results from HAVEN 7 (NCT04431726), a Phase 3 clinical study testing the benefit of preventive treatment with Hemlibra in infants whose ages ranged from newborn to 1 year.

"These initial results support the benefit of starting Hemlibra from birth given that early preventative treatment is essential in infants," Levi Garraway, MD, PhD, Roche's chief medical officer and head of global product development, said in a press release. Roche owns Genentech, the company that markets Hemlibra.

https://www.nejm.org/doi/pdf/10.1056/NEJMc2304262

Acquired Hemophilia A and ST-Elevation Myocardial Infarction (STEMI): A Rare Presentation and Management Dilemmaizer's

Acquired hemophilia A (AHA) is a rare autoimmune bleeding disorder in which antibodies attack clotting factor VIII. Recombinant activated factor VII (rFVIIa) is an agent that bypasses the acquired factor VIII deficiency and has been approved by the FDA for the treatment of bleeding and perioperative management in AHA. Thrombotic events are a rare complication of the use of this therapy [1].

We present a case of ST -elevation myocardial infarction (STEMI) after receiving rVIIa replacement therapy for AHA.
The BENEGENE-2 study met its primary endpoint of non-inferiority and superiority in the annualised bleeding rate (ABR) of total bleeds after a single intravenous (IV) infusion of Fidanacogene elaparvovec versus prophylaxis regimen with factor IX, administered as part of usual care.

The results showed superiority, with a mean ABR for all bleeds of 1.3 for the 12 months from week 12 to month 15 compared to an ABR of 4.43 during the lead-in pre-treatment period of at least six months, demonstrating a 71% reduction in ABR.

https://www.cureus.com/articles/151212-acquired-hemophilia-a-and-st-elevation-myocardial-infarction-stemi-a-rare-presentation-and-management-dilemma%23!/#!/

More Facilities For Thalassaemia Patients Urged

The founding chairman of Pakistan Sweet Home Zamarud Khan on Thursday said that there was a need to provide more facilities to patients suffering from thalassaemia and haemophilia.

https://www.dawn.com/news/1750883

Important Dates for HFQ Members

OBE's Monthly Lunch
Wednesday 7th June
Old Fernvale Bakery

Joint Men's & Women's Support Group BBQ Lunch
Wednesday 5th July
Captain Burke Park

Family Winter Event
Sunday 16th July
Lone Pine Koala Sanctuary

Women's Support Group Lunch
Sunday 6th August
Hamilton Hotel

21st Australian Conference, Melbourne
24th to 26th August

OBE's Monthly Lunch
Wednesday 2nd August
Broncos *Leagues Club*

*Please call HFQ on **0419 706 056** for more info on any of these events and other activities.*

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.

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