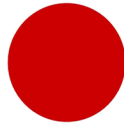


the

FACTOR

Haemophilia Foundation  
Queensland



**SPRING  
EDITION**

**Issue 76**



**SEPTEMBER 2023**

**HFQ MEMBER MAGAZINE**

# FROM THE PRESIDENT



Hi Everyone,

Welcome to another jam packed edition of the H Factor.

It has been a busy time for the bleeding disorders community and for our staff at HFQ.

The 21st Australian Conference on haemophilia, VWD & rare bleeding disorders was held in Melbourne this August; HFQ has held regional community outreach in Cairns, Mackay and Townsville; our winter event at Lone Pine Koala Sanctuary was a huge success and to top it off, Bleeding Disorders Awareness Month runs for the whole month of October.

Bleeding Disorders Awareness Month is a great opportunity to raise awareness of bleeding disorders in the community and is the perfect time to hold your own social event or morning tea with friends or colleagues, or maybe even share your story with others. More information and helpful resources are available on the HFA website here: <https://www.haemophilia.org.au/events-and-conferences/events/bleeding-disorders-awareness-week>

Make sure you also check out the HFQ website to keep updated on the events we have planned for the month of October.

As always, we couldn't have gotten through these busy times without the hard work and dedication of our HFQ staff and amazing volunteers. I'd also like to send a massive thank you to all of our members, volunteers and donors. It has been so amazing to see you all at our events. We couldn't do it without you!

We're currently planning for 2024 and looking forward to an even more successful year ahead. We have some exciting new initiatives in the works, and we can't wait to share them with you soon.

In the meantime, please stay tuned to our social media and the website for more updates and ways to get involved.

Thank you again for your support!

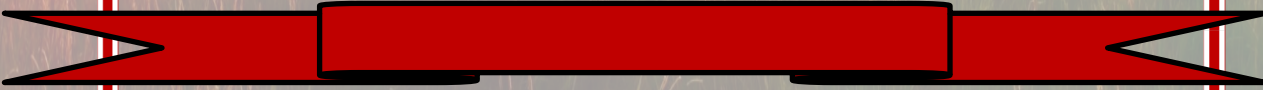
A handwritten signature in black ink that reads "S Gracey". The signature is fluid and cursive.

**Shannon Gracey**  
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](mailto: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](http://www.hfq.org.au) or at our Facebook page at [www.facebook.com/HFQLD](http://www.facebook.com/HFQLD)

### OUTREACH CLINICS

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

## 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](mailto: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](mailto: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 Klever - Clinical Nurse Consultant 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](mailto: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*

# What's On?

## SEPT TO NOV 2023

**SUPPORT BLEEDING DISORDERS**  
**HAEMOPHILIA FOUNDATION QUEENSLAND**

- SEPT 15TH**: HFQ YOUTH CAMP
- SEPT 19TH**: HFQ Board Meeting
- OCT 2023**: Bleeding Disorders Awareness Month
- OCT 3RD**: Government House Function
- OCT 7TH**: Bunnings BBQ Rothwell
- OCT 14TH**: HFQ Trivia Night
- OCT 21ST**: Plaque Ceremony Jeays Park Bowen Hills
- NOV 1ST**: Men's Support Lunch
- NOV 5TH**: Women's Carer's Lunch
- NOV 21ST**: HFQ AGM

**Haemophilia Foundation Queensland**  
[www.hfq.org.au](http://www.hfq.org.au)

**Save The Date**

HFQ 2023 ANNUAL GENERAL MEETING  
 and Member Information Night

**21 November**  
 7:00pm onwards

Grange Library  
 79 Evelyn St  
 Grange

**NOTICE OF ANNUAL GENERAL MEETING:**

HFQ invites all financial members to join us for our Annual General Meeting on Tuesday 21st November 2023 at the Grange Library, 79 Evelyn St, Grange.

Board nominations and proxy voting forms will be sent via email in the coming weeks. Come along and have your say on the future of our organisation.

All *financial* members of HFQ are entitled to a vote at the AGM. If you are unsure of your financial status, don't hesitate to contact us at the office on 0419 706 056 or [info@hqf.org.au](mailto:info@hqf.org.au)

# Getting to know...

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

*I was born in Ipswich and grew up mostly near Boonah and later in adolescence lived in Seattle, Washington for some of my schooling. My hobbies include listening to music, travel anywhere, jogging, pilates, yoga and great television. I am a Mum of two children (one nearly 3 and one 10) – so free time is spent with them and my partner Pete. We frequently visit my Mum on the coast to play at the beach. I am looking forward to getting into the ocean whenever I can this summer.*

**Q: What drew you to social work as a career choice?**

*I graduated from Journalism at QUT in my twenties and was always very passionate about social justice. After working in Immigration, Centrelink, Child Safety and now Health for many years...I saw a need for good social work within these agencies and the values and ethics of this profession suited my personality so I graduated a Bachelor of Social Work in 2007 and have stuck with it ever since.*

**Q: Can you tell us a bit about a typical day working as a social worker with the haematology team at the Queensland Childrens Hospital?**

*A: A typical day as a social worker with the Haemophilia team involves a daily handover with wider medical team to know events of our population in Queensland hospitals overnight and then usually a pretty full day of supporting families*

*alongside their emergency admissions, outpatient visits or inpatient admissions.*

*This looks like resourcing, advocacy, counselling and providing a psychosocial perspective within the wider team. It varies daily according to each patient, each family and their unique strengths and difficulties – I enjoy this variety and spend a lot of time getting to know*



*families and their existing support systems, sometimes working with families to access other supports either here at the hospital or in their local community.*

*What's really unique about this role is the close relationship with our partner HFQ and working closely with Lauren and the team to connect Haemophilia families with their crucially important existing Haemophilia community.*

# Lara Nicholson

**Q: What have been the highlights of your career?**

*A: For many years I worked various different clinical areas in both acute and chronic settings here at QCH and I would say a major highlight has been coming into the Haemophilia team where I could develop and deliver a model of care to Haemophilia families in a permanent space alongside such a specialised team. Finding my niche in Haemophilia has been hugely satisfying for me as there is always so much to learn in this area of medicine.*

**Q: What have been the challenges?**

*A: I have worked closely with children and families who become bereaved from incurable conditions such as certain cancers when I was in oncology. This would be my greatest challenge but also probably helped me develop and hone my practice.*

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

*A: You have a very smart and specialised team caring for you. Expect little from yourself in a state of shock and/or trauma...we are not our cognitive best when faced with a shock of a bleeding*

*disorder diagnosis. Reach out for support, even if you don't know what that is. It's okay to not be okay or for you or your child to feel distress around a diagnosis and/or treatment.*

**Q: What accomplishment are you most proud of?**

*A: I am very proud of my skills and experience in a variety of health and community settings, to identify the most pressing issue and working on that with a family in a way that is empowering and builds capacity for families outside of a hospital setting. I see families relax so much when they feel heard and validated.*

*My counselling skill in this context is probably my greatest accomplishment.*



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

*A: Would like to fly as if I was swimming breaststroke – wherever I wanted to go*



back to the  
**80'S**

# TRIVIA FUNDRAISING NIGHT



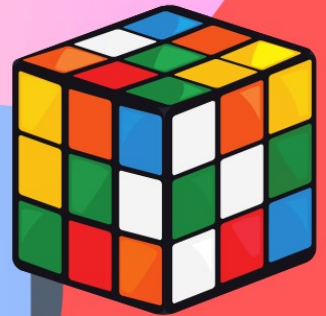
Put on your best 80's Outfit  
...prizes for best dressed and  
lots of Raffles to be won!

**Saturday**  
**Oct 14**

**ARANA LEAGUES CLUB**  
Doors open at: 06:00pm  
Game starts at: 07:00pm

**\$10**

per person  
including a  
welcome  
drink



**PLEASE HELP RAISE MONEY FOR PEOPLE WITH  
BLEEDING DISORDERS IN QUEENSLAND**

**Register Your  
Seat Here:**



**Or Via this link:**

<https://www.eventbrite.com/e/hfq-80s-trivia-night-tickets-688274416307?aff=oddtcreator>







We asked members of our community to share what Bleeding Disorders Awareness Month means to them.

Here's what they had to say...

*'It's good for other people to hear about what the issues are, how they're coping and how they're getting on with treatments' - Mike H*

*"I like Bleeding Disorders Awareness Month because it gives me a chance to teach my friends and other people about what a bleeding disorder is and how it affects my family' - Ruby A,*

*"I really like the opportunity it creates to raise awareness that it's still out there and it's still a problem. But I also like that it allows us to celebrate where we have got to (in relation to treatments). But also it provides an opportunity for us to remember those we have lost"*

- Graham N

*"It creates awareness and helps the public understand what a bleeding disorder is about and that there is support and understanding through HFQ and the bleeding disorders community" - Samantha W*

*"Being part of such a close knit community as HFQ has been a great way to feel supported through the ups and downs of being a family dealing with bleeding disorders. BDAM is a great way to increase awareness and break down the stigma of our experience and introduce more people into the community to grow and advocate together." - Leah E*



*"Bleeding Disorders Awareness Month is that time of the year where we get to make what are largely intangible & invisible conditions, noticed by the wider community" - Adam L*

*"BDAM is a great opportunity to reflect on the past, celebrate how far we've come and identify where we still have to go. It gives us an opportunity to raise awareness in the wider community and shine a light on the work of HFQ" - Lauren G*

*"For the younger community, for a family that has just had a new haemophiliac born into the family, I hope it creates better awareness for them to receive better support. " - Mike O*

## HFQ Dates to Remember

### BDAM - October 2023



- OCT 03** **GOVERNMENT HOUSE FUNCTION 'THANK YOU TO OUR GP'S AND MEDICAL SPECIALISTS'**  
 Tuesday - 5:00pm  
 (RSVP's close 1/09/23)
- OCT 07** **HFQ BUNNINGS ROTHWELL BBQ FUNDRAISER**  
 Saturday - 8:30am to 3:30pm  
 (Volunteers needed)
- OCT 14** **HFQ 80'S TRIVIA NIGHT**  
 Saturday - doors 6pm, trivia from 7pm  
 Register via QR code
- OCT 21** **PARK BDAM MEMORIAL PLAQUE CEREMONY**  
 Saturday- 10.30am  
 (RSVP's close 1/10/23)

**AVAILABLE NOW** **HFQ RAFFLE**  
 Tickets on Sale Now!  
 Scan QRcode



# HFQ WINTER EVENT 2023



**On Sunday 16th July, HFQ hosted it's inaugural Winter Community Event. 85 people joined HFQ staff at Lone Pine Koala Sanctuary for a day filled with fun, food and furry friends galore!**

**Everyone had a wonderful time and HFQ would like to thank Mr Real Estate - Josh Fisher, for his fundraising golf day, which made it possible for us to make this event completely free for our members!**



# Community Camp 2024



**HFQ  
Community  
Camp 2024**

**REGISTER  
NOW**

**SANDSTONE POINT  
BIG4 RESORT**

**MARCH  
22 - 24**

To register go to  
<https://www.trybooking.com/CLHHJ>

[www.big4.com.au/caravan-parks/qld/greater-brisbane/sandstone-point-holiday-resort](http://www.big4.com.au/caravan-parks/qld/greater-brisbane/sandstone-point-holiday-resort)



**Please be aware Community Camp is only open to financial members of HFQ and their *immediate* family.**

If you have any questions or need any further information, please don't hesitate to contact us at the office on 0419 706 056 or [info@hfq.org.au](mailto:info@hfq.org.au)



Enter  
to Win

SUPPORT  
BLEEDING  
DISORDERS

**H**  
HAEMOPHILIA  
FOUNDATION  
QUEENSLAND

**Fundraising raffle for  
Haemophilia Foundation  
QLD.  
Tickets available here:**



**1st Prize:** Framed autographed Cricket Australia Bat by Australian Squad for the 2009 VB Tour of South Africa. Complete with authenticity. - **Valued at \$2,000.**

**2nd Prize:** Riverlife Brisbane Adventure Voucher - **Valued at \$550**

**3rd Prize:** Flight Centre Voucher - **Valued at \$500**

**4th Prize:** Portland Gas BBQ Jumbuck 4 Burner with BBQ Kit—**Valued at \$380**

**5th Prize:** AirBag Man Heavy Duty Portable Air Compressor—**Valued at \$375**

**6th Prize:** 2 x bottles of Gentleman Jack with personalized engraving—**Valued at \$200**

**[Ticket sales via QR code or https://rafflelink.com.au/hfgraffle2023](https://rafflelink.com.au/hfgraffle2023)**

# HFA Conference 2023

Article by Lisa Bowdler

I'm Lisa Bowdler, probably better known to the HFQ community as "Craig's sister"! Craig, who has mild haemophilia A, has been involved with HFQ for many (many!) years, first attending family camps & events as a child, then as a youth mentor, fundraising volunteer, board member & he has represented HFQ as a delegate at both national & international conferences. After moving to the Sunshine Coast in 2019, Craig continues to help out with youth activities for HFQ & is a familiar face at family camps & organised events. I've more recently re-engaged with HFQ after the birth of my son Thomas, now 4, who was also found to have mild haemophilia A.

Last month I was fortunate to attend the 21st Australian Conference on Haemophilia, VWD & Rare Bleeding Disorders, held in Melbourne over 24 - 26th August.

Over the course of 2 days, I listened intently to presentations & panel discussions led by research and clinical professionals - haematologists, nurses, physiotherapists, a geneticist, gynaecologist & psychologist just to name a few! Topics of presentations included an overview of the history of haemophilia treatments spanning back to the 1950's, Australia's experience with new and emerging treatments, gene therapy, genetics & inheritance, women and girls with bleeding disorders, managing mild haemophilia and overcoming challenges to work towards good health.

Dr Glenn Pierce MD PhD, an independent biotech consultant, former entrepreneur-in-residence at Third Rock Ventures, serves as Medical VP for the World Federation of Haemophilia Board of Directors and National Haemophilia Foundation Medical & Scientific

Advisory Council, Jane Portnoy an Accredited Mental Health Social Worker and Professor Huyen Tran, Director of the Ronald Sawers Haemophilia Treatment Centre in Melbourne lead a plenary on Gene Therapy.

Dr Pierce described how gene therapy for haemophilia worked: a functional copy of a FVIII or FIX gene is placed into a viral vector (typically an adeno-associated virus) and delivered intravenously where it targets the liver cells. It enters the liver cells, travels to the nucleus where it becomes functional and instructs the cell to produce FVIII or FIX proteins which are then secreted into circulation providing more effective blood clotting.

He described some of the limitations identified for current gene therapy and Professor Huyen provided an overview into the AHCCDO gene

therapy roadmap.

Concurrent sessions I attended addressed the impact new treatments have had on young children & their families, and it was interesting to hear some of the challenges of new, sub-cutaneous prophylaxis. Some families found sub-cutaneous injections more traumatic and painful than their previous port-a-cath treatments and subsequent bleeds resulted in hospital visits as families were now unequipped to administer IV on demand factor treatments at home.



There were also many positive stories from young families such as the reduction of factor level peaks and troughs & reduced treatment burden; injections every two or four weeks compared to once every few days. Nicola Hamilton, a physiotherapist from the Royal Children's Hospital in Melbourne gave a talk detailing the importance of physical activity for all children and adolescents and provided practical advice for families when considering a suitable sport for their children affected by a bleeding disorder. Her take home message was no matter the sport or physical activity, it's important to stretch, stretch, stretch!

Plenary 3 focused on women & girls with bleeding disorders and Prof Sonia Grover, a Paediatric and Adolescent Gynaecologist explained how & why women with mild bleeding disorders are more likely to experience recurrent ovulation pain & endometriosis. I found this session really intriguing, endometriosis also runs in my family, and I was diagnosed with endo in my teenage years. Dr Briony Cutts gave a medical perspective on the diagnosis, treatment and care of women with bleeding disorders and reiterated the clinical phenotype of a women's bleeding disorder being an important tool for future management considerations.

Other sessions focused on inheritance, genetics, family planning as well as pregnancy, childbirth and newborns. I am familiar with the genetics of haemophilia but was interesting to learn from A/ Prof Kristi Jones and Genetic Counsellor Lucy Kevin about the autosomal recessive & dominant inheritance patterns of von Willebrand disease, with the vWF gene located on chromosome 12.

The topic of genetic testing was of significant interest to me; I learnt of my carrier status at age 14 which in hindsight was probably too young for me to fully understand how this may

impact my decision to start a family later in life. Many years on, girls & women are having their factor levels tested to monitor any bleeding issues, but genetic testing is offered in consultation with a genetic counsellor or geneticist before or as part of family planning.

As a parent of a daughter (Sophie, 6 years old) who may also carry the haemophilia gene alteration, it's refreshing to know there is so



much support & resources available to young girls & women as they navigate their informed decision to undergo genetic testing. And here in Queensland, we are very fortunate to have a dedicated Haemophilia Carrier Clinic.

Plenary 4 delved into managing mild haemophilia. Dr Heather Tapp, Haematologist at the Women's and Children's Hospital in Adelaide spoke about some of the diagnostic and management

challenges faced by mild haemophilia, factor levels >5-40%. It was fascinating to hear how physiological changes such as infection, inflammation, pregnancy and even age can influence factor levels and the inter and intra laboratory variability of factor level testing assays. Dr Tapp discussed some of the limitations for patients with mild haemophilia including the broad range of classification and possible bleeding phenotypes, less engagement with their HTC's, less experience recognising and treating bleeds, and the fact that mild haemophiliacs rarely receive home treatments or prophylaxis. People with mild haemophilia have also had limited access to modern therapies and not been eligible for clinical trials. With recognition of these challenges, there is future discussion for health professionals to re-classify mild haemophilia into subgroups and the realisation that mild

haemophilia may not always be "mild".

Throughout each plenary and concurrent session, there were members from the bleeding disorders community who bravely shared their own personal experiences with conference attendees. We heard from affected women, men, youth and parents of children with bleeding disorders. They spoke of their diagnosis, some with a family history & others a spontaneous mutation, how their treatment had changed over the years from whole blood/plasma transfusions, cryoprecipitate, freeze dried plasma, recombinant products & prophylaxis, and the more recent extended half-life clotting factor concentrates and non-factor products. They spoke about how living with a bleeding disorder affected their lives, bleeds leading to long hospital stays and absenteeism from work or school, development of inhibitors, limited mobility and arthropathy. Some talked of the dismissal they had received regarding their bleeding symptoms, particularly women relating to long, troublesome menstruation and others opened up about the psychosocial concerns their families faced raising a child and living with a bleeding disorder. I found the personal stories highly emotive and could relate with some common concerns and experiences.

At the conference dinner and organised breakfast, there was the opportunity for me to meet other people affected by bleeding disorders. A highlight was connecting with Caroline, her husband Tom and son Louis (20 years old) from Adelaide, with whom I shared



a very similar family history of mild haemophilia A. It was refreshing to talk so openly with them on similar issues we've encountered, and I used the opportunity to ask them about their lived experience on some future challenges I anticipate I may face with my son as he grows up with mild haemophilia. I'm hopeful our connection continues after the conference, and we remain in touch.

I came away from the conference feeling validated, motivated and inspired. It was validating to hear of the progress for women and girls with bleeding disorders, and acknowledgement of the gap in optimal management of people with mild haemophilia. I'm motivated to advocate for the bleeding disorders community, educate others, myself and help to raise funds so HFQ & HFA can continue to provide support.

I am inspired by the health professionals, the haematologists, nurse practitioners, genetic counsellors, gynaecologists, physiotherapists, scientific researchers, clinical trial participants and so many others who have dedicated their career and lives to better treatments and outcomes for those living with a bleeding disorder. A big thank you to HFQ and HFA for providing funding which allowed me to attend this conference. I would encourage anyone affected by a bleeding disorder to consider attending future Australian conferences, it's a valuable opportunity to learn from and engage with health professionals and members of the bleeding disorders community.

*HFQ would like to thank Lisa for taking the time to write an in-depth review of her experience at conference.*



# Regional Outreach

During July and August, HFQ staff, along with members of our board, have been attending the Regional Outreach Clinics held in Mackay, Cairns and Townsville.

HFQ provided morning tea at these clinics and provided a drop in area to engage with regional and remote families and identify areas where we may be able to provide assistance.



During these clinics, we were able to speak with both adults and children, as well as their families, and discuss the challenges faced by patients in more remote locations throughout Queensland.



HFQ is committed to engaging with ALL people with bleeding disorders, and this includes those who are further from a major centre than most.

If you have any ideas on how we can best serve the FNQ communities, whether that be through events, advocacy support or just a friendly phone call to check in, please get in touch with us.



# Navigating The Unknown

Interview & Article by Lauren Green

*During the conference, I met with the parents of a beautiful four month old little boy, who has recently been diagnosed with severe Haemophilia A. The diagnosis came as quite a shock to the family, as they had no family history of bleeding disorders and had only very limited knowledge of haemophilia. For the sake of privacy, the family has asked to remain anonymous so names have been changed,*

support. Jo McCosker, the haemophilia nurse at Queensland Children's Hospital, became a beacon of hope during a dark time. The family were grateful for the prompt assistance they received.

## Dealing with the Emotional Turmoil:

In the already emotional world of new parenthood, nothing can quite prepare you for the sudden news that your child has a severe medical condition.

This was the reality faced by Jack & Jane when their son was diagnosed with severe haemophilia at just a few days old. In this interview, we gain insight into their emotional journey, the challenges they've encountered, their hopes for the future and the hope that comes with newfound knowledge and support.



The emotional toll of the diagnosis was immense. Jane described her initial perception of haemophilia as daunting, especially given her knowledge of a friend whose father had the disorder, but unfortunately had suffered the impacts of receiving treatment that resulted in a blood borne virus.

For Jack, the diagnosis had a unique impact. As a professional tennis player, his life revolved around sports and physical activity. The thought of not being able to play and engage

in physical activities with his son weighed heavily on him. Jane expressed her own concerns, especially regarding the use of needles for treatment, something many parents struggle to come to terms with.

## A Shocking Discovery:

Jane and Jack had no family history or knowledge of bleeding disorders when their son was diagnosed with haemophilia. The diagnosis came swiftly, just four days into their hospital stay. It all began with a routine heel prick test on day three, leading to a formal diagnosis by day four. Their lives changed overnight, but so did their access to crucial

The emotional turmoil they experienced was not uncommon among parents facing similar situations. Many dads, like Jack, expressed their concern about their children being limited in their activities due to haemophilia. It's a reminder that while medical advancements have come a long way, the emotional toll on parents is still very real.

# A Journey Of A Newly Diagnosed Family

## Hemlibra: A Glimmer of Hope:

The family confessed to spending those initial nights scouring the internet for information about haemophilia, only to find it overwhelming and disheartening. The cost of Hemlibra was a daunting prospect, but they were relieved to live in Australia, where access to this innovative therapy was more feasible. Jack's concerns about funding their son's treatment were alleviated, and they began to see a glimmer of hope on day five.

## The Journey Begins:

As their son is still a newborn, he thankfully hasn't experienced any major bleeds as yet, however, they were well aware of the importance of managing potential bleeds and preserving his joint health. The knowledge they gained at a conference with other families dealing with bleeding disorders reinforced the significance of staying proactive.

## A Future Filled with Hope:

While their journey has just begun, Jane and Jack share their optimism for the future. They hope for a cure, as do many in the bleeding disorders community. But their primary aspiration is to ensure their son isn't limited by his condition. They want him to have the same opportunities and experiences as any other child. Their goal is to empower him with knowledge about his diagnosis without imposing unnecessary limitations.



## Education and Support:

One of the major benefits of attending the conference was the wealth of education they received. Jane and Jack admitted to having misconceptions about haemophilia and its treatments. The conference opened their eyes to the complexities and alternatives, including gene therapy. They left with a newfound understanding of haemophilia and the importance of considering various treatment options.

Jane and Jack's journey as parents of a child with severe haemophilia is just beginning. While the initial shock and grief were overwhelming, they have found solace in education, support, and access to innovative treatments like Hemlibra. Their hopes for the future are bright, driven by the desire to see their son live a life unburdened by his diagnosis. As they navigate the uncharted waters of haemophilia, they serve as an inspiring example of resilience and determination within the bleeding disorders community.

***HFQ would like to thank the family for taking the time to share their story.***



## INVITATION

*HFQ would like to invite our  
community members to attend*

### MEMORIAL PLAQUE CEREMONY IN THE PARK

OCTOBER **21** 2023  
10:30AM

#### **JEAYS STREET PARK**

Jeays Street, Bowen Hills

*rsvp by 1/10 on 0419 706 056*



Until the 1950's people with haemophilia seldom lived beyond 20 years old because there was no effective treatment available. In the 1960's it was found that precipitate from blood plasma could control bleeding, if used at the time of the bleed, but some people with haemophilia still died prematurely from bleeding incidents. In the mid 80's some batches of a new treatment for haemophilia made from multiple blood donations became contaminated, as some donations contained HIV and/or Hep C. Many treatment recipients became infected through the very blood that was saving their lives, causing them illness and death.

As a community many of our members and their extended family have lost a loved one with a bleeding disorder and we have arranged for a plaque to be installed in the Jeays St Park.

This plaque will be unveiled at 10:30am on Saturday 21 October 2023 at the park, with a morning tea to follow at the Community centre next to the park. Everyone is welcome to attend but must RSVP by calling the HFQ office on 0419 706 056 for catering purposes.



## ***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](http://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](http://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](http://www.haemophilia.org.au/research)

Or contact Suzanne at HFA:

E: [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au)

T: 1800 807 173

## Important Dates for HFQ Members

**BDAM October 2023**  
**Government House**  
 Tuesday 3rd

**Bunnings BBQ Rothwell**  
 Saturday 7th

**HFQ Trivia Night**  
 Saturday 14th  
 Arana Leagues Club

**HFQ Plaque Ceremony**  
 Saturday 21st  
 Jeays Park Bowen Hills

**Men's Support Lunch**  
 November 1st  
 Norths Leagues Club

**Women's Support Lunch**  
 November 5th  
 Tingalpa Hotel

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



**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](mailto: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](mailto:info@hfq.org.au). You can be removed from the list at anytime.

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