the H FACTOR

Haemophilia Foundation Queensland

AUTUMN EDITION

Issue 78

MARCH 2024

HFQ MEMBER MAGAZINE

FROM THE PRESIDENT

So, another amazing HFQ Community Camp is in the books, and what an event it was. Held once again at Sandstone Point Holiday Resort, it was a fantastic weekend of swimming, riding, tennis, pedal karts, and waterslides. A weekend of reconnecting with old friends and making new ones.

We had 140 people attending the camp this year; 30 more than last year, and a record for HFQ family camp attendance. It was great to see so many members of our community together.

All credit must go to the HFQ office staff Lauren and Sam for their tireless efforts behind the scenes. Months of planning, as well as their efforts across the weekend, ensure the camp is a success. Well done to both of you.

For those of you who can't get enough HFQ sponsored family activities, don't forget about the upcoming SeaWorld day on 7 July. We have 100 people already registered to attend, and I'm looking forward to seeing many of you there.

And for those guys in our community who love a free meal and great conversation, I thoroughly recommend attending one of the Men's Lunches. Back in February I attended the Men's Lunch at East's Leagues Club. They're a great way to connect with the guys in our community, and while they can be an opportunity to talk about shared bleeding disorder experiences that you can't talk about with anyone else, mostly it's just great chat with some great guys. Oh, and did I mention the free lunch?

HFQ's illustrious Secretary Tony Ciottariello is the main point of contact for the Men's Lunches, but the dates and locations are also promoted in this newsletter and on the HFQ Facebook page. All (guys) are welcome.

Finally, World Haemophilia Day will soon be here and it, along with bleeding disorders awareness month in October, is a key date for HFQ to increase awareness of bleeding disorders in the community.

Along with many venues 'Lighting It Up Red' across the state, and the HFQ board doing the Bridge Climb, HFQ has also been invited to be interviewed on SEA FM to raise awareness of haemophilia. Board member, Charles Eddy has volunteered his time to join Lauren on air to talk about having a son with haemophilia. So, on 16 April, keep it tuned to 99.7FM to hear Charlie's dulcet tones!

Until then, I hope you enjoy the holiday break, and as always, please reach out to the HFQ with your thoughts, ideas and suggestions, or if you need any support. This is your Foundation.

Shannon Wandmaker
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	... ...	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
		Mr Graham Norton

HFQ Delegate to HFA

Mr Shannon Wandmaker

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 (Thurs, Fri & 2nd Mon)

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
Lara Nicholson —Social Worker (Tues, Wed)	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?

APRIL - JUNE 2024

Dates to Remember

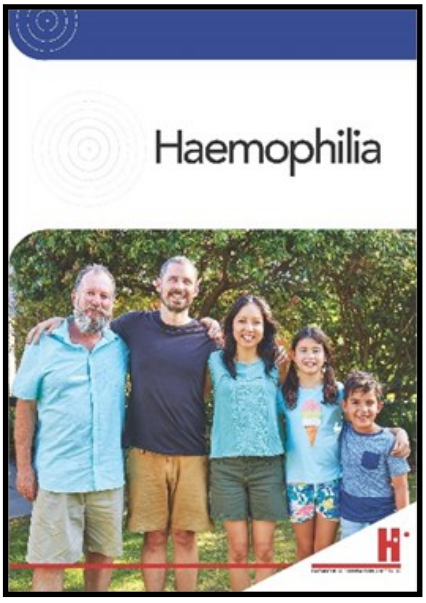
April - June 2024

APRIL 3	MEN'S SUPPORT GROUP LUNCH - BRONCOS LEAGUES CLUB 11:30am to 2:30pm
APRIL 17	WORLD HAEMOPHILIA DAY 2024 Wednesday - QLD landmarks will be illuminated in Red
APRIL 18	HTC ADULTS OUTREACH CLINIC - SUNSHINE COAST Sunshine Coast University Hospital, Birtinya
MAY 1	HTC ADULTS OUTREACH CLINIC - GOLD COAST Gold Coast University Hospital, Southport
MAY 18	WOMEN'S SUPPORT GROUP LUNCH - CANDLE MAKING Saturday - 10:00am (Scented by Harry, North Lakes)
JUNE 5	MEN'S SUPPORT GROUP LUNCH - BREAKFAST CREEK HOTEL Wednesday - 12:00pm

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

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

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



Accessing Haemophilia 2023

download it from the HFA website - https://tinyurl.com/HFA-haemophilia

ask HFA to post you a free print copy – hfaust@haemophilia.org.au

Get To Know Your Physio!

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

A: Well, I was born in Sydney and I grew up on the Gold Coast. Hobbies - I love hiking and I just like spending time with my family and friends and that kind of stuff.

I try to be crafty so I've been known to crochet but that's neither here nor there and interesting facts.

I go for the Richmond football team and why that's interesting is because I never liked AFL. But someone once gave me a jersey and that year was the first year they won the premiership.

So since then I just feel like I was meant to go for the Richmond Football Club.

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

A: My Mum is a physio so she suggested that I give it a go and I did and I loved it so I was very lucky in that regard.

Q: Can you tell us a bit about a typical day working as a physio?

A: So usually we start work pretty early and I get in and I check my phone for messages and my emails to see if there's been any people trying to contact me or get through to me for physio management.

And then I'm mainly working in outpatients and I see patients that come in to see me there. I also work in the haemophilia clinics as well. And I try to sneak in a quick coffee break if I can!

Q: What have been the highlights of your career?

A: One of the highlights of my careers was last year I organized the Queensland Paediatric Physiotherapy Clinical Network and we were able to fund and support physios from regional and remote areas to come to Brisbane. I was able to put together an event that was inclusive for all physios working in paediatric. I am split between the two hospitals so I like working in both adults and paediatrics .

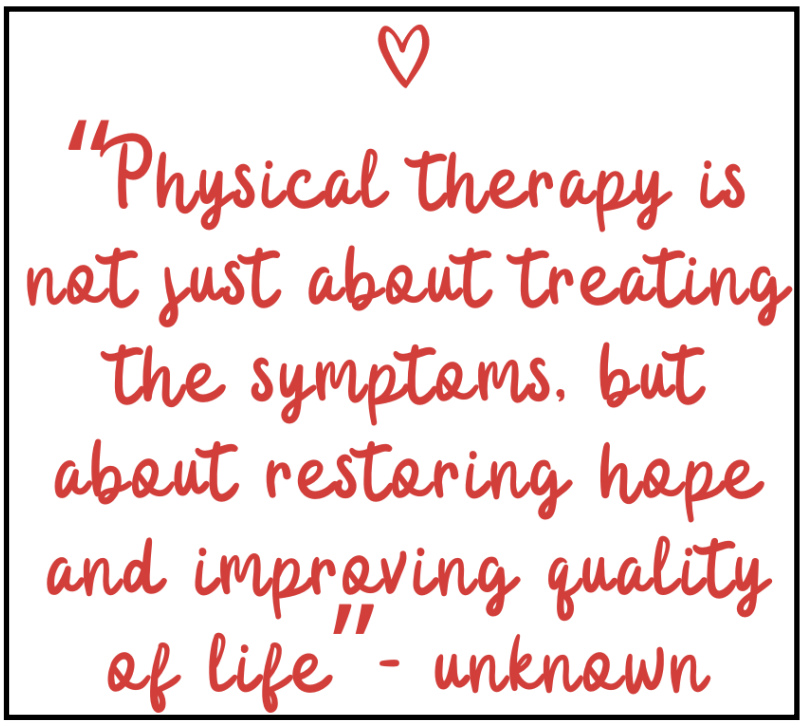
Q: What have been the challenges?

A: I think just getting to meet all the new people. Haemophilia is such an established group of patients, they've been coming to the clinics year after year for their entire lives and I'm just coming in and meeting everyone for the first time. So I love to talk and have a chat so it's a good opportunity for me to do that and get to know everyone. Everyone has been so welcoming and so happy to engage with me though.

Natalie Karlovic

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

A: I think from my physio hat, I would say don't play rugby. But I think from my more holistic view of it is that the haemophilia space is changing so rapidly and there's so many new therapies and ways that we manage these patients now that it's not what it used to be and it's much, much better. It's definitely a very different time to what it used to be. Certainly still not easy, but much moreso than in the past and there is so much hope moving forward.



Q: What accomplishment are you most proud of?

A: I think being able to work in the haemophilia space for me is an accomplishment. I really enjoy working in this team. The people are lovely and the physiotherapy is really interesting and unique.

Outside of work, I'm actually doing a postgraduate degree in some gardening subjects and that's to be finished in June this year. So hopefully that'll be a big accomplishment when I do that and my garden will be much better!

Q: What can those with haemophilia do to help prevent bleeds?

A: Anything that can be doing to keep themselves as healthy as possible. From a physio perspective, I think the biggest thing is making good choices about the type of exercise that you're doing and then definitely engaging in regular exercise. So trying to stay away from things that are too high impact such as running or sports that involve tackling like AFL or rugby, but making sure that whatever exercise you're doing, you're doing consistently because we know that the protective factor for the joints is increased. You can protect your joints much better if you've got the strength and the muscles around it. Regular, low impact exercise, such as swimming or cycling is always a winner.

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

A: That's an easy one. It would be to be able to teleport. I'd love to just be able to pop over to Europe for a week and then back. I'd save a fortune on airfares and parking!

Q: Anything else you'd like to let the bleeding disorders community know?

A: Just that I'm friendly and always up for a chat for all things physio, absolutely give me a call.

2024 Community Camp Wrap Up!

On 22nd—24th March, 120 members of the bleeding disorders community descended on Sandstone Point Resort for another wonderful HFQ Community Camp.

With our biggest numbers yet, it was a weekend full of community, bonding and LOTS of noise!

Camp kicked off with a welcome dinner of many, many subway platters on Friday night after everyone was checked in and settled in their lovely accommodation before heading to bed before a big day of activities on Saturday.

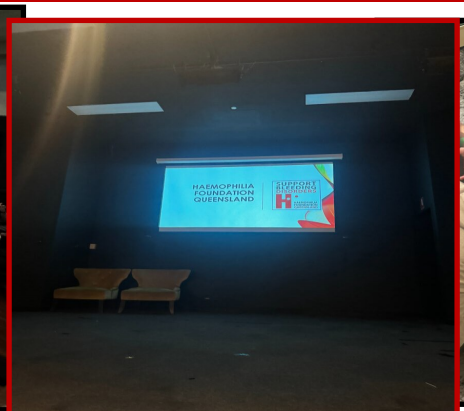
2024 Community Camp Wrap Up!

On Saturday, families (especially those with excited young children) were up early and ready to make the most of the impressive facilities Sandstone Point has to offer. Everyone got stuck into the go kart races, mini golf, jumping pillow, playground and arcade rooms. The parents made the most of the massage therapists hired by HFQ to give them some moments of relaxation amongst the chaos, while many a competitive game of basketball and tennis was taking place.

Saturday lunch was provided by the awesome team at the Bribie RSL before everyone got dolled up and headed to the Bribie RSL for a sit down dinner. Our new President, Shannon Wandmaker gave a fantastic presentation on the last 12 months and HFQ's priorities moving forward with the ever-changing bleeding disorder landscape.

HFQ screened the documentary 'Redefining Impossible: Elite Athletes with Haemophilia' during dessert while the little ones were entertained by bubbles, colouring books and board games.

HFQ staff are already back in the office and busily prepping to make next year's camp even bigger and better so keep your eyes on our socials and the H Factor for more details soon!



A Birthday, A Bleeder and a Big Day;

The History of World Haemophilia Day

Have you ever wondered why we recognise World Haemophilia Day on April 17? Well wonder no more, as we're diving into the history of this special day dedicated to raising awareness for our bleeding disorder community.

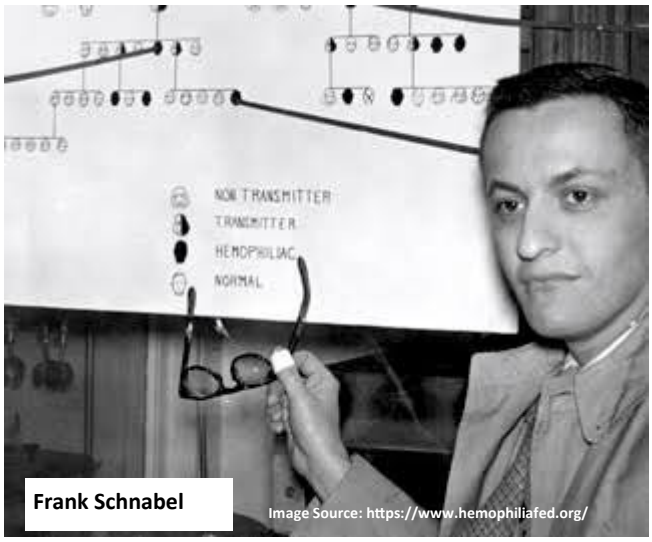
The story begins with Frank Schnabel, a Canadian businessman. Frank was diagnosed with severe haemophilia A, and his firsthand experience with the challenges of living with a bleeding disorder fueled his passion to improve the lives of others facing similar struggles.

He recognized the scattered efforts of existing haemophilia organisations and knew that if everyone worked together they could achieve so much more for the bleeding disorders community.

In 1963, Frank's vision materialised with the creation of the World Federation of Haemophilia. Starting with just six national haemophilia societies, the WFH soon became a platform for collaboration and knowledge sharing on a global scale.

Sadly, Frank became a victim of the HIV/AIDS crisis that tragically impacted so many in the haemophilia community around the world in the 1980's.

When the WFH needed a flagship event to shine a light on bleeding disorders on a global scale, what better date could be chosen than April 17, the birthday of their inspirational founder, Frank Schnabel. And so, in 1989, WFH declared April 17 the first World Haemophilia Day!



Frank Schnabel

Image Source: https://www.hemophiliafed.org/

It's not just about cake, candles,and red landmarks though. This day became a rallying cry for the bleeding disorders community. A chance to raise awareness, advocate for better treatment, and celebrate the resilience of those living with bleeding disorders.

Over the years, World Hemophilia Day has evolved. Each year comes with a new theme, focusing on particular challenges and triumphs. From access to care to the importance of prevention, these themes spark conversation and inspire action.

World Hemophilia Day is a day to celebrate the incredible progress we've made, a day to remember the fight isn't over, and a day to stand together as a strong, global community. So this April 17, wear your red, check out the amazing landmarks lit up in your area and raise your voice!

WORLD HEMOPHILIA DAY
17 APRIL 2024
#WHD2024

Being Mindful of the 'Zero Risk Bias'

In our quest for security and certainty, it's only natural to gravitate toward options that offer zero risk. Think about it: When you purchase insurance or opt for a product with a money-back guarantee, you're essentially seeking assurance against any potential loss. This tendency to avoid risk at all costs is what psychologists refer to as the zero-risk bias.

For people with disabilities like haemophilia, this bias can significantly impact daily decisions and behaviours. Take, for example, someone like my husband, Jared, who lives with severe haemophilia B.

We've witnessed other members of his haemophilia support group approach physical activity with reluctance, out of fear of triggering a bleed. In countries where access to factor products is limited, like the Philippines, where we live, conserving medication becomes a top priority.

Moreover, activities that involve venturing far from home may be avoided to ensure proximity to medical care and a stable supply of treatment.

The human brain is wired to seek certainty and avoid the opposite. The prospect of risk triggers a sense of discomfort, prompting us to opt for safer alternatives whenever possible. This instinctual response served our ancestors well when survival depended on avoiding immediate danger. However, in modern society, this bias can hinder personal growth and fulfillment.

No risk, no reward

The paradox of the zero-risk bias lies in its potential consequences. While prioritizing safety may offer a sense of security in the short term, it also deprives individuals of the rewards associated with taking calculated risks. This is especially true for those with haemophilia, where avoiding all physical activity can lead to decreased mobility in the long term and, in effect, a diminished quality of life.

Likewise, avoiding "risky" forms of self-expression without first researching the potential risks and ways to mitigate them can deprive people of potentially meaningful experiences. This is particularly significant for those with disabilities, whose opportunity for self-expression has often been marginalized.

Self-expression serves as a vital tool for individuals, including those with disabilities, to connect with others and assert their identity. It plays a crucial role in fostering emotional well-being, building relationships, and promoting a sense of belonging. Therefore, limiting oneself from forms of self-expression due to perceived risks may hinder the development of meaningful connections, as well as personal growth.

By educating oneself about the potential risks associated with certain forms of self-expression and exploring ways to minimize those risks, people with disabilities

In Daily Life With Haemophilia

can reclaim their agency within society and embrace their identity more fully.

Living fulfilled lives

To truly live fulfilled lives, we must recognize that meaningful experiences often involve some degree of risk. Whether it's pursuing a new hobby, embarking on a career change, or forming meaningful relationships, taking calculated risks is essential for personal development and happiness. For those with hemophilia, this could mean exploring the boundaries of their physical capabilities, engaging in fulfilling activities such as traveling, or delving into the realm of self-expression under the guidance of a knowledgeable care team.

It's important to acknowledge that people's risk tolerance varies based on individual circumstances. Factors such as financial stability, access to support networks, and personal health considerations can influence one's willingness to take risks. Additionally, striking a balance between risk and safety is key. While embracing risk can lead to personal growth, it's essential to approach it in a measured and thoughtful manner, taking into account potential consequences and safeguards.

In conclusion, while the zero-risk bias may offer a sense of security, it's important to recognize its limitations and potential impact on our lives. By acknowledging the role of risk in personal growth and fulfillment, people can make more informed decisions and lead richer, more meaningful lives.

Article sourced from: https://hemophilianewstoday.com/columns/it-pays-be-mindful-zero-risk-bias-daily-life-hemophilia/

Shining a Spotlight on von Willebrand Disease

Article by Charles Eddy

Haemophilia takes center stage in our community, it's in our name after all, but there's another inherited bleeding disorder that shouldn't be forgotten. We are here for all bleeding disorders, not just haemophilia.

von Willebrand disease (vWD) is often overshadowed but it is actually the most common inherited bleeding disorder worldwide, affecting up to 1% of the population – that's roughly 1 in 100 people. I'm sure we are all familiar with the name, but what exactly is VWD and how is it different to haemophila?

Unlike hemophilia, which involves a deficiency in specific clotting factors, vWD disrupts a protein called von Willebrand factor (VWF). This protein acts like a matchmaker, bringing platelets together to form a clot and seal off bleeding. When VWD is present, either the amount of VWF is low or its function is impaired, leading to prolonged bleeding times.

There are three main types of VWD: Type 1, Type 2, and Type 3. Type 1 is the most common form, affecting approximately three-quarters of people who have inherited VWD.
The history ofvWD is quite interesting. While documented cases go back to the early 1900s, it wasn't until the 1920s that Dr. Erik von Willebrand identified a young Finnish girl with a unique bleeding disorder. Thankfully, the medical community has come a long way since then, with advancements in diagnosis and treatment allowing people with vWD to lead active lives.

Graphic source: Haemophilia Foundation Australia

Now, let's talk about symptoms. Many people with vWD may have mild symptoms or even none at all. However, some common signs include:

- Easy bruising
- Heavy or prolonged menstrual periods
- Excessive bleeding after injuries, dental work, or surgery
- Frequent or long-lasting nosebleeds

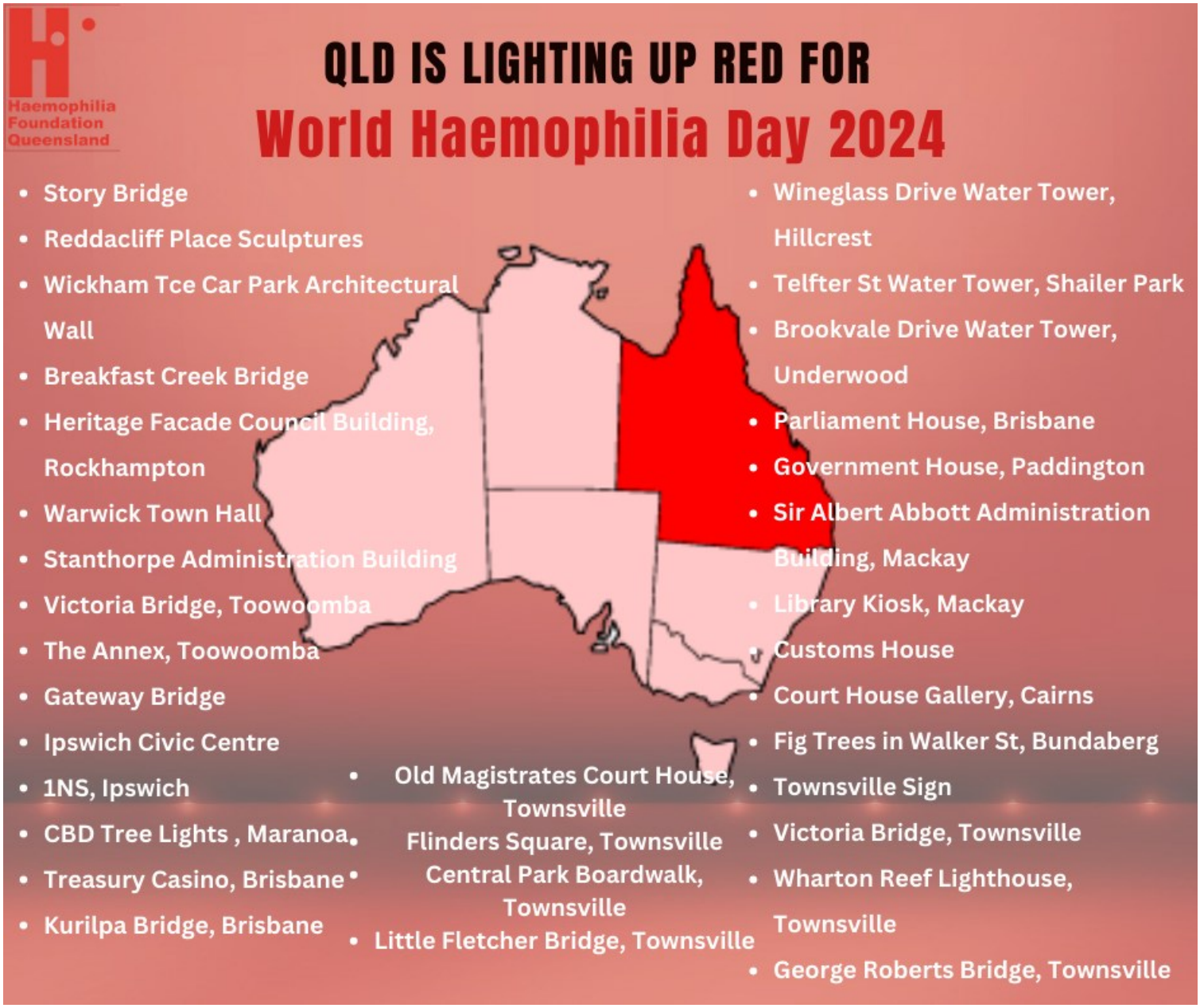
The severity of symptoms can vary greatly depending on the type of vWD. There are three main types, each with its own characteristics.
For people with vWD, daily life can present certain challenges. Activities that might cause minor bleeding in others, like shaving or menstruation, can become a concern. However, with proper diagnosis and management, most people with vWD can effectively control their bleeding and participate in the activities they enjoy.
If you suspect you or someone you know might have vWD, talk to your doctor. Early diagnosis is key, and with the right treatment plan, you can manage your bleeding effectively.
Remember, even though vWD may not be as widely known as hemophilia, it's a prevalent condition within the bleeding disorders community. By raising awareness and understanding, we can ensure everyone with vWD receives the support and care they need.

World Haemophilia Day 2024 Light It Up Red

HFQ has yet again increased the number of landmarks lighting it up red for

World Haemophilia Day on the 17th April.

Make sure to go past your local landmarks and send us any pictures you capture!



Leave A Lasting Gift In Your Will

Haemophilia Foundation Queensland relies on the generosity of the members of it's community to continue to provide ongoing support to those affected by bleeding disorders in Queensland.
One way you can assist us is to leave a bequest to HFQ in your will to allow us to help generations to come.

How?

STEP ONE: CHOOSE THE TYPE OF BEQUEST YOU WOULD LIKE TO LEAVE

Residuary Bequest

After you have looked after your loved ones and any debts, you may choose to leave whatever remains to Haemophilia Foundation Queensland. This is called a residuary bequest because it represents the residue (remainder) of your estate. This is the most effective type of bequest. It maintains the relative value of your gift in comparison to the value received by the other beneficiaries under your will.

Percentage of your estate

Again, this type of bequest has the advantage of not being affected by inflation, maintaining its value over time, and therefore the impact of your gift. The percentage could be any amount you choose up to 100%.

Specific Bequest

This is a gift of a specific monetary amount e.g. $1,000 or a particular asset or item such as real estate, shares or jewellery.

STEP TWO: TALK TO YOUR SOLICITOR OR ADD A CODICIL TO YOUR EXISTING WILL

If you do not have a will, it is best to seek legal advice to draft one that reflects your wishes and circumstances. If you already have a will, a codicil (instruction) can be added. This is an easy way of including a bequest without having to re-write your will. Your solicitor will be able to help draw up the document which needs to be signed and witnessed.

Muscle Loss Common In Haemophilia A Patients

Sarcopenia, or loss of muscle mass and strength, may occur in as many as half of adults with severe hemophilia A who experience recurrent joint bleeds, according to a small study in Turkey.

In addition, measuring muscle mass in the thighs with ultrasound, which is a noninvasive imaging test that uses sound waves, is better for diagnosing sarcopenia than measuring whole body composition, and offers a more accessible way for timely interventions, researchers note.

The study, "The frequency of sarcopenia in haemophilia patients: Effects on musculoskeletal health and functional performance," was published in the journal *Haemophilia*.

Sarcopenia can develop in later stages of joint disease

Bleeding into the joints can cause them to swell or become damaged and limit their range of motion. Sarcopenia can also develop in the later stages of joint disease and further worsen these problems, as weakened muscles cannot support the joints as well, making movement harder.

> ***'We believe that ultrasound is an excellent diagnostic tool for sarcopenia'***

In the study, researchers looked at how common sarcopenia was in 30 men diagnosed with severe hemophilia A who had recurrent joint bleeds as compared with 26 healthy men, and how sarcopenia affected joint health. The mean age was similar beween the two groups (35.4 vs. 32.8 years).

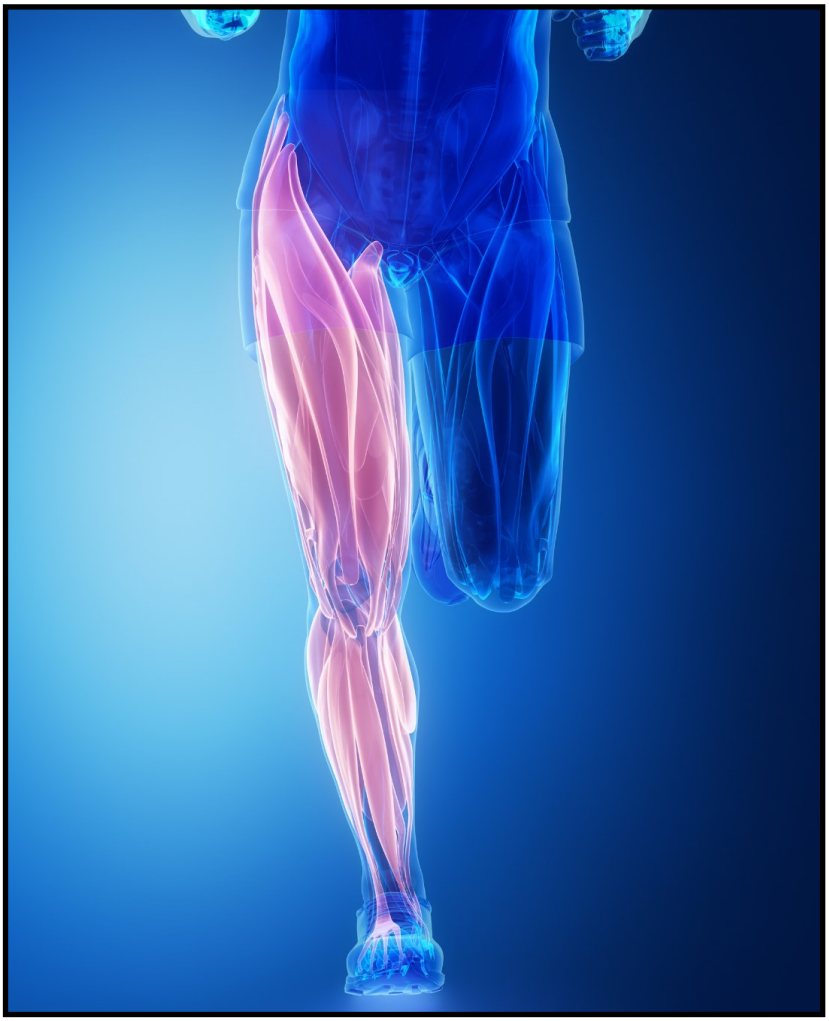
On average, patients experienced 25 joint bleeds a year. The joints most affected by recurrent bleeds were those in the knees, followed by the elbows and ankles. Four patients (13.3%) had undergone orthopedic intervention. Eleven (36.7%) had a history of synovectomy, a procedure used to treat joint inflammation.

With Recurrent Joint Bleeds

A modified Sonographic Thigh Adjustment Ratio (STAR) was used as a measure of muscle mass. It was calculated by finding the average thickness of the rectus femoris and vastus intermedius (two muscles in the front of the thighs) between the left and right sides, obtained by ultrasound, and dividing it by the body mass index.

The mean body mass index, a measure of body fat based on weight and height, was similar between the two groups (27.3 vs. 26), but mean STAR scores were significantly lower in patients than in healthy men (1.42 vs. 1.94). Based on STAR scores, 15 patients (50%) had sarcopenia.

The researchers also used bioelectrical impedance, which measures body composition based on how fast an electrical current travels through the body, as a way to diagnose sarcopenia.



However, when using this method, two patients (6.6%) met the criteria for sarcopenia.

In all patients with sarcopenia, regardless of how it was diagnosed, muscle strength and functional performance were below normal. Functional performance was assessed by how far and fast patients could walk, or how fast they could stand up from a chair.

"For the diagnosis of sarcopenia, decreased total and/or regional muscle mass together with decreased muscle strength and/or low physical performance are required," the researchers wrote.

The modified STAR was strongly linked to the Hemophilia Early Arthropathy Detection -Ultrasonography score, a measure of joint disease, as well as to the Hemophilia Joint Health Score.

For bioelectrical impedance, the link was weak.

Similar findings were obtained when looking at the link between the modified STAR and hand or knee muscle strength; measures of functional performance like walking speed; or the time taken to complete five repetitions of sitting and standing up.

"The routine use of STAR scoring … could lead to earlier diagnosis and more effective interventions against sarcopenia, such as exercise, protein, calcium, vitamin D, creatine [a source of energy in muscles] supplements, and lifestyle modifications," the researchers wrote.

Article sourced from: Sarcopenia common in severe hemophilia A with joint bleeds: Study (hemophilianewstoday.com)

Welcoming our newest Board member …

Tell us a bit about yourself.

.After marrying my husband Patrick, also an accountant, I moved back to Brisbane and was Financial Controller for a providoring company until we commenced our family. We had four children in 4.5 years (no twins), so life was terribly busy at that time. I have worked/consulted in our own family accounting practice since then and although I only work a couple of days now, I am looking forward to retiring over the next few years.

Growing up in Toowoomba laid the foundation for my journey to date. After my schooling I initially worked for the Justice Department before pursuing a Bachelor of Business majoring in accounting at the University of Southern Queensland. Post-graduation, I assumed the role of Chief Accountant at the then Jupiter's Casino.

The narrative took a significant turn after marrying my husband, Patrick, who shares my passion for accounting. Relocating to Brisbane, I transitioned into the position of Financial Controller at a providing company until the beautiful chaos of parenthood. Over the course of 4.5 years, we welcomed the arrival of four children, making life wonderfully hectic.

Amidst the joys and challenges of motherhood, I seamlessly integrated my professional life into our family dynamics. My dedication to our own family accounting practice has been a constant, even as my involvement has evolved over the years.

Currently, I choose to work part-time, balancing my responsibilities. As I approach the prospect of retirement in the coming years, I am looking forward to new challenges, including this new position with HFQ.

What was your introduction to the world of bleeding disorders?

One evening our daughter Elyse, slipped and bit her tongue. Initially it was just a little bleed but by morning it had not stopped, and we went to our GP. When the bleeding continued, we took her to a private emergency department who reassured us tongues bleed so not to worry. The bleeding continued and became more intense, so we returned to hospital where Elyse was taken into surgery and her tongue stitched. On our return home she continued to bleed. I was speaking to the surgeon every day, but he was not concerned as there was no history of bleeding in our family. One morning we entered her room to find her covered in blood and blood everywhere. She was rushed back to hospital; this time she needed her stomach pumped and tests revealed that she had Von Willebrand Disease. Testing of her older brother indicated that he also had Von Willebrand however her sister tested negative. I was heavily pregnant at this time and when the baby arrived, he too was tested and found positive. The medical team at the time were interested in our genetics as there had been no history of bleeding in either of our families up to that point.

With two boys and a girl with bleeding disorders we became regular visitors to the Childrens

Bernadette Staunton

Hospital and with further testing the diagnosis was changed to Mild Haemophilia A for the boys and symptomatic carrier of Mild Haemophilia A for Elyse. When Elyse was in high school, she had a fall and injured her knee. She did not respond as well as expected and required treatment for many months. Eventually she was diagnosed with both Haemophilia A and Von Willebrand Disease. All three children have led full active lives and although the boys have needed treatment from time to time it is Elyse who has had the most need for medical intervention.

As a family we were not overwhelmed by the children's diagnosis. Our approach has always been to mitigate risk whilst still allowing the children to have as full and active lives as possible. The playing of Rugby League, Rugby Union and motorbikes were the only things we outright banned and thankfully our boys both grew to love and succeed at a high level in Soccer. All the children's hospital treatments have resulted from minor trauma incidents.

What made you join the HFQ board?

I feel very privileged to have been able to raise my children to adulthood with the support of the Hospitals Haemophilia staff and HFQ team. My recognition and respect for those who have helped us on our journey has made me want to give back to the community in any way I can.

For some families, a bleeding disorder diagnosis can be very worrying, and the support, information, and friendship offered by the HFQ is a real lifeline. I would like to offer my help to those families to ease the burden and smooth the path for their own journey's.

I hope that my involvement may encourage my children to become involved and support and reassure others in the community as well.

What has been your favourite HFQ event so far?

As a large family we relied on each other for support throughout the children's early diagnosis but have always found the HFQ's regular publications offer a wealth of knowledge. We find these regular newsletters to be both very professionally produced and very informative. In 2022 Patrick, I and the three children with disorders attended the function at Government House for World Haemophilia Day. It was so wonderful for the children (now young adults) to meet with the specialist physicians, nursing and support staff that had supported them particularly those from the Childrens Hospital who they had not seen for years. It was great to have an opportunity to thank them personally for their time and talents and for them to see our children had flourished and are now happy successful young adults albeit still needing the care and attention of the wonderful RBWH staff from time to time.

When Elyse was in early high school, she was spoke at a Haemophilia convention on the Gold Coast. After speaking to other young women at the conference she understood that she was not alone and other females with bleeding disorders existed and had full happy lives. This realisation was a great benefit to her.

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

Over the 25 years that we have been part of the bleeding disorders community it has been interesting to see advances in treatment in drug treatments and gene recognition and therapy. With significant research, trials and advancements both in Australia and overseas I hope that not only my children and descendants, but the greater community, will be able to be accurately diagnosed quickly and have single vector doses available for one time treatment of the disorders.

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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