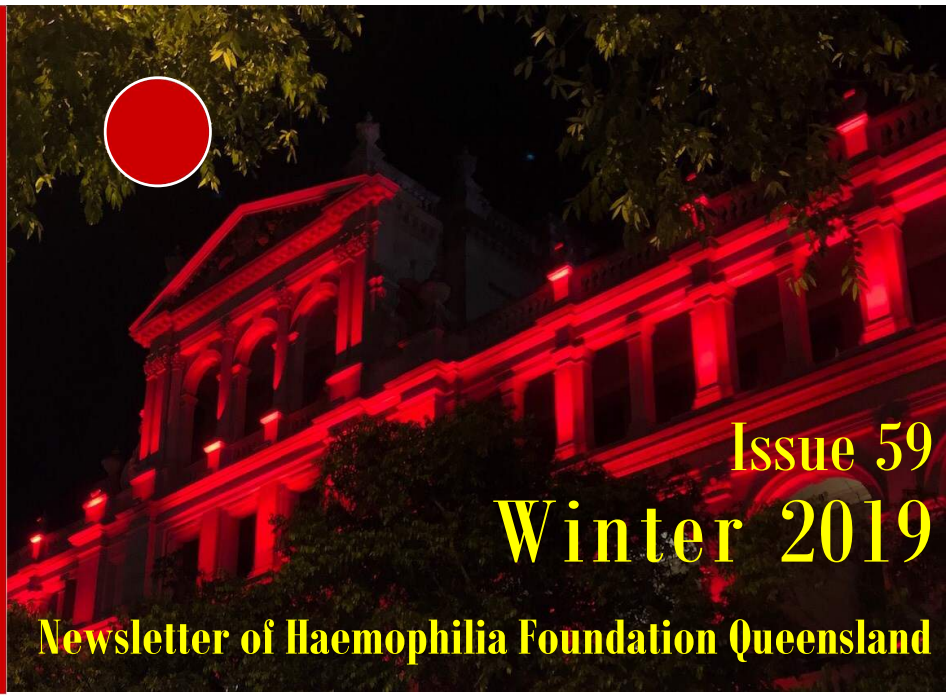
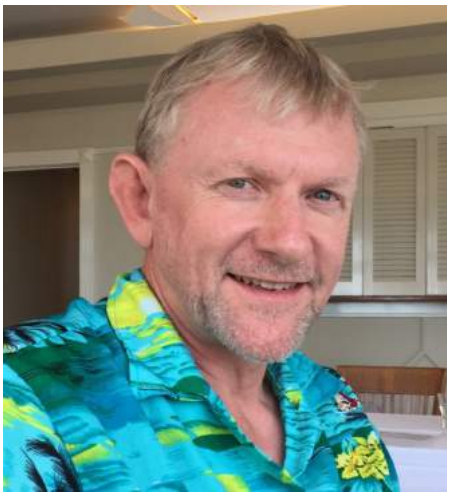
the I FACTOR



Issue 59
Winter 2019
Newsletter of Haemophilia Foundation Queensland

From the President



Hi again everyone,

We are nearly half way through the year and time is flying. This month I want to talk about treatment adherence - how closely do you follow your treatment plan. For many I know it can be a bit hit and miss as life can get in the way. Some tell themselves 'I will do it later' but later doesn't happen, whereas others are more rigorous and treat religiously to avoid bleeds and achieve what they need to. Remember every bleed causes some degree of permanent damage that accumulates over time.

A realistic responsible approach is ideal, which is fine, but is perhaps a little more challenging for young adults managing social change. It is clear from research that many young adults struggle. A US study back in 2016 found 17% of youth aged 13 to 17 were non adherent and it got worse at age 18 to 25 where 47% did not adhere to their plan. For some that miss a treatment, where there was no bad result, their thinking can change to 'do I really need this' as I am fine. But as we well know - missing a treatment increases the risk of a severe bleed. So my message to everyone is to take some time to talk about this with others, set up a reminder on your phone … look after your future health.

David Stephenson
President HFQ
president@hfq.org.au

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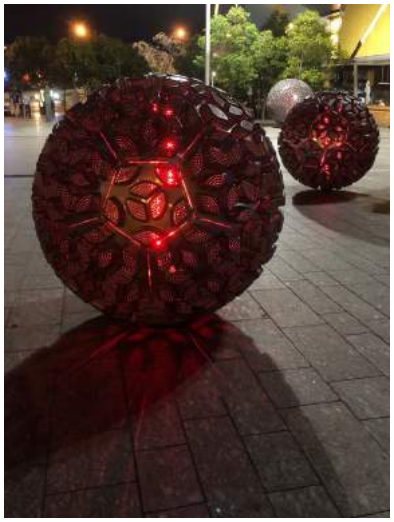
World Haemophilia Day

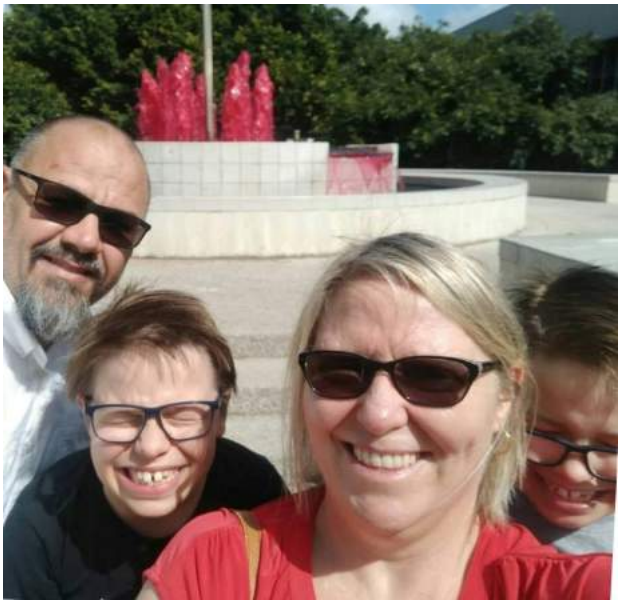
This April, landmarks all over the world were lit up in red in a show of support for World Haemophilia Day. Bridges, fountains, statues and buildings were lit as people come together to increase awareness of haemophilia and other inherited bleeding disorders under the theme "Reaching out - connect to your community!"

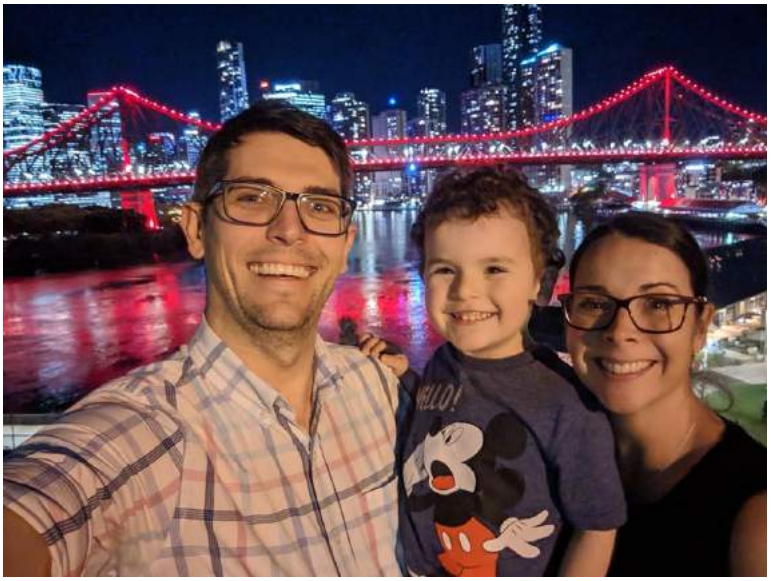
What a great showing Queensland had both in Brisbane and regionally. HFQ would like to thank you so much to everyone who participated in Light it Up Red! for World Haemophilia day on Wednesday 17 April 2019.

World Haemophilia Day is a great way for HFQ and our families and friends to bring awareness of haemophilia and other inherited bleeding disorders. The lights this year were spectacular!



Your support is invaluable and hope you'll be joining us again next year.





ABOUT HFQ

The Haemophilia Foundation of 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 assistant. 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 122 Fortitude Valley, Qld 4006

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)**
- **Discounted Movie Tickets**

HFQ Management Committee

President	Mr David Stephenson
Vice President ...	Mr Robert Weatherall
Secretary	Ms Lauren Albert
Treasurer	Mr Adam Lish
Members	Dr John Rowell
	Mrs Leanne Stephenson
	Mr Mike O'Reilly
	Mr Mike Holloway

HFQ Delegates to HFA

Mr Adam Lish & Mr David Stephenson

Acknowledgements

HFQ is grateful for the support of our patron: His Excellency the Honourable Paul de Jersey AC .

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*

QUEENSLAND HAEMOPHILIA STATE CENTRES

CHILDREN'S CLINIC

PAEDIATRIC CLINIC STAFF (QCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown – Haematologist

Haemophilia Fellow -– Dr Antoinette Runge

Haemophilia Registrar – Dr Nathan Morgan

Joanna McCosker – Nurse Practitioner

Amy Finlayson / Salena Griffen – Clinical Nurse

Stephanie Manning – Physiotherapist

Dr Moana Harlen - Senior Psychologist

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 LCCH-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 LCCH-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 2e outpatients Level 2, Thursday afternoons 1.00 – 3.30pm

ADULTS CLINIC

ADULT CLINIC STAFF (RBWH)

Dr Jane Mason - Haematologist	3646-8111 *(Mobile 0452 055 025)*
Beryl Zeissink - Clinical Nurse Consultant	3646-5727
Alex Connolly - Clinical Nurse (Part time)	3646-5727
After Hours - Page Haematologist	3646-8111
Scott Russell - Physiotherapist	3646-8135
Loretta Riley - Advanced Social Worker	3646-8769

Contacting the Clinic ***Please telephone in the first instance.***
Appointments 3646-7752 or 3646-7751 or speak to Beryl

Haemophilia and Genetic Clinic — Dr Jane Mason — Wednesdays 1.30pm New Patients Thursdays 8-9;30

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 LCCH-Haemophilia at QCH and Beryl at RBWH.

Home Delivery of Factor

The benefits of home delivery

In Australia, we are truly the lucky country we have access to free products and have the option to have it delivered to our door. How good is that?

Home delivery allows you to have your product delivered to your door. It is a very beneficial service to the majority of patients who use it.

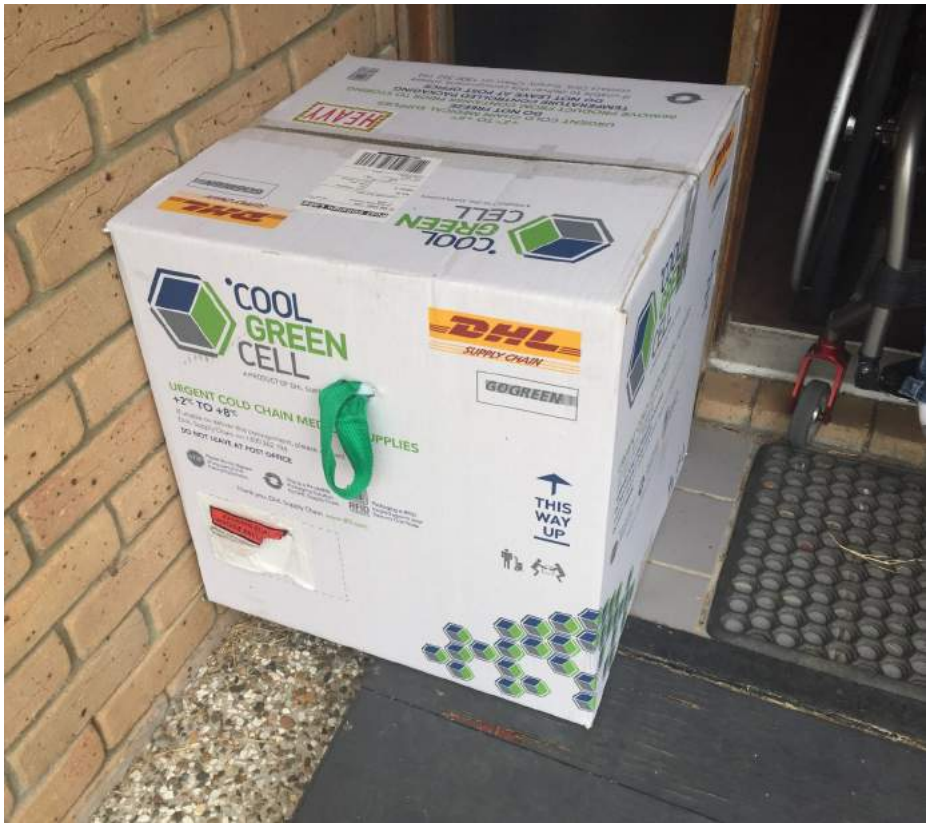
Regular home delivery means you have sufficient stock at home to treat bleeds or give your regular prophylaxis. This can make all the difference to being able to give timely treatment and not have to come to the hospital for product.

Home delivery also saves you time and money by having one less trip per month to the hospital and no paying for parking.

With benefits comes responsibilities?

As with all deliveries / services to the home there are a few things we need to do to make it work smoothly, which can sometimes be an inconvenience.

1. Please be available (via phone / email) to stock take your product a week prior to your next due delivery.
2. Please be home during your nominated delivery window
3. If you are not going to be home to accept your product at the agreed delivery window, a minimum of 48 hours-notice is required to have the delivery changed.
4. Please do not try and change times with the couriers on the day for a later delivery. This requires 48 hours' notice.
5. In the case of an emergency it is understandable if you need to reschedule the delivery. Please ensure you contact the company in the event of an emergency.



What happens if I am not at home?

Your product will be automatically redirected to your HTC or nearest nominated hospital.

You will then be required to organise your own pick up from the hospital and will not be able to renegotiate with the courier for a later time (even if it is only 15 minutes later)

If you are not home or are late then the couriers apply extra charges to the company who delivers your product for the first missed delivery but also for any subsequent deliveries.

If failed home deliveries continue to occur then your home delivery is put at risk and the company and the HTC will review your suitability for home delivery.

If home delivery is cancelled you will be asked to collect your product from a hospital near you that stocks factor products.

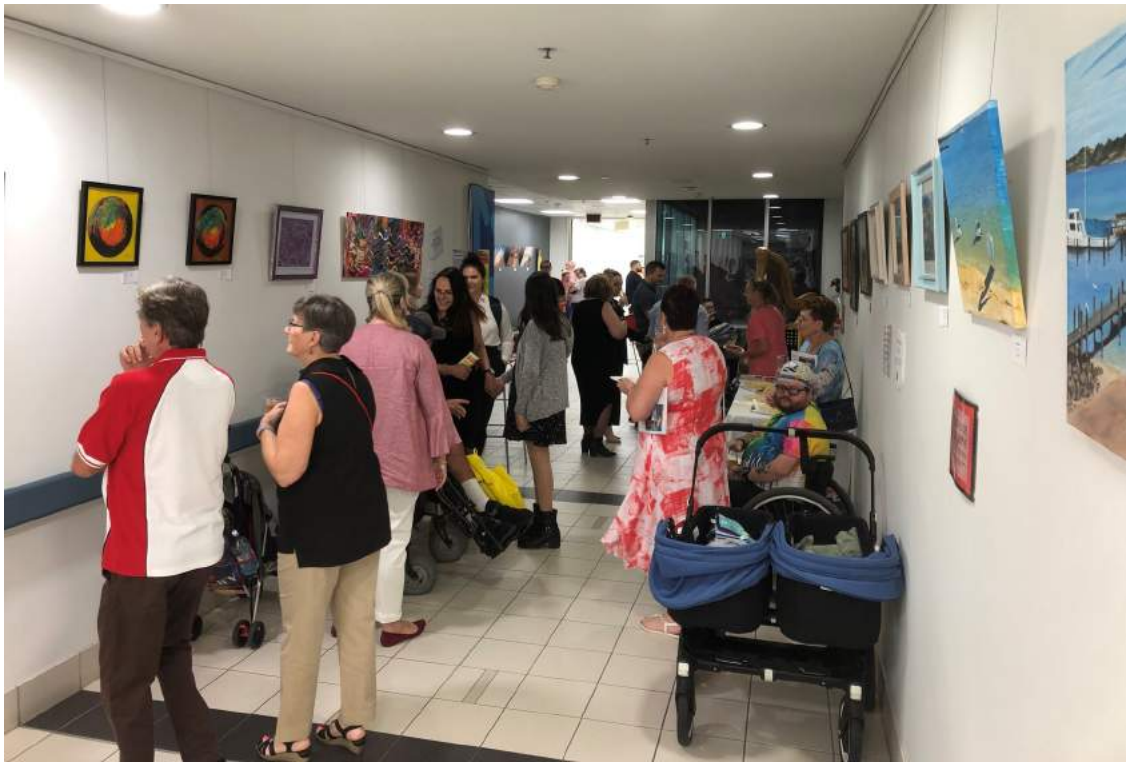
If you have any concerns or questions please talk with your HTC staff.

Joanna McCosker
Nurse Practitioner
Haemophilia & Bleeding Disorders
Qld Children's Hospital
M: 0438 792 063

Art and promoting community awareness

I have had quite a busy time since the last edition of H Factor, with little time for procrastination. The lead up to April and throughout April had Graham and I learning many new skills- hanging art work and organizing an "art gallery" opening event, and greatly enhancing our problem-solving skills to name just a few.

For our inaugural Art Exhibition event, we were able to show 35 pieces of work, from abstract art, graphic art, watercolours, photography, acrylics, feltwork, ceramics and woodwork (my apologies if I have incorrectly named your mode of work) from 10 talented artists. Four art works were sold, but many more created discussion within the wider community. I wish we could have captured the discussions along the corridor during the exhibition. My sincere thanks to all the amazing artists who bravely showed their work. I feel extremely privileged and humbled to be able to coordinate this event with you.



Not only were the pieces from different modalities, but the artists also covered a significant cross section of the community – from different diagnoses, people with a lived experience of a bleeding disorder, parents, carers, partners of people with a bleeding disorder. For me it showed the community that as people we are more than a role or a diagnosis – there are many facets of our identity and being a member of the inherited bleeding disorders community is just one part. The stories/bio's that were also presented as part of the exhibition spoke loudly about inherited bleeding disorders, as did the quotes that Graham was able to gather from around the world regarding what people in the wider inherited bleeding disorder community would like others to know. I think that the Art Exhibition was a small step for us into promoting the value of sharing the lived experience within the wider community.

We also incorporated a "exhibition opening event" – (although it was held in the middle of the exhibition) – to celebrate World Haemophilia Day. The artists were joined by their family and friends, members of the inherited bleeding disorders community, staff from Haemophilia Foundation QLD and their family, some of the QLD Haemophilia Centre Staff and their families and Welfare staff from Cancer Care Services for a social gathering in the RBWH Art Space, whilst guests were serenaded by Maddi and Bart from Duo Faun. An unexpected positive outcome was the connections that people were able to make with others in the community, by just being able to have time to talk informally within the event space. Hopefully these connections can continue to grow.

Given the resounding feedback that the event and exhibition was a success and that all people who gave feedback would attend next year, I am in the process of securing us another exhibition next year. I have learnt a lot from this event and hope to utilise the knowledge gained from these reflections and feedback for next year's event.

So, in view of my plan to reduce procrastination, I will use this opportunity to send out an early request for all "artists" to start drawing, photographing, sculpting, spinning, painting and any other creative, artistic endeavour to make the 2020 Art Exhibition even better. We also would like a creative name for our exhibition if anyone has ideas. I would like to ask for any musicians who would like to play a 'set' at next year's gathering to be in touch. We will perhaps see you on the 17th April 2020 at RBWH Art Space?

Loretta

Loretta riley
Advanced Haemophilia
Social Worker, RBWH

PROBE for real-world evidence

The real-world PROBE study is now available!
What is the impact of haemophilia and treatment on Australians? How can we have access to high quality evidence about this?

With new treatments becoming available this kind of evidence is particularly important. We need to be able to explain what it's like to have haemophilia and the impact of different types of treatments. HFA's advocacy relies on credible data. Without this data we have not had enough strong evidence to use in our advocacy for new treatments.

The PROBE (Patient Reported Outcomes Burdens and Experiences) study is a great opportunity for you and others in our community to give this evidence.

What is PROBE?

PROBE is a multi-national research study (*www.probestudy.org*) which allows people with haemophilia to report their haemophilia severity, treatment history and the impact of haemophilia on their daily life. It compares their answers to other people in their community who do not have a bleeding disorder.

You may have done the PROBE survey in the past. This was testing the survey. In 2015 Australia joined more than 20 other national haemophilia organisations around the world to successfully test and validate the questionnaire. The international PROBE team is led by well-respected haemophilia organisation and academic investigators.

This time the PROBE study is collecting real-world evidence. Statistics from Australians who complete the questionnaire will be provided to HFA by the international team for us to use in our advocacy and planning for the future.

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.

You may also like to pass the survey on to your partner/wife/ husband or other members of your family or interested friends.

We need a few hundred Australian participants for good quality results, so the more people who complete the survey, the better!

How to do the survey

The questionnaire is available:

Online at *https://plus.mcmaster.ca/PROBE/*
Or **call or email the HFQ office** (or **HFA**) for a **print survey pack**

What happens to your data?

All responses are anonymous and confidential. They are combined as statistics and will not identify individuals. The survey is voluntary – it is up to you if you want to complete it and no one will know if you have or haven't.

And our thanks to the many people who have already completed the survey. We are off to a great start!

More information

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

Or contact Suzanne at HFA:
E: *socallaghan@haemophilia.org.au*
T: 1800 807 173

What is tranexamic (tran-ex-amic) acid?

Tranexamic (tran-ex-amic) acid (TxA) is also known as "**Cyklokapron" (CY-klo-capron).**
TxA is used in haemophilia and some other bleeding disorders to help stabilise a clot and stop the breakdown of this clot by the body's natural processes.

Fibrinolysis is the process that prevents blood clots from growing excessively in your body and is the body's way of breaking down clots once they have done their job in stopping the bleeding.

Blood clots are made up of fibrin, a protein that forms a mesh across the site of injury which stops the bleeding; this is what we call a fibrin clot.

A blood clot is formed when factor VIII (8) and IX (9) do their job in the coagulation (clotting) cascade so it is important to seek advice about appropriate factor replacement before starting tranexamic acid.

To next page ⟶

Dr Lean spends 5 minutes with Brett

After seeing my GP for just over 30 years and he decided to retire. It was pretty hard trying to find a new GP.

After speaking to Robert Weatherall he suggested I should see his GP as his GP had been seeing him for the last 20 years and has knowledge and expertise in the bleeding disorder community.

In this issue of 5 minutes with Brett, I sat down with Dr Danny Lean...

How long have you been a GP for?

I've been a GP for the last 25 years.

What's your role in the bleeding disorder?

Apart from the usual GP things such as writing prescriptions, medical advice I also give factor VIII as needed.

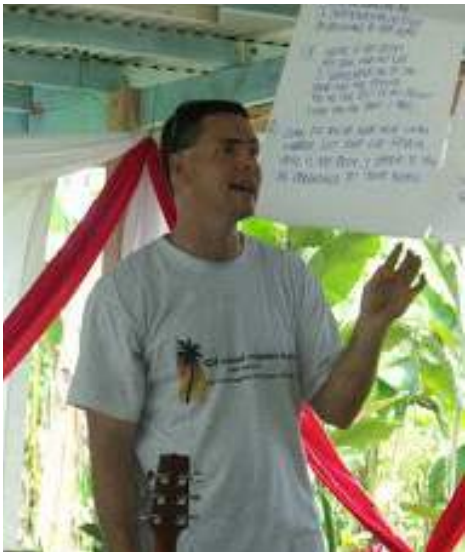
How long have you been treating people with a bleeding disorder?

Just over 20 years.

What are your hobbies?

Running, swimming, cycling, playing the guitar and singing.

You and I have spoken in the past about you donating your time/services to countries less fortunate than Australia. Can you explain what this is about?
One Salt Water is a not-for-profit charity and outreach program to countries such as Papua New



Guinea, Vanuatu, Tonga and Thailand. Where we've built foundations for hospitals, built fresh water pumps, give out medications,

Is it a bit like doctors without borders?
Yes, but without the huge infrastructures our group is a Grass Roots.

Is it just doctors that donate their time or are other people such as nurses, Psychiatrists, social workers etc?
We have everybody because we believe every Aussie is sufficiently educated and resourced to be part of the mission.

What countries have you been to and what are the reasons you go? Apart from Papua New Guinea, Vanuatu, Tonga and Thailand, we also go to Israel because my hero Jesus came from there.

How many years have you been donating you time?
15 years.

How does this effect you seeing people less fortunate then let's say Australia?
Relative because I see the same needs for help love just as overseas or outback and indigenous communities. We all need love and practical support.

If you would like to be a part of 5 Minutes with Brett please send me an email to silverbluearts@bigpond.com
Because of the amount of space in the magazine we can only do half a page to a full page.

From other Page…

Tranexamic acid slows the breakdown of blood clots, so bleeding does not restart.
TxA comes in 500 milligrams (mgs) tablets, these are white and easily crushed and dissolved in water, juice or milk.

One dose is not enough!
TxA needs to be taken three times a day for up to 5 – 7 days. It is particularly useful in mouth bleeding, post dental procedures and for heavy periods. Your health professional may sometimes prescribe TxA for longer than 7 days.

Important:
1) If you or your child has renal (kidney) problems please let your treating health professional know as TxA is excreted by the kidneys.

3) If you have blood in the urine do not take TxA unless you have been directed to do so by your health professional, as clots may form that block your kidneys.

Joanna McCosker
Nurse Practitioner
Haemophilia & Bleeding Disorders
Qld Children's Hospital
M: 0438 792 063

Using Ice for Bleeds

The RICE (Rest, Ice, Compression, Elevation) principle continues to be advised for bleeding episodes in patients with Haemophilia with ice being an integral component. However, we recognise that ice is not helpful in certain situations for certain patients. Here we will discuss how ice works so it can be best understood when to use it. To do this, let's talk about how ice affects the body through the following mechanisms: vasoconstriction, reduced secondary damage and reduced pain.

Vasoconstriction

Vasoconstriction is a process where blood vessels narrow. When exposed to cold temperatures, this process kicks in and has the effect of reducing blood flow to the targeted area (think of the pale appearance of your fingers in cold weather). This is beneficial since reduces the amount of blood entering a joint or muscle during a bleed.
Reduced secondary damage
Bleeding results in secondary damage to tissue (particularly a joint). Ice can reduce this by limiting secondary inflammation (through vasoconstriction) and keeping the tissue around the bleed from being affected.

Pain

Ice has a 'numbing' effect on areas it is applied to. It does so by affecting the ability of nerves to send the signals from the tissue, thereby reducing the feeling of pain.

When Ice may not be helpful.
Due to it's effects on blood flow (through vasoconstriction), ice can make an arthritic joint feel more stiff and uncomfortable by affecting the synovial fluid that lubricates a joint. If you are experiencing arthritic joint pain only, then it is perfectly fine to forego using ice if you feel it isn't helpful. However, if there are signs of bleeding such as increased swelling then ice is usually recommended. As always if in doubt, contact your Haemophilia Treatment Centre for advice.

Scott Russell
Physiotherapist

Community Camp 2020

HFQ Community Summer Camp

a great reinvergrating time away

Announcing our 2020 Summer Camp

Fri 3rd April to Sun 5th April

Noosa North Shore Retreat.
1 Beach Rd, Noosa North Shore

$75 per family
$50 per couple
$30 per individual

Camp is a space that allows everyone to be uniquely themselves and creates an atmosphere of support and inclusiveness

Online registration is now open

Noosa North Shore Retreat 3 - 5 April 2020

https://www.hfq.org.au/get-involved/events/camp Mob 0419 706 056

Haemophilia Foundation Queensland Inc.

Membership Renewal Time

HFQ membership subscriptions are due for renewal. The side of this page can be torn off and used as your 2019-2020 Haemophilia Foundation Queensland (HFQ) membership form.

HFQ is not like life insurance. It is not a union, nor a church or a school; but we are a community of people dealing with the issue of living with a bleeding disorder. We are a registered incorporated society that because of our financial members can prove that we represent people with bleeding disorders in Queensland.

Through the HFQ board and subcommittees we advocate for improved services and programs on your behalf and we provide direct programs and activities where you have made the need for these apparent to us.

We only have one part time staff member, so your fees are important to us. Over the past 12 months HFQ has continued to provide services to the bleeding disorders community in Queensland and we rely on your support in the form of membership to maintain these services.

Limited funding from Qld Health provides financial support which goes a long way in allowing us to deliver outcomes for our community. Although we are excited that our current grant has been renewed for another three years, there are a number of the activities that we do, that require us to raise money elsewhere and independently of Qld Health.

Community Camp, regional support activities, youth camp & mentoring activities, health & wellbeing seminars, welfare support for those in need, and a range of targeted services in partnership with the Queensland haemophilia centre addressing community needs could not be achieved on Qld Health money alone.

Having a membership base allows us to demonstrate we represent the bleeding disorders community and the fees you pay help make up the shortfall in the programs we currently provide.

We rely on fundraising to ensure these services happen and I thank those who donate to us or volunteer their time at events like Bunning's BBQ's and the like.

A significant part of fundraising is membership subscriptions and this is one easy way you can help HFQ help those in need in the bleeding community.

Please complete the attached membership form of go to our website where you can renew and pay on-line (*https://www.hfq.org.au/get-involved/memberships*). HFQ looks forward to your continued support and thanks you for your subscription.

We recognise that the small annual fee can still be too much for some people, so we also have provision for accepting members in financial distress so that you still remain part of our organisation. Please talk to Graham if you are in this situation

Regards,

David Stephenson

President HFQ ..... Advocacy, Health promotion, Education, Support

HFQ MEMBERSHIP RENEWAL

Haemophilia Foundation Queensland Inc.

Please tear off this section & fill out the details on the reverse or renew your membership online at: http://bit.ly/2s1XtYd

Membership of HFQ for 2019/20 is $20 per annum for each membership or $100 for a lifetime membership. These fees are due at 1 July each year and membership is open to all people with a bleeding condition, their families and people wanting to support a person with a bleeding condition.

Please fill out this form, tear if off and return to HFQ at PO Box 122 Fortitude Valley Qld 4006

Name: _____ **Email:** _____

Address: ☐ _____

Phone No: _____ **Donation : $** _____

☐ **Membership:** Annual ($20) or one-off payment ($100) **Total: $** _____

Helping out at HFQ

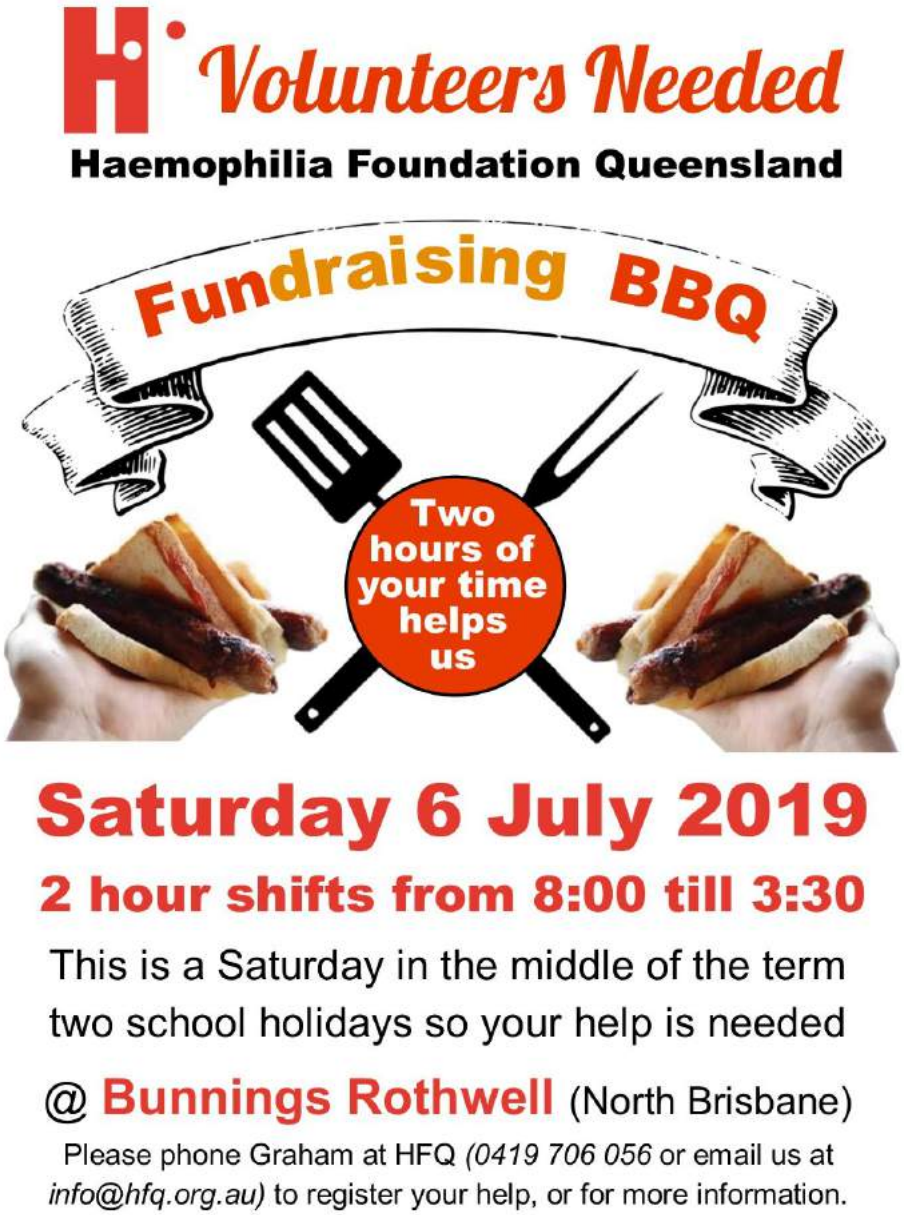
We often need help at HFQ, Right now we are looking for fundraising volunteers and board members.

HFQ is Queensland's only organisation advocating for and supporting people affected by haemophilia and other bleeding disorders in this state. The organisation is run entirely by family members and friends of people living with a bleeding disorder.

If you are active in our community (or want to be) and are willing to be an ambassador and advocate for the values and mission of HFQ, then consider becoming a volunteer or joining the board. Volunteering for fundraisers can be fun and so can working as a board member.

With your help we can accomplish good things for the Queensland bleeding disorders community.

Please talk to Graham at HFQ (0419 706 056 or email us at info@hfq.org.au) for more information



Thinking About Your Condition

The way you think about your condition can make a difference

Are you in charge of your condition, or does it always have the upper hand? Learn how some people have gotten back in control. It could happen for you, too.

Does your bleeding disorder own your life, or is it just another part of you?

Let's say your condition is like a piece of clothing. What does it feel like? Is it light and easy to wear, like a t-shirt? Or does your condition slow you down and weigh a lot, like a wet and heavy winter coat?

If your condition feels as heavy on you as that coat, do you wish there was a way to feel better? To take away the weight of the "coat" and get on with your life?
There is.

Mind over matter

The way you think about your bleeding disorder can actually make a difference in how you feel and in how healthy you become. Your mind plays a big part in how you feel from day to day.

Think about this: When people with chronic pain believe they're able to handle it, they don't feel the pain as much as people who believe nothing they do can help. The control that you can have over your health is called self-efficacy. With self-efficacy, you're more in charge of what happens to you. Which means your bleeding disorder will be less in charge of your life.

How do other people get in charge of their chronic illness?

There are lots of different ways that people take control of their condition. Let's look at a few of them:

Keep a positive attitude.

Staying positive has a big impact on how you feel. Pay close attention to your thoughts so you can notice when negative thoughts creep in and make a point to change them. Try and remind yourself that not every day is the same and be grateful for better days.

Get out the door.

It can help to save your energy and plan your activities for the day – to "get up, get dressed, and get out," no matter how you are feeling. Try not to focus on your condition all the time. It will always be there, but if you have a project that you're working on every day it can help to redirect your attention from your bleeding disorder.

Find fulfilling activity.

Sneha Dave has ulcerative colitis. She believes it's important to find something to do that makes you feel good. For her, it was helping others.

She created a support group while at college. "After coming home from my first surgery, I was certainly depressed," she says. "While this severe depression lasted only a short while, my mother convinced me to do something that would take my mind off the situation. For me it was philanthropy and giving back, but for many people it is art or music. Surround yourself with some or many activities that can be an escape from your illness."

Edited for size from an article by Fiona Akhtar that first appeared in RareMark on 22 May 2019
https://raremark.com/articles/the-way-you-think-about-your-condition-can-make-a-difference--1051?utm_campaign=Hemophilia_Newsletter_May_2019&utm_medium=email&utm_source=Net_Results&utm_content=Hemophilia_Newsletter_May_2019#

A Woman's Perspective: life with a partner

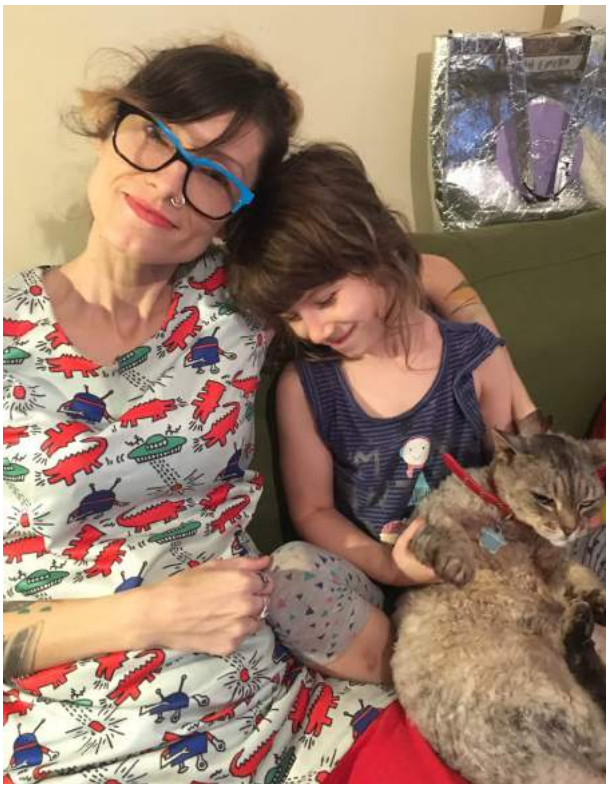
When I first met Michael it took me a month or so to twig that he had haemophilia. I'd noticed the band aids on the back of his hands, but as a 6"5' chef, I assumed his hands got in the way of dicing and slicing more often than a mere mortal. His niece sweetly referred to him as a haemophiliac at a dinner one night, and I thought it was a really weird term of endearment. Then later I got the full story, and witnessed the full extent of what it meant to have severe haemophilia A.

There was the potential for us to have girls with bleeding tendencies, as most of the females in MJ's family would likely have mild haemophilia but didn't get diagnosed or treated in the past. So I sought a HTC appointment, as well as genetic counselling with both pregnancies to cover all bases. I was told 'NOT TO WORRY' because the likelihood of a 'symptomatic carrier' (an outdated, offensive term) female being born to a father with haemophilia was 5%. We now know that carriers have an 'up to 50%' chance of having significant bleeding tendencies, thanks to advances in the understanding on females who carry the gene.

My first obligate carrier daughter was born via von teuss extraction - a vacuum delivery - which would in no way be recommended for a boy with the potential of having haemophilia, so why would it be a default option for a girl? After doing some research, I complained when compiling my next birthing plan that knowing I had an obligate carrier daughter, a vacuum extraction should not have been offered. Their solution was to use forceps next delivery, which is similarly bad, but how is the patient to know? After Eartha's diagnosis at 4 months, I felt sick for nearly a year after, thinking about what could have happened to her if the forceps birth caused any additional trauma.

Getting the girls checked

Linka, my first obligate carrier, was in hospital for a bad virus around her 2nd birthday (when I was heavily pregnant with my second daughter). She was having so many blood draws, I thought it would be a good time to get her levels checked, acknowledging there were carriers in my husband's family with low levels (who were never encouraged to seek diagnoses). I was denied time and time again by hospital staff, but luckily I ran into Jo McCosker and had my first 'business' chat with her and she organized some bleed tests to get her levels checked.



When Eartha was 4 months old, she began to get haematomas on her chest from being handled. I was confused by the first one, and ran her to my family GP when the another one popped up the next day. I had previously told my GP how hard it had been to get Linka's factor levels checked, and she was forethinking enough to give me a pathology slip for a factor check for Eartha when the time was right. So I was already armed with the paper, and raced to a child pathology lab on the way to our GP appointment because, having lived with a husband with severe haemophilia for nearly 10 years, luckily it was the first thing on my mind. The GP said the haematomas were nothing she could place, and to wait to hear back from the results of her bloods. At 11pm that night, I got a call from the lab telling me to race Eartha straight to emergency, and that her factor levels had come back as being less than .01%.

I'd never been to the children's hospital and didn't know where it was so took her to RBWH and the doctor who saw us, along with an army of 5-10 student doctors told me that I had heard the lab's results incorrectly and that there was absolutely no way a girl's factor levels could be that low, I didn't have the skills and vocabulary or energy to advocate properly for us that day, but I never miss a chance to do so now! Again, the paeds HTC team saved the day, and we began to be diagnosed and treated accordingly. And there began an amazing relationship with all the magical staff at the Children's Hospital who we adore.

Living with a Port-a-Cath

Every time a patient with a port experiences a fever over 38 or so, they are required to head straight to emergency to have blood cultures tested to rule out the possibility of a port infection, which can be life threatening. For a young child starting out in the public care system, a fever is pretty much a weekly occurrence. So for several years we were off to hospital to get blood cultures taken most weeks. And initially, we were required to stay for 48 hours each time as a safety precaution, but I sweet talked our way out of this, as the medical team deemed it safe and getting back to hospital wouldn't be difficult as we're local. The hit on a parent's ability to work when they're always in hospital is very draining, financially and emotionally.

Her first port which was installed when she was 10 months, and was never very good at providing

and child with haemophilia

blood samples, contracted an infection, we were told was a rare internally occurring bug. After trying for months to hit it with different antibiotics, the decision was made to replace it. The surgery recovery was so much easier than pumping a tiny child with a ridiculous amount of antibiotics (as much as I'm eternally grateful for modern medicine, it's a shame to rely so heavily on antibiotics). Within a day she was bouncing around and the recovery was super smooth. That year, along with other issues, we were in hospital for 4 months over 6, and I decided that if or when anything went wrong with the replacement port, I wouldn't put her through the ordeal of another one and would try peripheral treatment.

The 2nd port lasted a few years, and was far less problematic than the first. We were still heading to ER often, sometimes weekly, to get fevers investigated. After a few years, Eartha contracted a yeast infection (which I was told can occur from a million different sources, such as spores in the air! Very hard to protect against). There's no treatment that can clear a yeast infection from port lines, so that was the end of my career as a port infuser. Even though she'd just turned 4, and is incredibly strong when it comes to resisting medical interference as a result of being traumatised by so much hospital in general, I wanted to try for a life with less hospital time due to fevers. Our HTC is so generous with their time when supporting parents through the treatment choices they make for their children, and I'm so glad to have had my hand held through the early days of learning to dose at home, both with a port and peripherally! Thanks team!!

After each port, Eartha took around 2 months to be at peace with the new regime. She's quite easy going once she can identify that the latest medical interference doesn't pose a threat and can be tolerated. She still prefers me to perform all her treatments - even in hospital I would always access her port. The nurses know us well enough that they would just supply me with a tray and I'd unpack all the supplies I always carry around - which for port accessing is a LARGE volume of bits and bobs - and when they came back, she'd be accessed with blood cultures ready to be sent to the lab!

Peripheral Dosing

Now that we're moved on to peripheral dosing, our lives are smoother, although the ease of port accessing tiny toddler veins was great at the time. Now that she's 4, she is much more aware and the transition to veins was very tough. I've always treated her by myself, where a second set of hands would often make life much easier! It took a little under 6 months to get to the point where she is happy to have me treat her, and even begs for her treatment sometimes, or gets disappointed when it's not prophy day (because she gets a lollipop and a few episodes of Bluey for treatments and that's all she cares about!). Mind you, she used to beg for port accessing too so she could get treats!

She violently protested the new regime until we turned a corner recently, thanks to endless tips from Jo, Amy, Moana and a few hookups with an OT. Now we get instant prophy success most treatments and life is far more 'normal' than it ever has been! So much perseverance and patience is necessary to get to this point though, and the ride is incredibly hard, but very well supported through the HTC.
Constant discussions to normalise our situation helps. If someone asks why she's all bandaged up, I'll say 'her blood doesn't work properly' which is easy enough for kids to understand. I'll highlight differences in others too, so she can see that basically everyone has their own issues and challenges. My mum has MS and is in a wheelchair, and so many of her friends and cousins have allergies, so she's being brought up in an environment where disability and physical challenges are normalised and often celebrated, so we're at peace with our own personal challenges. So far! And as Linka says, she has 'a little bit of philia, and Eartha and Daddy have a 'lotophilia'.

Looking after family

I've gone from being the breadwinner, prior to having kids, to having very little ability to earn money, and higher expenses, so we are quite 'financially challenged'. But the decision to put half a year into our shiny new life of peripheral infusions have allowed me to see the light at the end of the tunnel, and I'm about to move from casual to part time work, and it's the first time I've been able to commit to the increased workload, so I'm very excited.

I constantly forget to look after myself, and ended up in hospital last year and now have an improved health regime, and make sure to sleep more. Art is my vice, and when I can find time and space to work on art or making things with the kids, I'm a much happier camper.

Leah Emery

Looking To The Future - QLD Haemophilia Centre RBWH

We thank Leah for sharing her journey with the community. The QHC recognises that historically issues affecting girls and women who have haemophilia or who carry the gene may have been under recognised by haemophilia centres both in Australia and internationally. Dr Jane Mason is a Haematologist at the QHC with experience in managing children and adults with haemophilia and other bleeding disorders and has a special interest in women's and pregnancy related issues. Management plans for pregnancy and delivery are routinely discussed with women and with their consent the Children's HTC and their treating antenatal team. This allows all clinical staff to work together to ensure that women feel heard and are appropriately supported during the perinatal period.

Conference Update

Conference Grants and Scholarships now open

The 19th Australian Conference on haemophilia, VWD & rare bleeding disorders will be held at the Novotel Manly, in Sydney, from 10 - 12 October 2019.

The conference will bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn, discuss and plan for the future.

The theme of the Conference, Challenging the Status Quo sets the program up for interesting discussion, debate and opportunities to build a better future. Topics that will cover a range of areas including:

- New and emerging treatments
- Approaches to care in the future
- Von Willebrand disease and rarer bleeding disorders
- Living with a bleeding disorder over the lifetime
- Participating in clinical trials
- Women and girls

The program will include presentations from people living with bleeding disorders as experts as well as health professionals and other specialist speakers.

At HFQ, we believe in enhancing the capacity of our members and the sustainability of the organisation, and one way we do that is to provide small grants to people interested in furthering their understanding and participation in the haemophilia and related bleeding disorders community in Queensland and the conference is an ideal opportunity to do this.

What are the HFQ Conference Grants and Scholarships all about?

Monetary grants, usually up to a maximum of $500 each will be available to successful applicants to enhance their knowledge and skills as they relate to Haemophilia and related bleeding disorders. The grants will be made available at times of known conferences and workshops, but may also be granted to individual applicants at any time. The success of applications and the level of funding offered will be determined by the HFQ Board.

The objectives of the current round of HFQ Conference Grants and Scholarships is to assist Queensland people affected by a bleeding disorder to attend and participate in the 19th Australian & New Zealand Conference on Haemophilia and Related Bleeding Disorders. The conference is being held Novotel Manly, Sydney from 10-12 October 2019.

(please go to the following website; *https://www.haemophilia.org.au/conferences/2019-conference* for more information). These grants are for expenses as identified by the applicant but would usually be towards; Conference registration, travel or accommodation costs.

Submission guidelines

- You must be a person living with or affected by von Willebrand disease, Haemophilia or a related bleeding disorder.
- You must be a Queensland resident.
- You must be a member of Haemophilia Foundation Queensland
- Your application must be received no later than 24 June 2019.
- You must be willing to report back or share something of your experiences and learnings form the conference.

Application.

The application form is included with this magazine and can be downloaded from *https://www.hfq.org.au/get-involved/events/hfq-sponsorship-fund-for-the-2019-conference*

The deadline for the receipt of submissions is 5:00pm (Brisbane time), Monday 15 July 2019. The HFQ board will review all eligible applications and determine suitability based on the application and any supporting correspondence from the QHC social workers or clinical team members

Enquiries should to be made by email to *info@hfq.org.au* or mobile 04 1970 6056.

Ultra-processed food and health outcomes

Over recent decades, the volume of industrially processed products has increased. This trend has coincided with a transition towards diets linked to a rising prevalence of obesity and non-communicable diseases in many countries.

The term ultra-processed foods is used to describe savoury snacks, reconstituted meat products, preprepared frozen dishes, and soft drinks.

Two large European cohort studies recently found associations between consumption of ultra-processed foods and cardiovascular disease and all causes of mortality. The authors adjusted for sociodemographic and anthropometric risk factors and for established markers of dietary quality. There findings follow a previous study reporting an association between consumption of these foods and an increased risk of cancer.

The studies report an association between an absolute 10% increase in dietary ultra-processed food and significantly higher rates of overall cardiovascular disease, coronary heart disease, and cerebrovascular disease. Sensitivity analyses reveal further associations for specific groups of ultra-processed food, including beverages, fats and sauces, meats, sugary products, and salty snacks. Participants in the highest quarter of consumption (>4 servings/day) had a 62% higher all-cause mortality rate than those in the lowest quarter (<2 servings/day).

Secondary analysis shows a statistically significant association between unprocessed or minimally processed foods and lower risks of all reported disease outcome measures and a recent randomised controlled trial comparing diets controlled for energy and nutrient composition showed it was the proportion of ultra-processed food rather than the amount of risk nutrients in the diets that caused weight gain. These findings have important implications for dietary advice and food policies. The dietary advice is relatively straightforward: eat less ultra-processed food and more unprocessed or minimally processed food.

The researchers say that in modern societies it is unrealistic to advise people to avoid ultra-processed foods, and reformulating the nutrient composition of processed foods maybe a more effective way to reduce exposure to “risk” nutrients such as saturated fat, but the view that it is better to reformulate ultra-processed foods than avoid them altogether underplays the complexity of potential harm: these foods deliver risk nutrients into the body, displace nutritious foods from the diet, and as the products of industrial processing they can have peculiar physical structures or chemical compositions that are also risk factors for adverse health outcomes.

Future priorities include shifting away from food reformulation—which risks positioning ultra-processed food as a solution to dietary problems—towards a greater emphasis on promoting the availability, affordability, and accessibility of unprocessed or minimally processed foods.

From a report on Ultra-processed food and adverse health outcomes published 29 May 2019 in the BMJ https://www.bmj.com/content/365/bmj.l2289

The partner or parent of someone with a bleeding disorder is a key and often overlooked support for them and as important as the clinical support they get. It may not be a formal care role, but it can still cause stress and anxiety and this forum is designed to focus on you and your needs so you can continue in the roll.

At this half day event for partners and/or parents of adults living with a bleeding disorder you will meet people in a similar situation. We will have time to discuss the importance of self care and the day includes lunch and there will also be a free pamper session just for you.

Every act of self-care enhances your ability to support another so please consider coming to our free workshop at Pacific Golf Club conference rooms (430 Pine Mountain Road, Carindale) from 10:00 till 2:00 on Sunday 18 August. Lunch and all workshop activities are included and there’s lots of free parking on site.

Registrations are essential, so please RSVP by Monday 12th August to: info@hfq.org.au or call 0419 706 056

Future proofing

An important aspect of the health and wellbeing of bleeding disorders community members?

Preetha Jayaram

I took up the position of Project Officer at HFA in February 2019 and, as a first step in the project, have been looking into the needs of people with bleeding disorders in the future. This has involved consulting with community members, state and territory foundations, medical specialists, haemophilia nurses, psychosocial workers and physiotherapists to explore current issues and how to 'future proof' as people grow older.

Getting Older is a priority project of HFA. The project aims to identify, understand and respond to the range of needs people with bleeding disorders may have as they are getting older and help find appropriate solutions for them and their partner/family or friends/ carers.

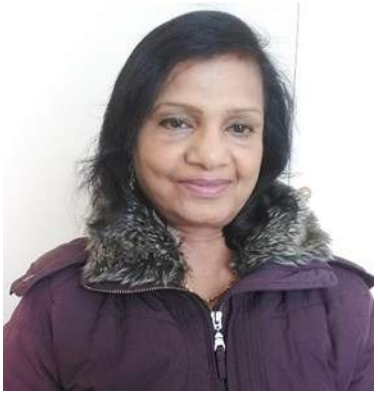
In the second stage of the project we will look at some solutions to enable people in the bleeding disorders community and their partner/family to manage their health and wellbeing into the future as they grow older. These will be taken from the recommendations in the needs assessment. To reach the community in this digital age, this will include online options for community members to inform themselves and connect with each other. This may involve, for example, expert information about exercise with arthritis or travelling as you get older. It will be important to give a voice to men and women – both people with bleeding disorders and partners/family or carers - so that they can share thoughts about what is needed and the strategies and services they have found useful. It may also involve strengthening current peer support groups.

I am looking forward to speaking with bleeding disorders community members and their partners/family around Australia to hear the issues they see around 'future proofing' their lives.

If you are interested in sharing your thoughts about 'future proofing' and getting older with a bleeding disorder, please contact Preetha Jayaram at HFA to talk about your availability.

Partners/family also welcome.

Phone: (03) 9885 7800
Email:
PJayaram@haemophilia.org.au



Preetha Jayaram is the HFA Getting Older Project Officer

Hemlibra use in Australia

HFQ recently wrote to Dr Jeannette Young, the Chief Health Officer for Queensland expressing our concerns about getting access to publicly subsidised emicizumab (Hemlibra©) as a treatment for Haemophilia A. This is a new non-clotting factor product registered for prophylaxis treatment for people with moderate to severe factor VIII deficiency with or without inhibitors.

Applications for emicizumab are being appraised by the Medical Services Advisory Committee (MSAC) for inclusion on the National Blood Authority's National Product List (NPL), for routine prophylaxis to prevent bleeding or reduce the frequency of bleeding episodes in patients with haemophilia A with factor VIII inhibitors (application 1510 and 1510.1), and without factor VIII inhibitors (application 1579).

HFA was invited for stakeholder input on MSAC application 1579 by 30 May 2019, which they have done and we have since received a reply from Dr Young to our letter. She says that the MSAC is considering these applications and that once both reviews are completed, the final decision on whether emicizumab is approved as a product listed on the NPL will be determined though the COAG Health Council.

The outcome of the 1510 and 1579 applications will be made public on the MSAC website - *http://www.msac.gov.au/internet/msac/publishing.nsf/Content/application-page.*

Health Updates

Genetic Screening for newborns supported

The vast majority of people in the haemophilia community support the implementation of newborn screening for the bleeding disorder in the United Kingdom, a study in Haemophilia journal has reports.

The researchers gathered data on attitudes toward newborn genetic screening among people living with hemophilia A or B, or those with affected relatives.

They developed a written and online survey and distributed it to every family known to the Haemophilia Society UK. Results indicated 77% of Participants supported newborn screening and preferred it to other forms of screening, either preconception or prenatal.

Participants supported newborn screening primarily because they believed it would facilitate early support and treatment, help make informed decisions about future pregnancies, and prevent the long journey patients often go through before they finally get a confirmed diagnosis.

https://onlinelibrary.wiley.com/doi/10.1111/hae.13706

Lessons From 'Tainted Blood Era' Are Essential to Avoid Future Outbreak

The emotional toll of the "tainted blood era" is still vivid in the minds of Canadian healthcare professionals who felt helpless to stop the spread of epidemics among patients receiving treatment for blood disorders during the 1980s.

Healthcare practitioners' testimonials from Canada were recently published in the journal Haemophilia and the researchers suggest that a parallel can be drawn within haemophilic communities in other countries.

In the study, the authors collected the testimonials of 76 healthcare practitioners, most of whom worked at haemophilia clinics in Canada during the 1980s, to evaluate the emotional effects the epidemics had on their lives.

Most interviewees expressed feelings of guilt, hopelessness, tension, grief, and fear over their inability to change the fate of patients with haemophilia whose lives were lost.

The authors say that looking back, it has been recognized that there was a general failure to recognize the importance of integrating public health and clinical data for decision making.

https://onlinelibrary.wiley.com/doi/abs/10.1111/hae.13805

Bayer Announces Partnership with WFH Humanitarian Aid Program

Bayer announced a five-year partnership with the World Federation of Hemophilia (WFH) Humanitarian Aid Program. According to a Bayer press release, the partnership will allow them to bring education, training, and access to Bayer's recombinant factor VIII (rFVIII) therapies to healthcare providers in more than 60 countries. The partnership will include a donation of 50 million international units of rFVIII therapies in 2019.

Bayer press release dated May 23, 2019

BioMarin Provides Trial Updates for Hemophilia A Gene Therapy

BioMarin recently announced clinical trial updates to its investigational gene therapy for the treatment of adults with haemophilia A.

The recent updates focused on a phase 1/2 trial in adults with haemophilia A in which participants were placed in two groups, one in which patients received a higher dose and a second group where patients received a lower dose.

The results showed significant clinical improvements in annualized bleeding rate (ABR) and use FVIII replacement therapy. Data also suggested that bleeding was well controlled in the larger dose group. The company also reported a "continued absence" of target joints and target joint bleeds during the three years observed.

In addition, FVIII product usage in the large dose group demonstrated sustained efficacy three years post-administration. Rates of study participants who experienced zero bleeds necessitating FVIII infusions were 71% in the first year and 86% in both the second and third years. Overall, there was a 96% reduction in mean FVIII usage over three years.

BioMarin press release dated May 28, 2019

Sigilon Releases Study Data on Hemophilia Cell Therapy

Sigilon Therapeutics presented data on an investigational cell therapy the company is developing to treat haemophilia A.

The therapy, known as SIG-001, includes human cells that are modified to produce factor VIII (FVIII). The therapy is further enhanced with a "shield" composed of a synthetic biomaterial called Afibromer which effectively blocks an unwanted immune response.

Investigators are evaluating the therapy in mouse models with haemophilia A. A single dose of SIG-001 administered via the abdomen of the mouse subjects controlled bleeding and sustained therapeutic levels of FVIII for more than six months.

https://hemophilianewstoday.com/2019/05/17/candidate-cell-therapy-controls-bleeding-in-mouse-model-of-hemophilia-a/

Youth Camp 2019

Haemophilia Foundation Queensland (HFQ) runs an annual Youth Camp at Emu Gully. The camp is based around an ANZAC theme, and all of the activities promote the character values of Courage, Mateship, Perseverance and Sacrifice and are conducted by qualified recreational educational facilitators.

This year's camp is at the end of third term (from Friday night 20 Sept to Sunday lunch on 22 Sept) We have the camp booked from 6:30pm but participants arrive from then on, at a time that works for them as we start with supper and welcome.

The HFQ youth camp is quite physical but although everyone is encouraged to participate, no one is forced to do any activities. However, it's a chance to try things you might not do at home, in a safe and supported environment. It lets kids be themselves without parents hovering over them, and yet because it follows the values and ideology that the ANZAC theme it promotes resilience within the camp participants and helps shape them into better people.

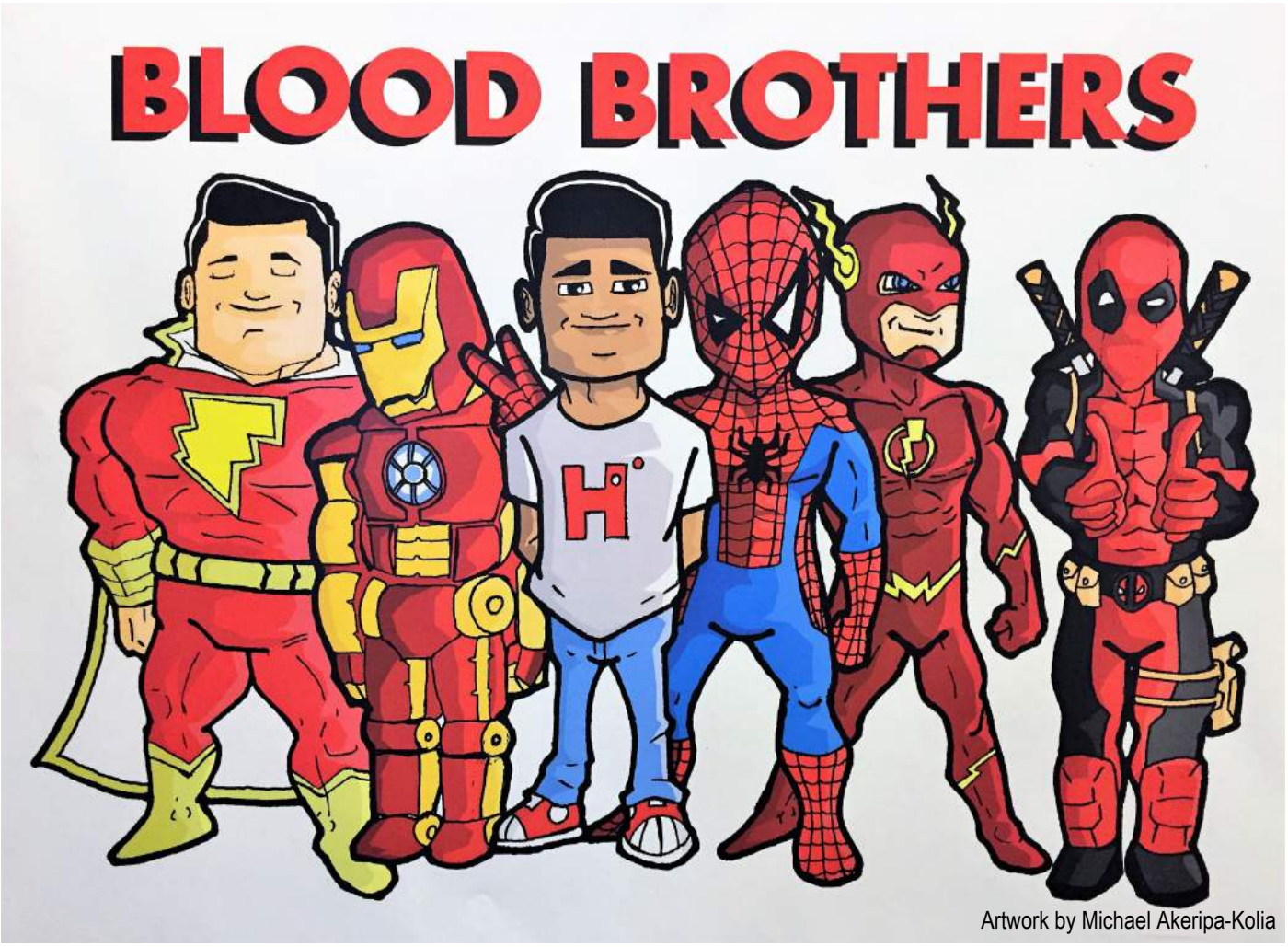
You'll be introduced to new and old friends on the Friday night before it's time for bed and some much needed shut-eye for the busy weekend ahead. On the Saturday we'll start with a briefing from the Emu Gully co-ordinators on the themes and the ideas behind the whole camp and the individual activities.

The camp activities incorporate some elements of the ANZAC theme, such as "The Tunnel Rats of Vietnam" a twisty exercise underground; or the night walk where you'll carry one of your members on a stretcher through a bunker and a maze! Other activities are less arduous, there's a swimming dam and all meals are catered for us. And of course there is time to talk about living with a bleeding disorder as well!

After a good night's sleep (and you'll need it) Sunday will come all too quickly with the last of the camps activities which include "Twister Buggies" where you get to do a few lightning fast laps in the little buggies, before we send you home to start your school holidays proper.

To register for youth camp please go to our website at https://www.hfq.org.au/get-involved/events/youth-camp or call the office on 0419 7906 056 for more information.

Artistic Fun



Artwork by Michael Akeripa-Kolia

Recently we had an art exhibition showing the artistic talents of members of the bleeding disorders community. We're hoping to do it again for next year's World Haemophilia Day and we'd love to show your work.

Art can help you express your thoughts and feelings without talking. It's a different way of sharing how you feel about living with a bleeding disorder, and it can be fun. If you're ever feeling sad, mad or scared, it's important to be aware of it and then figure out how to handle it. The same goes for happy feelings, like excitement, thankfulness or love. Art can help you let stuff out and get your creative juices flowing.

Anyone can be an artist so why not give it a go. The theme for next year is 'Red' so it's easy. Instead of using words when you see or feel red, why not grab a brush, a sponge or even a pencil and make an artwork? You don't have to stick to red in colour, pick colours that match how you feel or mix a few colours to create a whole new range of colours. Then, let the lines, shapes, textures or whatever else you feel come out on the paper or canvas.

If you're new to art, this may feel strange. But you can start by asking yourself a question, like: "How did I feel during my last joint bleed?" or "What was I thinking when that kid at school made fun of me?" Then show that in your art project. If you can't paint or draw you could cut out pictures and words from old magazines that show how you feel and paste them together in a colourful collage.

All artists invited

Art is not about creating something beautiful or perfect; it's about showing your feelings. No one's marking you or judging you on your talent or effort. Be open to whatever thoughts or moods come out. Art really can help you not only express your feelings, but also discover them. If your artwork says something you think is important, why not share it with someone who can help you work through any issues or feelings that concern you. That person could be your parents, grandparents or Moana at the haemophilia treatment centre. And when you've got one you like and you're ready to share it with the world, consider showing your art in our exhibition next year. So open up to the artist within you. It will help you express your feelings creatively.

Important Dates for HFQ Members

OBE Lunch Forum
Informal support group for men with a bleeding disorder. Usually meets first week of the month. Partners are welcome at the next meeting on; 14 July 2019.

Women's Brunch
11 August 2019 Café 63 Stanley St E. East Brisbane

SelfCare Workshop
18 August Veue TBA

Youth Camp
20 - 22 September 2019
Emu Gully, Hildon

Haemophilia, VWD & Rare Bleeding Disorders Conference
10 - 12 October 2019 Manley NSW

Bleeding Disorders Awareness Week
13—19 October 2019
World Café Event TBA

Regional Meetings
Please ask for events and activities happening in your area.

Community Camp
3 - 5 April 2020
Noosa North Shore Retreat

Please call Graham at the office on **07 3017 1778** for more info on any of these events and activities.

Rare Finds

They're the rarest of the rare: bleeding disorders like platelet storage pool disorder and factor XIII deficiency that affect only a miniscule percentage of the population. Getting to a diagnosis can be challenging enough, when most doctors have never seen a case and treatments are often a work in progress. HFA has some good information and links at *https://www.haemophilia.org.au/about-bleeding-disorders/other-factor-deficiencies* but we thought we'd share with you some of the rare bleeding disorders our members have...

Factor XI (FXI) deficiency

Also called hemophilia C, plasma thromboplastin antecedent deficiency and Rosenthal syndrome, FXI deficiency occurs in an estimated 1 in 100,000 people in the general population. FXI deficiency is inherited in anautosomal recessive pattern, meaning both parents must carry the gene to pass it on to their children. It affects men and women equally. People of Ashkenazi Jewish heritage are at higher risk.

There is a good article about FXI deficiency at *www.hemaware.org/story/factor-xi-deficiency-facts*.

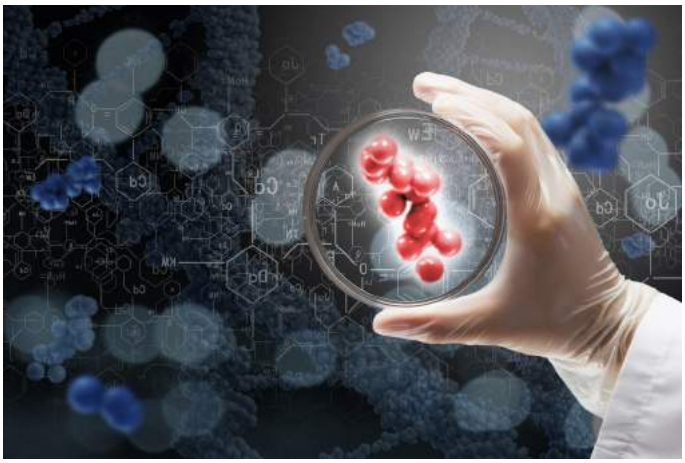
Factor XIII (FXIII) deficiency

Also called fibrin stabilizing factor, FXIII deficiency is the rarest factor deficiency, occurring in 1 per 5 million births. Both parents must carry the gene to pass it on to their children. It affects men and women equally. FXIII deficiency can be harder to diagnose because people with the condition form a clot, so clotting tests come back normal. FXIII assays and a clot solubility test are needed for a diagnosis.

There is a good article about FXIII deficiency at *www.hemaware.org/story/factor-xiii-deficiency-one-rarest-bleeding-disorders*.

Glanzmann thrombasthenia

This platelet function disorder is caused by an abnormality in the genes for glycoproteins IIb/IIIa. In people with Glanzmann thrombasthenia, platelets do not stick to each other at the site of injury, making it difficult for a normal blood clot to form. Because it's an autosomal recessive disorder, both parents must carry an abnormal gene to pass it on to their child, even if they don't have the disorder. It affects men and women equally. About one in 1 million people worldwide have this disease.



There is a good article about platelet disorders at *www.hemaware.org/story/inherited-platelet-disorders*

About The H' Factor

The 'H" Factor is published four times each year by HFQ by the HFQ manager and assisted by Brett Williams, our communications volunteer. 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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