

the

FACTOR

Issue 56
Spring 2018
Newsletter of Haemophilia Foundation Queensland

From the President



Hi everyone.

I cannot believe it's spring already, this year has flown by. It made me think back to 2015 where HFQ and you looked at the issues facing the bleeding

community – let me summarize the main points for you:

60% of females & 40% males completed the review, there were a real mix of issues across the demographic – mixed emotional concerns, lack of support issues, practical understandings of bleeding for some, The responses regarding MYABDR were:

- 20% did not know about it
- 35% did not use it
- 42% using it
- 3% no mention.

Most people were reasonably happy with their GP's skills with most having one annual visit to the GP. Hepatitis C status was

interesting;

- 30% cleared the virus
- 30% had it
- 23% not tested
- 17% no mention or not applicable

Women who carry the gene reported little issues.

The HFQ newsletter was reported as the major connection to information, regional voices indicated problems linked to distance, waiting too long for appointments was also a reported concern, the big one that stood out from the crowd was anxiety and depression – how people feel about themselves in their world. And the last one is about connectedness - with some

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From the President cont...

indication of social isolation for some. So that was back in 2015 but what about now You may recall the PROBE Study (Patient Reported Outcome Burdens) which is an international study which aims to deliver data on treatment and health experiences. This is looking to be on track for 2019 where you can answer a few questions, which in turn can help the HFQ's & HTC's of the world better understand today's issues for those touched by bleeding disorders.

It's thanks to your time taken for these reviews that allows HFQ and the Haemophilia Treatment Center (HTC) to deliver services to address issues - we are indeed lucky to have the professional team at the HTC to help everyone in the bleeding community – medical and psychosocial support is at your fingertips – give them a call – or call Graham at HFQ who can help key you into support services – HFQ is there for all people affected by or touched by a bleeding condition. Until next time – take care.

David Stephenson

President HFQ
president@hfq.org.au

World Congress Update Session

Dr Jane Mason reported back from the Glasgow World Congress that haemophilia treatment is really at the edge of a therapeutic revolution. She reviewed three of the most promising new therapies that seem to have some proven efficacy behind them.

The NBA through the National Blood Agreement (63% Commonwealth funding and 37% state funded) funds these treatments, but the existing supply contracts have a long time to run, so the NBA has negotiated limited access to extended half life products for about 200 people across Australia until due diligence is done and funding secured and there is no timetable for this yet.

Probably the most promising therapy that Jane told us about is Hemlibra (emicizumab). This is not a clotting factor replacement

and will require less dosing than the extended half life products coming on stream.

Hemlibra is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with haemophilia A with or without factor VIII inhibitors.

Hemlibra was approved in the US last year. It mimics the factor VIII protein with a half-life of 4 to 5 weeks, so will only require weekly to monthly subcutaneous injections. The drug candidate is also effective in patients that have developed inhibitors to the standard treatment.

This might compete effectively with the recombinant clotting factor VII drug, called NovoSeven.

Jane said that Hemlibra seemed to be easier, simpler and faster. At HFQ, we think it could be truly, life-altering and transformational for those of our members with Haemophilia A and inhibitors - in the first instance and all severe patients after that.



Disclaimer: All articles, advice and information included herein are written by various individuals who volunteer their input. While the 'H' Factor magazine puts every effort into providing honest and accurate information and where possible, reference to research articles are made to validate content, it cannot be held liable for any errors or inaccuracies in published articles. The views expressed in this newsletter are not necessarily the opinions of the Editor, their associates or supporters. Publication of contributions will be at the discretion of the Editor. Any articles containing racist, sexist, homophobic or defamatory remarks will not be published. Other original contributions and letters are welcomed and encouraged. Articles in the 'H' Factor cannot be reproduced without permission.

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. 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	Mr Erl Roberts
			Dr John Rowell
			Mrs Leanne Stephenson
			Mr Mike O'Reilly

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.

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 (LCCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown – Haematologist

Haemophilia Fellow - Dr Jonathon Holzmann

Haemophilia Registrar – Dr Terence Lim

Joanna McCosker . Clinical Nurse Consultant

Amy Finlayson / Salena Griffen – Clinical Nurse

Hayley Coulsen - Physiotherapist

Moana Harlen - Senior Psychologist Thur, Fri & alt. Weds.

Cheryl Kadinsky - Psychologist Mon, Tue & alt. Weds.

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

Desdemona (Mona) Chong - Advanced Psychologist (On Leave) 3646-7937

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: Book through Joanna at LCCH and Beryl at RBWH.

Build a Better Support Network

For people living with a bleeding disorder and for parents and carers of a child with a bleeding disorder, life can seem pretty overwhelming at times.

It can be helpful for people with a bleeding disorder and/or their families to build a solid support team - one they can rely on to ease stress, worry and isolation, for everything from baby sitting to relationship counselling and medical assistance.

You can create this support network by tapping into existing supports, groups and services.

Your QHC Team

Medical issues can arise that leave you confused. At times like these, the Queensland Haemophilia Centre team are there for you to lean on.

For parents with children, talking with the QHC will help you anticipate situations and circumstances so you can better respond to situations in your child's life.

For adults, having a team of impartial but knowledgeable health care professionals can help you negotiate other hurdles that occur throughout life.

The adult and children's QHC teams are believers in patient centred care, putting the person with the bleeding disorder and their needs at the centre of any treatment and response plans so you become part of the care team, reducing stress in many situations.

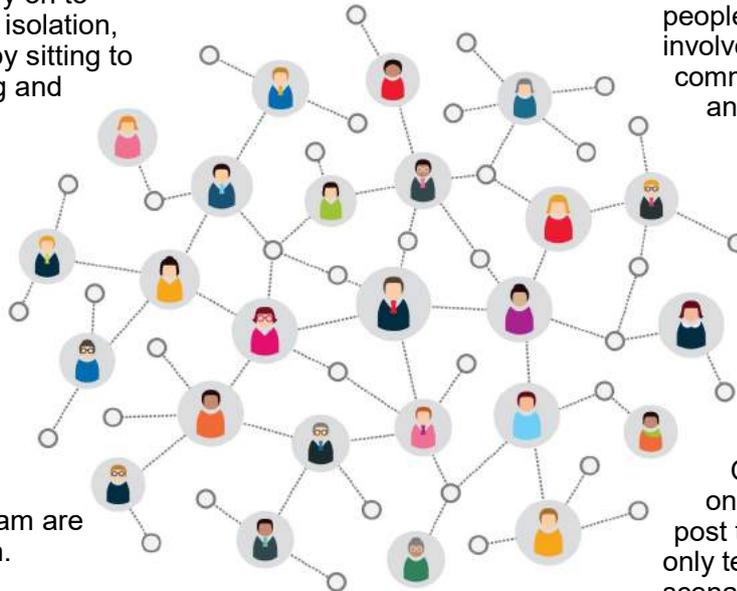
Family and friends

The people closest to you are likely to be your most ardent supporters. However, adjusting to changes in treatment or physical circumstances can be just as hard as accepting and acting on a new diagnosis of a bleeding disorder.

A lot of times family members and friends are well-meaning, but if

they've never had to live with a bleeding disorder, sometimes they may not completely understand what you're going through and you'll never stop having to educate and inform others about your condition.

But it's worth it, because family and friends are



the ones who love you unconditionally and they are the ones who are most willing to learn and help you. It can be harder for people who don't see you every day to respond appropriately, but don't give up, while your friends and family may never be experts on bleeding disorders, they will be the ones who will stay with you when you have a concern.

Queensland & National foundation and gatherings

Haemophilia Foundation Queensland (HFQ) membership connects you to Haemophilia Foundation Australia (HFA). This is especially helpful for resources and information you can use for yourself if you who are new to bleeding disorders, or for the community at large when you have to act as educator.

HFQ offers members and their families a range of opportunities to connect with other people going through similar experiences. We encourage participation in the activities that match your needs

and interests as it can be really overwhelming when your own your own. This is especially true when a family first learns about the diagnosis, or when we reach different 'change' points in life. careers, relationships, retirement and everything in between.

Having peer support from other people and families who are involved in the bleeding disorders community can make it less scary and less stressful.

Social media

There are some great social media supports out there because you can access the entire world. But there are risks as well as benefits to seeking social support online.

One of the risks of going online is that the people who post their stories on some sites only tell you about the worst-case scenarios or a bad experiences they have had with their treatment centre or their doctor. HFQ's facebook page follows pages we have found to be reliable and helpful over time.

Instagram can be a great social media support tool and HFQ has just started our Insta post. It's amazing to see, and then to be able to share your experiences instantly with other people in the community. It can help you feel like part of something even when your on your own socially or geographically.

Starting with the HFQ and HFA on-line resources is a good way to find other social media sites that may interest you.

[Links to HFQ Facebook and Instagram pages are available via our website: .hfq.org.au](#)

[HFA links are via their website: .haemophilia.org.au](#)

Making connections through Telehealth

During 2018, the Adult Haemophilia Centre at the Royal Brisbane and Women's Hospital has worked to increase opportunities to connect with the community by starting a monthly telehealth clinic. Most months through 2018 have had a well-attended telehealth clinic (with additional appointments offered to meet the needs of the community).

We introduced telehealth clinics for people living outside the greater Brisbane area, to decrease the costs for travel, reduce your time away from home and family and reduce your time off work to attend appointments. Sometimes it may be important to see you in person, so telehealth is unable to replace all face to face appointments.

Telehealth is just like a regular appointment, only the team is not in the room with you, but seen on a monitor (or TV screen) and sound comes through the speakers. It is like Skype or Facetime. The Royal Brisbane and Women's hospital uses a secure portal if you link in from home (for example) through a smartphone, iPad (or similar), laptop or computer. If you live in an area with patchy internet connection, or don't have access to the internet or device; you can link in through your local hospital, community health centre or even a

GP clinic. You may have also heard it called videoconferencing.

Just like a clinic appointment here at the hospital, you can bring other family members or support people with you. The appointment has the same privacy and confidentiality commitments as other hospital appointments. If you are linking in through your local hospital, a nurse from the hospital may also attend with you to provide support in using the equipment and may also be helpful in writing notes from the appointment in your medical chart at your local hospital.

We have even started using telehealth for education sessions, with the National Disability Insurance Scheme workshop being our first

experience in using the telehealth portal to enable people outside Brisbane to participate. Although there were a few hiccups, hopefully we can continue to grow this side of telehealth and provide more opportunities for the community across Queensland and Northern New South Wales to connect with education sessions.

So, where to next? If you are interested in using telehealth for some of your appointments with the Royal Brisbane and Women's Hospital or would like some more information about telehealth, please call Loretta (Queensland Haemophilia Centre Social Worker) on 3646 8769.



Brett's Life with Haemophilia

Hi All, Welcome back to the next part of my story about living with Severe Haemophilia A.

We moved from Cooma to Canberra when I was around two years of age. At that stage there were two main hospitals that I went to, which were Royal Canberra Hospital & Woden Valley Hospital (now The Royal Canberra Hospital).

My mum had found some old diaries that she started when I was born way back in 1976 noting down all my bleeds.

Going through the diaries and seeing how many bleeds I had and where they were, I see that most of them were into joints such as ankles, elbows, knees, hips. I also had a head bleed and muscle bleeds in the legs and arms and in 1978 a bottom bleed, though I was only 2, I was a pain in the bum as a child. 😊

The clotting factor that I was having for these bleeds was Cryoprecipitate, but in 1979 at the age of 3, I was developing antibodies to the Cryo, making it less effective. Now days these antibodies are called inhibitors.

On 18th of October 1981, while my mum was 8 months pregnant with my sister, I had fallen off my bike. Later that night I was taken to Woden Valley Hospital, in which I had x-rays taken and learnt that I was bleeding internally and end up in ICU in a serious way and almost lost my life. The doctors performed what's called 'cut downs' where the doctors would slice a small insertion on both ankles to pump as much blood as they could into my body.

As I had developed inhibitors, there wasn't any clotting factor in Australia that I could use effectively. A call was made to the manufacturer in Los Angeles

to have 30 vials of Autoplex on standby to fly the product to Canberra within 36 hours, costing \$17,000, which in today's money would be around \$65,000.

In 1981 Autoplex was an extremely rare drug and wasn't available in Australia. A special clearance was sought from the Department of Health to bring Autoplex to Australia and this was granted

In the end fortunately, I didn't need to have it and 5 days later, I was back in the children's ward.

For the next 7 years I continued to have bleeds into joints and muscles, and Mum and I would spend several hours in the emergency department where doctors would make multiple attempts to find a vein (nurses weren't allowed to access veins back then) only to be told to go home, where I would lay in bed screaming as I was in so much pain.

Also having inhibitor's and going many years without treatment, was good in one way because it meant that I missed out on contracting HIV.

With all the bleeds that I had, and not having any treatment while living in Canberra, my joints were becoming damaged, which meant that I would eventually need a wheelchair, but at that stage I could get around with only 1 crutch most of the time.

Between my hospital stays and my looks (caused by my Neurofibromatosis—see issue 54) I didn't really have many friends when I lived in Canberra expect for one friend, all the girls didn't like me. It was also hard watching other pupils playing sports, climbing on playground equipment.

Next time, I'll be talking about moving up to Brisbane changing my life for the better, so stay tuned for the next edition.



Getting Enough Sleep

More than a third of Australian adults are not getting the sleep they need. It's easy to feel overwhelmed by the many messages on sleep out there, so these ones have been reviewed to help you get better-quality sleep.

Message 1: Waking up early is always best

There's no evidence that going to bed earlier and waking up at the crack of dawn is the best sleep pattern for everyone. We generally perform at our best when we sleep and wake in terms of our natural preference.

So if you're someone who works best at night and feels sluggish in the morning, try preparing for work the evening before, and plan to hit the gym after work rather than early in the morning. That way you can set the alarm later and still get to work on time.

Message 2: Switching off TV's before bed will improve sleep

Blue light from mobiles and other screens can keep you awake. But turning the TV off or putting your iPad away shortly before bed isn't enough. Fifteen minutes of blue light will have a two hour impact on sleep quality.

You could try enabling the "night mode" function if your electronic screens if you have one. It's also worth noting, even dim light from table lamps and night lights can interfere with a person's circadian rhythm and melatonin secretion.

Message 3: Waking during the night equals bad sleep

It's not harmful to wake two to three times during the night — but worrying about it can cause you to stress.

Small, brief awake periods should be tolerated and accepted as perfectly normal, as long as they don't interfere with your functioning or feelings.

getting 20 to 30 minutes of outside light to suppresses melatonin ...and that will invite sleep at a healthy time the next night.

Message 5: You can train yourself to need less sleep

Trying to get away with less sleep than you need can mess with your mood. Reducing your sleep down below six hours not only makes

you more easily irritable, but it also tends to interfere with rapid eye motion sleep.

REM sleep helps maintain emotional equilibrium, and as a result, one of the effects of sleep loss is that feelings of anger and rage get triggered a lot more easily.

Message 6: Caffeine is the main culprit

It's best to avoid caffeine in the afternoon, but if you're stressed out of your mind, caffeine is probably not your main problem.

On the ranking of things that are going to make the brain switch off at night, that amount of caffeine is just not that significant.. High stress levels are always going to outweigh the effects of caffeine.



If you find you're having regular instances of being up for more than half an hour overnight — especially if you're annoyed or frustrated, and feeling fatigued and unrefreshed during the day may indicate insomnia.

Message 4: Get your bedtime right, and the rest will follow

Rather than fixating on setting a particular bedtime, try prioritising your wake-up time because it sets when your body is ready to go to sleep the next night.

Day light suppresses melatonin, so you're better off waking up at the same time every day and

Edited for size from an article by Grace Jennings-Edquist called Sleep myths on ABC Life

<http://www.abc.net.au/life/sleep-myths-experts-debunk-common-advice-for-sleep-problems/10230440>

Bleeding Disorder Awareness Week



Of course we can't forget everyone who came down to the park. The weather threatened all day but it remained fine which encouraged lots of visitors – at a guess we think about 200 enjoyed the perfect weather on Sunday afternoon. We all had some delicious food, heard some great music and made the most of the fabulous Brisbane sunshine while supporting a great cause.

thanks go to the many businesses who gave goods and services to make up a fabulous raffle. We also have to thank Brisbane City Council for letting us invade the park on the Sunday and the food trucks and stall holders who made it a wonderful day.

Thanks to the business and people who helped

Hopefully I've not forgotten anyone, from this list:
Virgin Australia. Crown Metropol. Melbourne Blackwoods. The Tasty Pocket. MR. TOKYO DOG. Roadside coffee shop. Banyo Discount Drug Store. Spirit House.

The local fete holds lots of fond memories for many of us. This year, as part of Bleeding Disorders Awareness Week, Charles, his partner Shannon and their son Lachie held a similar event for us, billed as a "Picnic in the Park".

And what a fantastic and successful day we had, thanks to everyone who helped, especially Charles and Shannon.

All our raffle prize winners have been notified, thank you to everyone for buying tickets and congratulations to all of the winners!



It also meant that, thanks to everyone's support from both raffle tickets and our cupcake and plant stalls at the event, The provisional figures show that we



Theluxeproject. Sofitel Brisbane Central. Lone Pine Koala Sanctuary. Sirromet Wines. Ray White Banyo. Morris Brothers Musical Store. Blue Room Cinebar. Riverlife Brisbane. Broncos. Brendale Brewing Company. Leanne Linard MP. Councillors Adam Allan & Vicki Howard. Wayne Swan. Australian Red Cross Blood Service. Costco. North Lakes Banyo District Community Group Inc. Coles Toombul. Woolworths Banyo.

We will be doing it all again next year so if you couldn't make it, mark it down in your diaries for the 6th October 2019.

raised over \$3,000 on the day and hopefully, including donations and after expenses are taken out it should be nearer \$2,500.

Thank you to the amazing people who donated their time and talents. To our volunteers, musicians, bakers, green thumbs, food truck operators, stall holders and the businesses that contributed to our raffle, the event would not have been possible without all of you. Special thanks to James from Banyo District Community Group Inc. for your advice and lending a hand when we needed it.

We cannot wait to see what next year will bring! Make sure you lock in the 6th October in your diaries!

We want to offer everyone who helped make the day a huge success. Particular



Exercise Success Plan

Keep It Up: Tips for Sticking to Your Exercise Plan

Getting moving in the first place is a great start. Here's how to keep yourself on a roll

Forget New Year's, winter is over and NOW is a good time to make a resolution to get fitter. As you've heard over and over (and over...), regular exercise has numerous health benefits, ranging from reduced risk of heart attack, stroke, cancer and diabetes to better memory and overall brain function.

Exercise also strengthens muscles and bones, providing better joint support, which is critical for people with bleeding disorders of any age because stronger muscles and bones help prevent bleeds and help you recover quicker from bleeds.

So, good for you for getting active. The trick now is to keep yourself motivated so that exercise becomes a regular habit and you don't backslide into inactivity. The following tips and ideas can help keep your exercise routine fun and less, well, routine:

Take it slow and steady

Even if you're feeling super motivated in the early days of a new workout regimen, don't jump in too quickly. As you ramp up your activity you don't want to get injured or increase your risk of a bleed, which will force you onto the sidelines for a spell. Second, trying to do too much too early is a good way to burn yourself out mentally. Better to rein it in a little and leave yourself with plenty of physical and mental energy for the long haul.

Find a buddy or group

Making your workout a social event has a double benefit: When you intertwine exercise and socializing with friends, it's more fun, plus you're more likely to stick to a regular schedule when friends are relying on you to show up and

sweat with them.

Don't limit yourself

When starting out you've likely chosen one activity that speaks to you, be it walking,



swimming, cycling or circuit training at the gym. As time goes on, sprinkling in some new activities keeps things fresh. Getting tired of the elliptical machine? Skip it occasionally and do yoga, tai chi or a Zumba class instead.

Reward yourself

Hit 60/90/120 days of exercise? Celebrate with a dinner out, or buy some new workout clothes or gear. It may seem shallow, but if getting to don shiny new shorts, tops or sneakers is motivating, view it as a worthwhile investment in your health.

Track your progress

This is particularly helpful after the

first rush of enthusiasm for regular exercise begins to wear off. Seeing how much you've accomplished already pushes you to want to keep adding to your list of achievements. Keep track of your workouts in an exercise app on your smart phone, wear a fitness tracker or log them in a notebook.

Don't be too hard on yourself

If you find your motivation lags after a while of steadily working out, don't worry. It's OK to miss a few workouts and take a break to recharge. Same goes if you miss out on exercise due to illness, a bleed or a hectic schedule. Keep the big picture of your health in mind. A few missed days don't diminish the overall gains you've made. If you fall off the exercise wagon, just jump back on when you're ready and pick up where you left off.

For more information check out "**On the move with haemophilia**". An education resource on sport and exercise in young people with haemophilia. It includes information on rehabilitation after a bleed and participation in school activities. Developed in collaboration with HFA and Haemophilia Foundation of New Zealand it can be downloaded at: <http://invivoacademy.org/on-the-move-with-haemophilia-toolkit/>

You can also check out "**Fitness and Exercise Guide for Young Adults with Haemophilia**" – by Ian d'Young (2012): available as a booklet from the QHC or online at: https://issuu.com/willhemina/docs/3500-01_novo_physiobooklet_issuu

Another resource with information on the benefits and risks of dozens of sports and physical activities is the NHF booklet **Playing It Safe – Bleeding Disorders, Sports and Exercise**. https://www.hemophilia.org/sites/default/files/document/files/Playing-It-Safe_0.pdf

Ian Zaro spends 5 Minutes with Brett

Hi all,

We are excited to be introducing a new ongoing column in our newsletter called '5 Minutes with Brett', where our editor at-large Brett Williams will interview members of our community.

The first interviewee is our own funny man and internet sensation, Ian Zaro from Townsville. If you don't know who Ian is, he has quickly become an online celebrity through his hilarious Dubsmash and Facebook videos.

I sat down for a 5 minute chat with the 23-year-old, which was no easy feat as Ian is a very busy man as he is an advocate for mental and physical wellbeing through public speaking gigs, marketing roles and youth mentoring for the Indigenous and also for HFQ.

Ian who has severe Haemophilia A and told me in a joking way that "living with severe Haemophilia is time consuming and it sucks but it part of my life". I asked Ian how he got into



are making funny videos for Dubsmash and YouTube. At 18 Ian was diagnosed with depression and told me that he finds that doing comedy and making people laugh or just making someone smile gives him a sense of purpose and feels like he is helping others.

"What's next for Ian?", I asked. He replied "continuing being an advocate for mental and physical wellbeing through public speaking." Ian also MC's and hosts events from festivals to corporate conferences around

Australia and is a casual worker at a homeless shelter for the youth as well as a volunteer youth mentor HFQ.

Ian is proof that if you set your mind to it, you can achieve your dreams, despite your haemophilia or other restrictions.

comedy he replied, "I was the class clown at school and then I started making videos for Dubsmash and YouTube, which went viral resulting in ABC recruiting me for the 2 season of Black Comedy, starring one of Australia's most famous Indigenous actor Deborah Mailman".

"Working with Deborah", he said "it was the best time of my life. She was so down to earth and reminded me of family. When I wasn't filming I would wander around the back lot and found Deborah's trailer and asked her for an interview and some acting tips." Ian had some hilarious suggestions for, of course, chicken nugget related scenes, and he and Deborah have shared many laughs.

Ian's major hobbies

In a separate interview with Ella Archibald-Binge on NITV; Ian said that if he could put a smile on someone's face and make them feel better, it made him feel better too. Many people have told him that he has helped them rise up from their depression just by laughter.

Ian advocates for mental and physical wellbeing through public speaking gigs, marketing roles and youth mentoring.

If this article has raised any issues for you or you need help or support, you can call Lifeline on 13 11 14 (24 hours -a-day)



A Patient Who Doesn't Want to Be Cured

Sarah Zhang from the Atlantic interviewed Jeff Johnson, a 40 year old man from Washington State, living with haemophilia in August because Mr Johnson says, he does not want a genetic cure for his haemophilia!

He sees his genetic disorder is part of his identity, and the fast approaching gene therapies threaten to erase it.

While patients from gene-therapy trials are reporting they no longer have to worry about bruising and bleeding, it is still unknown how long the effects of the therapy will last and Mr Johnson wants to hedge his bets. Like many of our members he has been told the haemophilia cure is just around the corner for at least the last 30 years.

So, at a time of increasing optimism about cures or manageable treatments, his perspective is thought-provoking.

All his life Jeff Johnson has been going to the emergency room for regular injections. He progressed from cryoprecipitate to the current treatments. He has lived with fellow patients getting HIV or dying from bleeds and he now lives with the after effects of bleeds such as arthritis in his knees and damage in his spine from bleeds. Although he was lucky not to contract HIV from blood products, he did acquire Hep C.

Despite these challenges of living with haemophilia, he is not personally interested in a cure.

It's partly because he sees himself AS haemophilia. He doesn't say he has it, he says he is haemophilia, it really is who he is and he doesn't see it as

something that needs a cure. Additionally, the whole principle of permanently changing his DNA is something he's not comfortable with.

For people who grew up in the '70s and '80s when treatment was not as good and then lived through the HIV epidemic - there is a really strong sense of identity and community. He sees the enthusiasm for a genetic cure as being more among new parents or those with young children with haemophilia. He says as parents they are experiencing the condition in their child, so it's not part of their identity and it raises fears. They see haemophilia as an intruder that needs to be cured and taken away from their lives.



Even as he grew up, a cure was all they talked about for the first few years. And then when he and other kids got to primary school and they're going to summer

camp for kids with haemophilia and managing their disorder; his parents talked less and less about a cure. By time he was a teenager he and his friends had graduated on to, "It is what it is." If there's a cure, cool, but he's doing fine.

This isn't true for people with a bad inhibitor or something which prevents the use of clotting factors and neither is it true in young parents because the idea of a cure removes a burden that seems to have no solution.

Written by Graham from an interview by Sarah Zhang published in the Atlantic <https://www.theatlantic.com/science/archive/2018/08/hemophilia-gene-therapy-cure-identity/540987/>

How does gene therapy treat haemophilia?

Gene therapy offers the promise of correcting genetic diseases with a one-off treatment by delivering a functional DNA copy, commonly using viral vectors. Gene therapy could significantly reduce the cost of treatment for patients and healthcare providers.

Haemophilia B has traditionally been the main focus because applying gene therapy to haemophilia A is more challenging; The gene coding for the factor IX protein missing in haemophilia B is smaller than that for factor VIII missing in haemophilia A and therefore easier to fit in the viral vectors used for gene delivery.

However, this has not discouraged bio-techs from tackling haemophilia A. To overcome the size limit, some companies have deleted a region from the factor VIII protein that is not necessary for clotting.

Gene therapy is not a perfect solution, though. In some cases, patients can develop immunity against a particular viral vector or foreign DNA sequences. So some companies are trying to circumvent this problem by using lentiviruses, which are less immunogenic and protect the DNA cargo by inserting it into the host genome.

Viral vectors are not the 'magic bullet' to make gene therapies work in the long run and a cure for haemophilia doesn't seem feasible yet. Still, the multiple treatments that are underway might significantly improve the quality of life of patients with haemophilia, by getting rid of frequent infusions and hospital visits, and transitioning patients from severe to mild haemophilia.

HFQ Community Camp

Community Camp is a weekend with new activities, good food and the chance to meet and discuss current issues for people with bleeding disorders in a relaxed and safe environment.

We're back at Noosa North Shore Retreat because it's a natural haven for wildlife and the venue has better quality food and accommodation. They also have a host of new activities that we will tap into.

Building strong and healthy relationships is an important part of the camp experience. At camp you have your own accommodation, but we encourage you to mix with each other and share experiences with people who will soon become friendly faces.

We have booked self-contained motel style units and have a dedicated function area we can use. The retreat also has a

General Store as well as the restaurant, 3 swimming pools and a tennis court but we have pre-booked some activities. The retreat staff are ready to take us on some challenging but fun activities that will help us improve our spirits and learning as well as expand our own capabilities and expectations.

On the Friday people will be arriving at different times but we are offering a dessert to recharge you in time for night walk down to the beach (the bus will bring us back to camp). On the Saturday we have Stand Up Paddle boarding with a difference! These are group boards and can take a family each as we work out how to work together.

After lunch we have the Giant Swing before a discussion session on the future of bleeding disorders in

Queensland. Hopefully it will be good weather as we will continue the conversation after dinner around the fire drums.

On Sunday it'll be a bit more low key with Putt Putt Golf, the climbing wall & giant jumping pillow to amuse the kids while we finish off envisioning the future of living with a chronic health condition.

At the end of those amazing two nights, it will be time to say goodbye, but we think everyone will come away with a smile and a real sense of achievement. Going home with newly found confidence and readiness for the futures we face!

If you haven't booked yet and want to attend please call the office ASAP on 0419 706 056

HFQ 2018 COMMUNITY CAMP
NOOSA NORTH SHORE RETREAT

\$75 per family \$50 per couple \$30 for individuals \$25 day visitors
 (subsidies available on request)

Nature, outdoor adventure, play, explore, share and interact

FRIDAY 9 TO SUNDAY 11 NOVEMBER

Contact the HFQ office on info@hfq.org.au or 0419 706 056
 to register & for more information

Haemophilia Foundation Queensland Inc

Where To Next? - life after school ends

Thinking about tomorrow is hard, let alone thinking about some distant future, in the work force. The end of school and the start of a job or further education doesn't mean that you must leave fun behind. By finding a job you enjoy or a course of study that leads to a job you'll enjoy, you won't feel like you're stuck in the work force,"

It's really hard if you don't have a clear vision about what that future will be. It can be hard to imagine a career that will give you satisfaction.

Explore what you like to do in your free time. Think about how you can turn it into a career.

See if your school counsellor has a career interest quiz you can complete to see what jobs are out there.

The right job can offer you more than just money. A successful job or career can also give you a sense of self-worth. Being able to support yourself and the self-esteem that goes with that can help you gain true independence.

Your school's career counsellor can help you assess your interests, talents, and skills and plan future education and job training you may need for a career.

People with bleeding disorders need jobs that will not cause frequent bruising or bleeding. As you set your career goals, think about your mental and physical abilities and limitations. When evaluating job options, you should consider avoiding;

- Work that puts stress on joints,

such as jobs that involve a lot of heavy lifting or bending

- High-impact occupations like construction and contact sports
- Potentially hazardous occupations with increased risk of injury

Talk to the QHC team about the likely areas you need to avoid putting stress on, so you can take that into account too.



Ask yourself what special skills you already have. Consider whether you prefer to work with people or alone. You may also need to carefully consider how a bleeding disorder could affect your career choice. And remember, there are many more jobs you can do than jobs that you can't.

But it's not always easy to find a career that's compatible with a bleeding disorder. In fact, what you dreamed of as a career might be unrealistic and you'll need to work out the difference between what you want to do and what's feasible.

As a kid you may have wanted to become an AFL player or do some other very physically demanding job. If you are set on working in a physically demanding job, think creatively.

Instead of stocking shelves at a Bunnings, for instance, see if you can drive the vehicles that carry the merchandise.

Try and figure out where a job can take you five or 10 years down the road. For example, if you want to build homes, find out which job would best position you to grow into a supervisory role.

Some people simply can't see themselves working for a corporation or the government. Others dream of becoming an artist or musician, or even opening their own business. It's important not to deny your dreams, but if you're an artist, think about pursuing a solid

job in the arts, such as in advertising design or public arts work. A musician can teach music while performing on the weekends. If you want your own business, grow it on the side while you work full-time for a company that provides health benefits.

No matter what career path you pursue, obstacles will lie ahead. Always aspire to achieve excellence, set your goals high, work hard and remember to make time for the things you love along the way. If you keep those things in mind, your final destination may remain unchanged or continue to evolve, but the end result will be happiness and an overwhelming sense of accomplishment.

Edited for size from an article by Diane O'Connell that appeared in Hemaware <https://hemaware.org/life/career-decisions-teens-bleeding-disorders>

Get the Benefits of PE while Minimising Risk

At the beginning of every school term, many parents, sit down with their children to go down the list of school sports and PE offerings. AFL/NRL? No. Too many tackles. Hockey? Probably too many sticks flying. Soccer? Possibly OK.

It's hard to know how to strike the right balance for children with bleeding disorders when considering how—or if—your child can participate in gym and sports classes at school.

You don't want your child to think of their bleeding disorder as a hindrance to being active; but there are the risks of injury that could lead to major bleeds.

Despite the risks, physical education is an important part of growth and development for all children and a health plan can outline any accommodations a child may need during the school day and it can include gym and sports.

Children with bleeding disorders can and do excel in physical activities. They have to understand the risks, but you also have to talk about what their quality of life will be like if they can't do things they love.

If your child has bleeds from certain activities, you should have a discussion with them about other roles they can play, such as serving as referee or other roles.

Getting the benefits without the risks

Because of the benefits of physical education, an Australian

study, published in 2012 looked at how much the risk of bleeding increased with vigorous exercise. Study author Dr. Carolyn Broderick and her team of researchers rounded up 104 boys with moderate to severe haemophilia ages 4 through 18. The researchers monitored the boys' bleeds and physical activity for one year.

Eighty-eight participants had bleeding episodes, usually in the



knees, ankles and elbows and most frequently before and after school.

Researchers found that some sports are associated with a higher risk of bleeds, depending on the activity's intensity and how often the child played. So there are tables available that look at which activities are safe for young people with bleeding disorders.

Activities are categorised by their likelihood of a severe collision, so swimming, for example, is a category one activity, while sports where collision is inevitable, like rugby, were ranked in category three.

Surprisingly, children with severe haemophilia can take a lot more in the way of impact sports than is

often attributed to them.

Proceed with caution

In recent times many parents have shifted away from fearful exclusion towards cautiously embracing gym and sports participation for their children.

The basis for the decision should include the child's age. By high school, students are more competitive, so gym activities that were okay in primary school may be more dangerous in later years.

That means it's important to find appropriate ways for children with bleeding disorders to participate in activities, based on their individual symptoms. Kids with bleeding disorders can and should engage in routine physical activity, but with appropriate

accommodations. If they want to play a particular sport, you may have to restrict the role they play in that activity to avoid the harder knocks or obvious accident areas.

It's important to understand how the exercise is good for children, how it can strengthen muscles around the joint, so they are less likely to have a bleed. It can also help them become more independent and able to voice their own concerns with any activities and that's what we want for our kids, to participate as they want and to make the best decisions for themselves!

Edited for size from and article by Kadesha Thomas called Get the benefits of gym class while minimizing risk

<https://hemaware.org/life/physical-education-kids-bleeding-disorders>

The Power of Talking

From an early age, it has been obvious to me that talking helps people ...but I'm a talker and the benefits of talking are not always apparent to everyone. In fact, some guys are so negative about talking through problems and issues that they say, "Talking is a waste of time." But talking can help—whether you talk with a friend, a family member, a councillor or yourself and here's why!

Self-talk is good

Believe it or not, talking to ourselves can be very beneficial. There is an entire branch of psychology devoted to cogitative behavioural therapy, but you can start it by talking to yourself. It's a safe and easy way to change the way we think.

Take an inventory of the negative thoughts that pop into your mind throughout a normal day and work on some positive statements to counteract the negative thoughts. By reminding yourself during the day of your own answers it's a bit like re-programming a computer. Old thoughts that are counterproductive are erased and new thoughts that are positive and constructive can entered your mind.

Talking makes you feel better

When I was a young man, I didn't fully understand the power of talking. I would be surprised after time with friends that I felt good or better about myself. I would think to myself, why does friendship feel so good? Over the years I came to realise that friends, like all good counsellors listen and

give you time to talk though your own stuff. They don't move the focus on to themselves, but spend time listening and being with you. Listening to others is far from doing nothing. Listening gives people an opportunity to tell their story, and, in the telling, they can find relief and a quieting of their emotions.

Talking with others is cathartic

There are many experiences in life that at times leave us emotionally overwhelmed. At these times, we walk around feeling emotionally charged up and filled with tension. Frequently, what has happened to us cannot be changed, such as when someone we love dies, a tragic accident occurs, or we have

Talking leads to new solutions

Sometimes, when we talk with a friend, a family member or a counsellor, we have been stuck. We don't know what to do. But as we talk, we hear ourselves express feelings and information in different ways than before. It is this experience of hearing ourselves that allows us at times to suddenly think of what to do. A solution pops into our mind.

In my experience a good therapist asks a lot of questions to keep me exploring what's troubling me and in doing so I discover my own solution. Very often, I get surprised at how I suddenly work out how to solve my problems.

A counselling appointment is 'me' time

I have found that talking about myself can be very beneficial. Having a therapist to help me explore my situation gives me a second perspective, the counsellor can reframe what I've said or ask for clarification and in those moments, I often discover the meaning and answers I am seeking.



made a mistake that impacts on ourselves or others. When these experiences descend upon us, we feel emotionally frozen. We find ourselves stuck in a state of despair and pain. At these times, talking can help.

Talking leads to a feeling of relief. The charged feelings within us become less charged. Nothing has changed that caused the suffering in our lives but talking can drain off some of the pain and this brings relief.

If you don't know or trust a psychologist or counsellor you can work with, start with your GP if you trust them or talk to the psycho social team at the QHC. Make some time to meet yourself in a counselling session. It costs nothing but time and perhaps a bit of momentary embarrassment, but the results are often an improved focus and a reinvigorated you.

Graham

Bridge to Brisbane

This year's Bridge to Brisbane Day rained and from a field of 8 HFQ runners and walkers we were left with three brave souls who risked melting in the rain.

Never-the-less, Sarah and her son Lachlan enjoy a walk that took in some of Brisbane's most iconic landmarks including the Story Bridge and finishing at the beautiful South Bank Parklands even if we couldn't see them for the rain.

We took on the 5km challenge which was enough for Sarah who is vision impaired so walking a little slower than some, but

Lachlan stayed with us for the entire course. Good on you mate!

Between us we were able to raise over \$400 for HFQ, all vital funds for people in Queensland affected by bleeding disorders.

If you'd like to do something to raise funds for HFQ

please call me at the office on 0419 706 056 or email info@hfq.org.au



Use Music to Beat that Pain Away!

Boom, chaka chaka, boom! Hear that? That's the sweet sound of your pain going away.

See, pain from bleeds happens. Even if you get medicine to help with pain, sometimes you still hurt. But, after you've told your parents about it, you might not feel it so bad if you lean back, close your eyes and listen to your favourite songs.

Here's why: Your brain is like a really powerful computer—but one that can only open one window at a time. That's why when you listen to music, your brain can't "hear" the pain signals coming from your joints, your port or from a needle stick. So, whether it's Thomas the Tank Engine songs, Broadway musicals or hip hop, music can help you when you hurt.

The best part? You can enjoy music anywhere! Play some tunes at home or in the car. Your family may find a professional music therapist who can teach you how to use music to deal with the pain. Either way, all you need

is to tune in, sing aloud and play along.

Tune in to the music you like and that makes you feel good all over. Your parents may put a few rules around it, like how loud the music can be or they may even say no to certain bands. But other than that, if it gets your toes tapping and your body moving, it'll help drown out the pain.

Ask them to help you create a playlist of your absolute favourite songs. If you listen to them when you are chilling out—like when you're getting ready for bed—your brain will know that it's music to help you relax. Then when you play that music when you're in pain, it will calm you even faster.

Listening to music is great for pain relief, but singing and playing along are even better! That's because your whole body and brain are involved, putting a "Go Away, Pain!" sign out that sends the pain signals packing in a hurry. The pain will still be there, but you won't notice it as much.

Don't own an instrument? That's OK. Do you have fingers? Toes? Snapping and stomping and drumming out the beat on your chest or leg can get you in the groove. Now's the time to pull out Rock Band, karaoke CDs or your air guitar. If your parents have a tablet personal computer, they might have an app that turns it into a musical instrument. All you have to do is swipe a finger across the screen, and you're in the band!

No matter how you engage with the music, humming your favourite tune or just listening can make healing from a bleed or sitting through an infusion more fun—and less painful.

Edited for size from an article by Heather Boerner that appeared in February 20124 issue of Hemaware called *You've Got the Beat*
<https://hemaware.org/life/youve-got-beat>

Health Updates

Liver Transplant Benefits, But May Not Cure Haemophilia

A liver transplant can be life-saving for haemophilia patients, but may not always fully cure the disease, according to the case report about a haemophilia A patient.

The authors detail the case of a 41-year-old male haemophilia A patient who had a liver transplant. In the first eight days after surgery the blood levels of factor VIII, the clotting factor deficient in haemophilia A patients, were recovered. But then factor VIII activity began to gradually decline.

The results suggest that liver transplantation may not necessarily result in a full phenotypic [symptoms and characteristics] cure of haemophilia A, the researchers wrote.

<https://onlinelibrary.wiley.com/doi/abs/10.1111/hae.13604>

Hemlibra Looks to Reach 'Ultimate Goal' of Treating All with Haemophilia A

Haemophilia A patients may have a treatment they can use regardless of inhibitor status, with a choice of dosing schedules that might better match their lifestyle. Hemlibra is already approved as prophylaxis for hemophilia A with factor VIII inhibitors in Australia, the USA, and elsewhere.

Its approval was a landmark event for patients with inhibitors, since for long time all research was focused on prolonging the half-life of factor VIII therapies.

New data from the ongoing clinical trials show that the therapy greatly outperforms current standard-of-care therapies. Researchers tested Hemlibra's safety and effectiveness as twice monthly, and a possible once-a-month injection. (Both trials are due to conclude in the second half of 2019.)

<https://www.roche.com/media/releases/med-cor-2018-10-04c.htm>

SPK-9001 Reduces Bleeding Rates by 98% in Haemophilia B Patients

The latest results for Spark Therapeutics investigational gene therapy SPK-9001, showed that the annualised bleeding rates of all treated haemophilia B patients were reduced by 98%. which allowed patients to discontinue routine infusions of recombinant factor IX concentrates.

During the trial, six participants had to receive additional factor IX infusions due to reported spontaneous bleeds, surgery, and for prophylaxis for a minor traumatic non-bleeding event.

Evaluation of factor IX activity in the first 10 patients treated revealed that it increased from less than 2% before the trial to 14.3% at week 12, and to 76.8% at week 52. All 15 participants, including the first four participants who have been followed for more than two years, continue to show that a single administration of SPK-9001 has resulted in dramatic reductions in bleeding and factor IX infusions, with no serious adverse events"

<https://hemophilianewstoday.com/2018/06/01/spk-9001-promotes-sustained-factor-ix-increase-hemophilia-phase-1-2-trial/>

utm_source=Hemophilia+News&utm_campaign=9967a972b7-RSS_EMAIL_CAMPAIGN&utm_medium=email&utm_term=0_ab10fd11a-9967a972b7-71884349

Developing Inhibitors Inflates Treatment Costs and Impairs Quality of Life

A study in the European Journal of Haematology showed that Haemophilia patients who develop inhibitors face markedly higher healthcare costs — about three times those of other patients — and experience poorer quality of life.

NovoSeven (Novo Nordisk) and Feiba (Shire) – two bypassing agents – are used against acute bleeds in patients with inhibitors. Hemlibra has also been shown to

markedly reduce bleeding rates. This benefit and its less-invasive method of delivery suggest a possible significant improvement in care for HA patients with inhibitors.

Given "this changing scenario," researchers studied the socio-economic burden of haemophilia with inhibitors, aiming to provide a reference to measure the impact of new treatment methods. Results showed that costs associated with inhibitors are over three times greater.

The data also showed that developing inhibitors reduced patients' quality of life, especially physical aspects. Patients reported pain, problems with mobility and daily activities, missing school or work, and more frequent hospitalisations.

<https://onlinelibrary.wiley.com/doi/pdf/10.1111/ejh.13108>

uniQure Granted 2 New Patents Covering Gene Therapy Approach for Haemophilia B

A gene therapy approach acquired by uniQure was recently granted in two new patents. The therapy has a nucleic acid encoding the hyperactive Factor IX (FIX) Padua variant — a factor IX protein carrying a leucine (an amino acid, or building block of proteins) at the R338 position. The patent covers the use of adeno-associated virus (AAV) gene therapy with FIX-Padua to treat haemophilia B and other disorders.

Trial data released in January showed that AMT-060 is to be safe and effective in treating severe and moderately severe haemophilia B for up to two years. Overall, adult patients required fewer doses of replacement therapy and showed a marked decrease in spontaneous bleeding rates.

<http://www.uniqure.com/investors-newsroom/press-releases.php>

Dental Care for Kids with Bleeding Disorders

Taking oral health seriously

It is important for children with bleeding disorders to take good care of their teeth and gums. Regular visits to the dentist will reduce the chance of future problems such as extractions or mouth infections, which can lead to further problems.

Attending the Dentist

Your child can attend their own dentist for routine care such as check-ups, x-rays, fissure sealants, fluoride treatments, fillings, cleanings, root canal treatments and crowns. You should inform the dentist about the bleeding disorder and advise them that further information is available from your child's haematology treatment centre.

Should your child need a tooth extraction or certain injections you can check with your child's QHC care team and arrange for your dentist to connect with them before proceeding in case the proposed treatment need to be provided at a specialist centre.

Never-the-less, for dental matters, your dentist is the best person to advise you and your child on how best to avoid dental problems and they can provide regular interventions such as fluoride

treatments and fissure sealants to prevent dental disease. All children with bleeding disorders should attend their dentist frequently as oral hygiene is very important.

Top tips for healthy mouths

-  Use a soft, child sized toothbrush to brush teeth twice a day.
-  Children over two years should have their teeth brushed with a full strength fluoridated toothpaste.
-  For children under two, you should consult their dentist regarding toothpaste use.
-  Drink only milk and water during the day.
-  Drink only water at night.
-  Avoid fizzy drinks, juice and diluted fruit drinks.
-  Restrict sweets and sugary foods.
-  Attend the dentist by one year of age.
-  Have a check-up every six months.

Frequently asked questions

Many parents have questions about their child's dental care.

These are some of the most common. If you have more questions just ask your dentist or the QHC team at LCCH.

What type of dentist can my child attend?

Your child can attend a family dentist, a school based, or a private paediatric dentist. The QHC team can work with you and your child's dentist to give any necessary advice.

Should I brush my child's teeth if they bleed?

Bleeding gums are usually a sign of gum disease and this is usually caused by poor brushing. If your child has a bleeding disorder this may mean that their gums bleed more easily. The best treatment is to improve your child's tooth brushing and attend your dentist for a check-up and cleaning.

Edited for size from an Irish Haemophilia Society publication on Dental Care for Children with Hereditary Bleeding Disorders at; <http://haemophilia.weareopen.ie/wp-content/uploads/2015/07/Dental-Care-for-Children-final-3.pdf>

Tooth Fairy Time

For young children, their first wobbly tooth is a sure sign they've officially earned big kid status. As tempting as it is to wiggle a loose tooth around to help it fall out, it's best to leave it alone. Bleeding occurs when a tooth is pulled before the root has resorbed and the tissue around the tooth tears. Left alone, the erupting permanent tooth puts pressure on the area and then significant bleeding is rare. Talk to the QHC staff ahead of time about procedures you can take if nuisance oozing occurs after the tooth falls out.

Engage your child in some quiet activity time after the tooth is out and safely tucked away for the tooth fairy. During this time, the child should bite down firmly on a small piece of gauze for several minutes. To help prevent bleeding during the next few days, skip over the area with the lost tooth when brushing teeth and give your child soft, cool foods to eat. If there is a significant bleed, contact your haematology team. Some tips for managing bleeding caused by a lost tooth include:

-  Have your child bite down gently on a moistened black or green tea bag. The tea leaves contain tannic acid, which constricts blood vessels to help form a clot.
-  Don't let your child rinse his or her mouth. Swishing water around can disrupt the formation of blood clots.
-  If, after following these tips, the bleeding continues or you are still concerned, call The QHC team for a consultation.

Storm Season Fun

When a summer cyclone puts a damper on playing outside and cabin fever is driving everyone bonkers, these quick activity ideas will keep the children occupied and happy for a few hours:

Put on a Show with Homemade Puppets

We've all created puppets out of cotton socks, paper bags, markers, and a handful of buttons. But kids can get really creative with a cool grab-bag of puppetry accessories that you gather and store in a special Puppet Box. As you're cleaning the house or shopping at grocery, thrift, or dollar stores, keep an eye out for fun adornments for homemade puppets.

Collect and buy: glitter, dried beans, sequins, tinsel, pipe cleaners, string, ribbons, yarn, buttons and appliqués, holiday decorations, stickers, seashells, etc. (beware of small objects, though, that could pose a choking hazard for small children).

Also keep your Puppet Box stocked with must-have items like glue, scissors, washable markers, Popsicle sticks, and a needle and thread (when sewing, supervise young kids or do sewing projects yourself). Also, keep a few small cardboard boxes — folded and flattened for easy storage — to

cut out and colour for nifty background scenes and props.



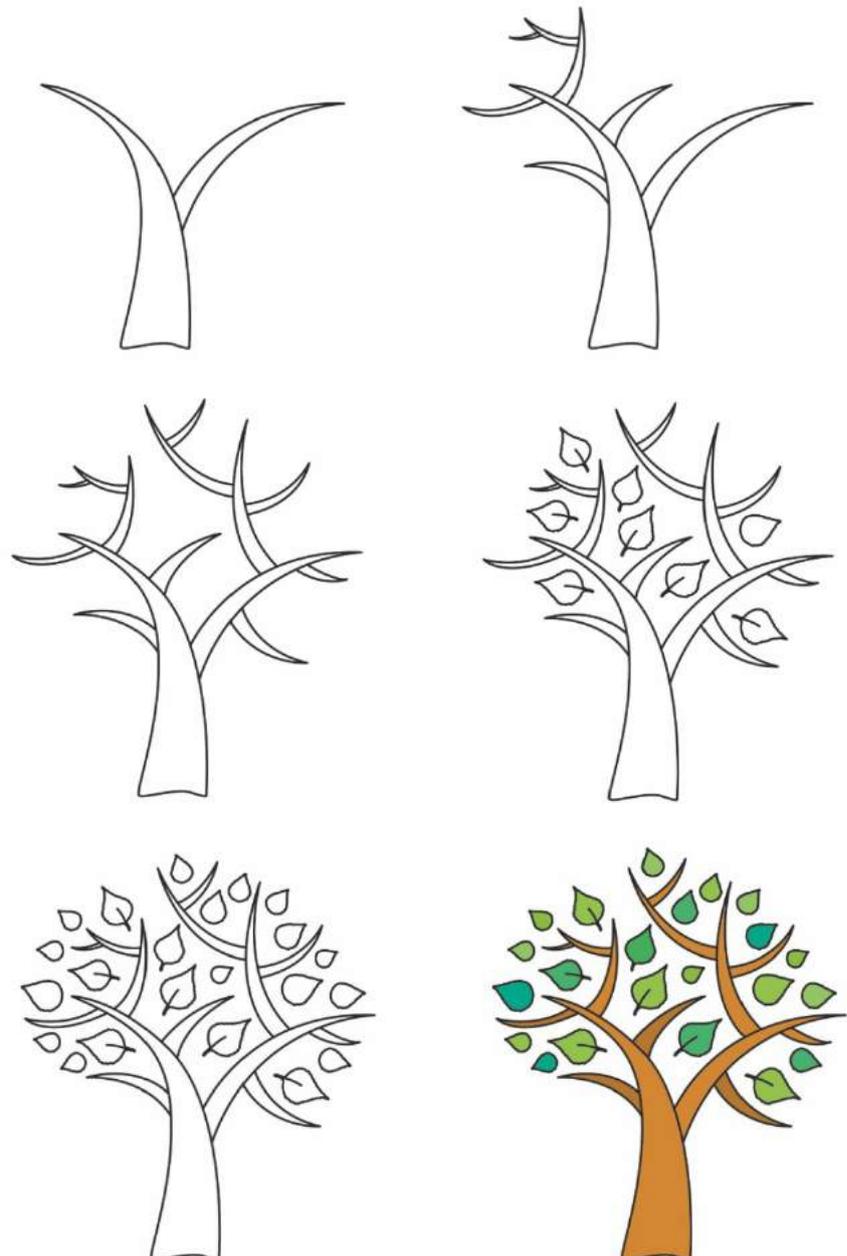
Make Thank-You Gifts

Kids often like to thank their caregivers, grandparents, aunts and uncles, teachers, babysitters, neighbours, and childcare workers. Bake a few batches of cookies that your child can lovingly decorate and wrap with coloured plastic wrap and

ribbons; or create thank-you cards on regular old printer paper or construction paper. Add special glued-on adornments like family photos, ribbons, glitter, and buttons (again, beware of small objects that could pose choking hazards for babies and toddlers).

Help improve kids' spelling and letter identification skills by letting them type and print out their own messages in fancy fonts on the computer. Instead of doing crafts just to get through the day, this project will help kids feel like their time and efforts are being spent on a greater purpose — giving to someone they care about.

Learn to Draw a Summer Tree



Important Dates for HFQ Members

- 🔥 OBE Lunch Forum**
informal support group for men with a bleeding disorder. Usually meets first Tuesday of the month. Next Meetings;

 - 🔥 13 November. Travelling with a bleeding disorder
 - 🔥 9 December. Christmas get-together. All welcome
- 🔥 Women's Brunch**
18 November 2018
venue TBA
- 🔥 HFA Youth Canoe Trip**
Mid November. See HFA website for further details
- 🔥 Regional Meeting** *Please ask if one is happening in your area.*

 - 🔥 **Note:** Planning's underway for a Cairns event in 2019
- 🔥 Community Camp**
9-11 November 2018 Noosa North Shore Retreat

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



On a very blustery Sunday in August, Craig and Hayley met up with some of our young folk (and their parents) for our first official youth paddle. The parking was highly competitive at the Enoggera Reservoir, but once we got down to the water we were greeted by the staff from Walkabout Creek adventures who had our double kayaks ready for us.

There were 8 kayaks in total, so a nicely sized group. After a quick welcome and a briefing, we donned our lifejackets and paddled out through the floats onto the lake. The plan was to get around the lake and there was a lot of enthusiastic paddling at the start until we were out on the water. Our thoughts then turned towards survival. More; "Please, let the wind die down", rather than "Wahoo, that's challenging!"

The wind was so strong that we spent a lot of time asking, "where are we?" And "where's the beach?" By time you figured that out, the wind had pushed us further out and our kayaks were at risk of crashing into each other. You could say the winds defeated our circumnavigation, but we got back to shore with some kayaks a bit full of water (and the paddlers a bit wet) to a standing ovation. Well, Craig clapped at least.

There are not many photos from the day because iPhones might be waterproof but they can sink! We ended up back at the café where we had a chat after 2 hours on the water feeling tired but challenged after our paddle. Whether you are a first-timer or an experienced paddler, come and join us for the next HFQ youth event.

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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