the H FACTOR

Haemophilia Foundation Queensland

AUTUMN EDITION

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HFQ MEMBER MAGAZINE

From the President

Hello everyone, this edition I wanted to look briefly again at gene therapy (GT) and give you my opinion on where it's at today.

There are about seven GT trials for both haemophilia A & B with four in phase 3. I thought last year we would have seen approvals from the American regulator (FDA), however they are not convinced on the data and want to see more over time – this means at least a further year before approvals can be looked at again. GT has the possibility of a curative treatment (remember it's not a cure in the true sense).

For all the great life changing possibilities that GT could bring, there are still many questions unanswered – last year one trial participant developed liver cancer, however this person had multiple other medical issues going on so GT may not have been a 'factor'. Also last year there was a report about haemophilia dogs (Virus used in gene therapies may pose cancer risk, dog study hints | Science | AAAS (sciencemag.org) – these dogs were treated with GT ~10 years earlier using a modified viral vector (transport method used to deliver GT to liver cells - adeno associated virus – AAV) and the study has shown that the vector can insert into the dogs DNA – "integrating into many spots across the genome in dogs liver cells, sometimes near genes affecting cell growth" raising long term safety questions.

Other questions about how long would a GT treatment last, or will GT be affordable to governments, or why is it that factor levels vary between people treated with the same GT, or what lifestyle changes may be required – for example what effect would alcohol have on factor production. As you can see I believe there are still many outstanding questions surrounding GT. So I don't don't think GT is near 'done and dusted' just yet … time and more research will tell.

In closing, I would like to thank all those brave people who signed up to GT trials & to the researchers – looking for the curative treatment that could change lives, with your involvement the science has progressed – great job!

David Stephenson
President HFQ
president@hfq.org.au

Inside this issue:

ABOUT HFQ

Haemophilia Foundation Queensland Inc. (HFQ) provides representation, health promotion, education and support for people in Queensland affected by inherited bleeding disorders. The Foundation receives a grant from Qld Health and employs a part time manager and an administration 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)**

HFQ Management Committee

President	... ...	Mr David Stephenson
Vice President	...	Mr Robert Weatherall
Secretary	... ...	Ms Lauren Albert
Treasurer	... ...	Mr Adam Lish
Members	... ...	Mrs Belinda Waddell
		Mr Charles Eddy
		Dr Jodie Caris
		Mrs Leanne Stephenson
		Ms Shannon Gracey
		Mr Shannon Wandmaker
		Mr Tony Ciottariello

HFQ Delegate to HFA

Mr Adam Lish

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 Chintaki (Chinthi) Jayasekera

Joanna McCosker – Nurse Practitioner

Amy Finlayson / Salena Griffen – Clinical Nurse

Elise Mosey (M,T) - Physiotherapist

Hayley Coulson (W,Th, F) – 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 QCH-Haemophilia@health.qld.gov.au

After hours—call switch and ask to speak with on-call haematology consultant or present to the emergency department

Appointments — Outpatient Bookings Office on 1300 762 831 or email QCH-Outpatients@health.qld.gov.au
Your health care team does not make these bookings or any changes to your appointments. Referrals can be sent to the Referral Centre Fax Number 1300 407 281

Haemophilia Outpatient Clinic — Dr Simon Brown — held in 3c outpatients Level 3, Thursday afternoons 1.00 – 3.30pm

Haemophilia Carrier Clinic – as needed Thursdays 1pm – 3.30pm

ADULT CLINIC

ADULT CLINIC STAFF (RBWH)

Dr Jane Mason - Haematologist	3646-8111
(Page through switch)	
Haemophilia Registrar	3646-8111
(ask to page Haemophilia Registrar on 59716)	
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
For all non-clinical/non-urgent enquires please email RBWH-Haemophilia@health.qld.gov.au

Haemophilia and Genetic Clinic — Dr Jane Mason — Wednesdays 1.30pm New Patients Thursdays 8-9.30

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 *CHQ-Haemaphilia@health.qld.gov.au* at QCH or *RBWH-Haemophilia@health.qld.gov.au* at RBWH.

World Haemophilia Day

One of the reasons that 17 April is recognised as World Haemophilia Day is that despite continuous advances in research, treatment and awareness efforts, there is still much work to be done for people with bleeding disorders.

While it is called World Haemophilia Day, it is used worldwide to increase awareness of haemophilia, von Willebrand disease and other inherited bleeding disorders. This is a critical effort since with increased awareness comes better diagnosis and access to care for the millions who remain without treatment.

Many people in the broader community equate haemophilia with all bleeding disorders and they aren't exposed to the nuances of living with a bleeding disorder as they are not directly impacted by a diagnoses for themselves or a family member. So World Haemophilia Day is an effort to promote a positive, proactive approach to addressing bleeding disorders.

This year the theme is Adapting to Change. Living during a pandemic can pose many challenges, as does responding to treatment changes and changes in diagnostic understandings. These all impact on our health, as well as our mental health and wellbeing.

Get involved

You can mark World Haemophilia Day by raising awareness of bleeding disorders in your local area, or to raise money for us. You can also get involved with World Haemophilia Day by creating social media content on anything from Instagram or facebook to a few Tweets or a blog article, perhaps you could run a 'wear red' competition at your work of school, or you could run your own event at home.

If you work for or own a business you could promote World Haemophilia Day through online and in-store marketing. Tweeting and blogging about how your business supports the campaign theme, and what the business is doing to help tie into the campaign goals can be a good way to start support an awareness day.

You may be able to display official marketing and promotional material to help support World Haemophilia Day if you have a shop, warehouse or office.

Please call (0419 706 056) or email the HFQ office (info@hfq.org.au) if you'd like help in making an event happen in your area.

What's On?

MAKE IT YOUR EVENT

April to July 2021

Some of the HFQ programs and activities already planned

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

APR

- **OBE's Monthly meeting** Sunday 11 April, The Gap Tavern
- **WHD Art Display** RBWH Art Space 30/3/21 - 24/4/21
- **World Haemophilia Day** 17 April 2020
- **Women's Lunch** Sunday 18 April 11.30am to 1.00pm
- **HFQ Board Meeting** 21 April, 298 Gilchrist

MAY

- **OBE's Monthly meeting** 2 May, Venue TBC
- **National Volunteer Week** 17– 23 May
- **HFQ Board Meeting** 18 May, 298 Gilchrist Ave, Herston
- **World No Tobacco Day** 31 May 2021

JUNE

- **OBE's Monthly meeting** 2 June
- **Men's Health Week** 11 - 20 June
- **World Blood Doner Day** 14 June
- **HFQ Board Meeting** 15 June, 298 Gilchrist Ave, Herston

JULY

- **OBE's Monthly meeting** 7 July
- **Women's Lunch** Sunday 18 April 11.30am to 1.00pm, Everton Park Hotel
- **HFQ Board Meeting** 17 July, 298 Gilchrist Ave, Herston
- **World Hepatitis Day** 28 July

Get a Flu Vaccine.

When the start of winter, colds and flus start to appear. The same precautions we're taking to help protect ourselves from Covid19 - steps like wearing a mask, social distancing, washing hands frequently and disinfecting high-touch surfaces - will help decrease the spread of cold and flu viruses too.

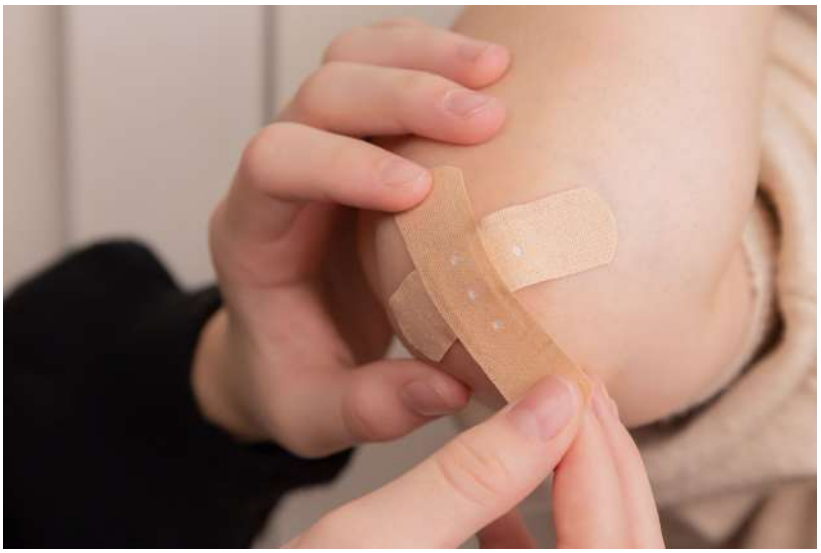
The single best way to avoid getting the flu is the flu shot! It's recommended for everyone from six (6) months and older, but especially for people who are at high risk for serious complications from influenza, such as adults 65 years and older, and those with chronic health conditions.

Getting a flu shot is even more important this year, because getting COVID-19 and the flu at the same time increases the likelihood of complications. A recent study revealed that people who had Covid19 and the flu were sicker than those who had Covid19 alone.

The best time to get your flu shot is April or May this year. Flu activity usually peaks between June and July, but it can continue to circulate as late as September.

Ben's Transition to Hemlibra

Ben transitioned from Adynovate to Hemlibra in late October 2020. The timing of this life changing treatment could not have come at a better time for Ben, my athletic young boy. Ben had experienced a good run on Adynonvate, it was life changing in itself compared to the second daily dosing he was on with Advate. Adynovate's coverage was much more effective and for a while Ben had hardly any bleeds. Dosing twice weekly meant he could actually be out of my watch, visit friends, go to school camp without me. He had completed a whole year of school without a cast of some sort and his confidence was blooming. In the 'clear water' the lack of injury provided, Ben discovered tennis and that he was actually very good at athletics. Without the constant cycle of injury and recovery of joints, we almost forgot about Haemophilia in moments, almost!



Last year was tough for everyone and despite not having as much time at school, the spontaneous joint bleeds started to re appear. Every holidays saw Ben in hospital with a bleed from riding a bike, jumping, digging at the beach or no apparent reason at all. When they happened, it was always on every third or fourth day after prophylaxis, when the Adynovate was at the lowest, zero. The return to the twice weekly visits to physio, A and E, time in casts and commencement of vein training was a very emotionally exhausting time for both of us. A return to the cycle of injury and recovery. Ben would ask, "Why can't I have Adynovate every third day? I wouldn't get bleeds."

Ben's confidence and trust was sliding. I was watching him become disheartened. Worn out of being brave, being bigger, overcoming disappointment at missing the sporting events he had been training towards and everything he loved to do. He never complained, but his confidence and enthusiasm were slipping and there was nothing I could really do. I was so sad for my brave boy who tried so hard and had no option but to dig deeper every time he was 'set back'. We had started vein training and it was proving more challenging than expected; a bit hit and miss with staff turnover and Ben's elusive veins. It was just another layer of challenge to cope with.

Early October, whilst in Physio, he was told he needed yet another cast. Ben hung his head and cried. We had never seen Ben like this, needless to say, Ben's physio of 5 years and I cried too. Haemophilia had taken over our whole lives again and I'd run out of coping strategies. I rang Jo the next day desperate to ask if we can PLEASE do Adynovate every third day. Instead, she gave me the news of this new treatment called Hemlibra; second weekly subcutaneous delivery, half-life of a month, constant coverage of 15-20% "factor eight like" activity. No more troughs in coverage! Needless to say, I cried, again! We started within two weeks.

So, three and a half months into Hemlibra. We have had NO haemophilia related bleeds. This is over the 2-month holiday break where we have walked kilometres through rocky National Park tracks, had two full charged days straight at a water park with plastic slides and metal stairs to climb. Days of swimming, digging in sand, playing tennis, climbing, jumping, riding and rowing. We had NEVER had a holiday anywhere where Ben did not end up in a local hospital or wrapped in tubigrip awaiting hospital on return! The world of possibility is opening up for us!

Furthermore, Ben is doing his own subcutaneous injections, in the tummy, every second week.

We are in hospital as I write this, having his port of nine years removed. Hoping this will be the last two weeks break from sport, due to Haemophilia for a while. I think Ben is cautiously relaxing into this reality, we have had good runs before. His confidence is quietly returning though and so is mine.

We have had our very own miracle.

Hemlibra Safely Treats Children

Prophylactic (preventive) treatment with Hemlibra (emicizumab) safely and effectively lowers bleeding rates in children and adolescents with severe haemophilia A, according to a recent study.

These findings support Hemlibra's use in the haemophilia A paediatric population, regardless of inhibitor status.

Data also suggested that routine laboratory monitoring may be unnecessary in most asymptomatic young patients, but warranted in those with bleedings, as they may have developed antibodies against Hemlibra, researchers said.

Hemlibra, administered as an under-the-skin injection, is a bypassing agent that was recently approved by the NBA for use in Australia as a routine preventive treatment for haemophilia A patients with or without FVIII inhibitors.

While Hemlibra's safety and effectiveness was evaluated in both children and adults with haemophilia A in clinical trials, real-world data on Hemlibra's use and monitoring in paediatric patients has remained limited till now.

Researchers evaluated the safety, effectiveness, and monitoring of Hemlibra prophylaxis in children with a median age of 5.5 years (range: 1 month to 18.5 years). Who has severe haemophilia A, regardless of inhibitor status. Nine were less than 1 year old.

Hemlibra's loading dose was given once a week for four weeks, followed by weekly maintenance doses and followed-up of about 10 months (range: eight to 102 weeks).

Results showed that 50% of patients had trauma-related bleedings during the study period, with no reports of spontaneous bleedings. Most bleeding episodes were treated with a single dose of factor

The researchers said that the high proportion of children experiencing bleedings may be because of the study's long follow-up period. Children's median annualised bleeding rate fell after Hemlibra initiation, with no differences between those with or without inhibitors.

Treatment duration was significantly longer in children with FVIII inhibitors, and the risk of having a bleeding event was significantly associated with the treatment's length.

Twelve children underwent 16 minor surgical procedures, with no blood clot-related complications or thrombotic microangiopathy.

Hemlibra's blood levels increased after treatment initiation, which was associated with normalized blood clotting speed and an increase (but not normalization) in the effectiveness of blood clotting.

Blood clotting did not differ between children experiencing bleedings and those who did not. But it was lesser in the younger group, consistent with a previously reported age-dependent increase in such effectiveness. As all bleeds were trauma-related, laboratory monitoring could not predict bleeding risk.

However, laboratory monitoring is needed in children with bleeds while on Hemlibra, as antibodies against the therapy have been previously reported, they added. Saying that measuring Hemlibra blood levels or blood clotting speed are practical and accessible tests in the clinical setting. Future studies are needed to better assess the clinical implications of routine laboratory monitoring, particularly in patients undergoing surgery.

Hemlibra was generally safe and well tolerated, with no serious treatment-related adverse events. The most commonly reported side effect was an injection site reaction (10%), which were mostly mild.

Edited for size and content from "Emicizumab treatment and monitoring in a paediatric cohort: real-world data" https://onlinelibrary.wiley.com/doi/epdf/10.1111/bjh.16964

Overcoming Unique Haemophilia Challenges

In a recent study by a panel of U.S. experts published in the journal Haemophilia proposed new strategies, such as improving access to data, increasing interaction in the haemophilia community, and providing more and better resources, to help overcome barriers faced by people with mild to moderate haemophilia, in particular women with the disease. Many of these challenges are specifically linked to a lack of information and insufficient engagement with other patients and healthcare providers, according to the panel.

They found that people who have mild to moderate haemophilia experience different challenges than those with severe disease. They are less likely to recognize a bleed when one occurs, and their healthcare providers may be less likely to identify bleeding related problems, such as joint pain.

They say there is very little available information on the experiences of people with mild-to-moderate haemophilia, and concluded that insufficient education about their disease and a lack of involvement with the haemophilia community were major challenges for these individuals.

The researchers noted that many resources in the haemophilia community (for instance, published guidelines on disease management) are oriented toward people with severe disease.

The experts also noted that mild-to-moderate haemophilia can have a substantial impact on school, work, daily activities, and interpersonal relationships. Also, mild haemophilia can cause physical problems that make certain kinds of work or sports difficult or dangerous.

The panel highlighted that many of these difficulties are particularly pronounced for women with haemophilia. Girls and women who have haemophilia are sometimes labelled as "just a carrier," for example, leading to a lack of education and exclusion from the haemophilia community — even though females with haemophilia can still experience substantive symptoms. Notably, menstruation and pregnancy also can pose unique complications to women with haemophilia.

The team of experts urged that more data be collected on how mild-to-moderate haemophilia affects patients, and that resources be dedicated to increasing education within the community as well as among healthcare providers.

They also called for auditing of existing educational materials from advocacy organisations, and for developing better guidelines for the treatment of mild-to-moderate haemophilia. Specifically, they pointed to the need to highlight different key goals and timelines for patients with mild-to-moderate haemophilia, adding that a focus should be placed on developing healthcare self-management skills between clinic visits.

The panel also called for increased engagement of women with the haemophilia community.

They highlighted these patient sub-populations to demonstrate and highlight the significant unmet needs and opportunities for [haemophilia treatment centres], national organisations and local communities to become partners in their disease management.

Overall, the suggested initiatives could empower these patients and lead to better health outcomes, the researchers concluded.

Edited for size and content from "Identified unmet needs and proposed solutions in mild-to-moderate haemophilia: A summary of opinions" published in Haemophilia Journal . https://onlinelibrary.wiley.com/doi/10.1111/hae.14168

Living Regionally with a Bleeding Disorder

When someone with a blending disorder outside of SE Queensland experiences a bleed, they are often kilometers away from hospitals with expertise in their treatment. However the teams at Hemophilia Treatment Centre's (HTC's) in Brisbane can still help and supervise your care and if you need the support and services of the Brisbane Hospitals, patient travel subsidies can be offered for approved procedures and HFQ can also help defray expenses.

If you live in a regional or remote town, it pays to be organised and resourceful to make sure you or your child get the care they need.

The Haemophilia Treatment Centres can help connect you with local medical professionals and will work in partnership with them, but you can help by making sure the local emergency room and other doctors in your area have a file on the patient and also by making sure that you have plenty of medication on hand, or that it's stocked at the local hospital pharmacy in case of emergencies.

The challenges faced by regional and remote members are similar for all families who live in rural areas who need to manage a bleeding disorder. They often contend with emergency departments that don't know the urgency of treating bleeds or using certain medications, and have little or no experience handling these disorders.

Extending the Network of Care

Research consistently shows that adequate treatment to stop or prevent bleeding episodes not only improves outcomes but also reduces costs. In Queensland the HTC's provide an integrated model of multidisciplinary, comprehensive care to treat people with complex and rare inherited bleeding disorders. The HTC teams consist of a paediatric or adult haematologist, a nurse coordinator, a physical therapist and a social worker or psychologist.

Studies in the USA by the Centres for Disease Control and Prevention indicate that people with haemophilia who get care from HTCs are 40% less likely to be hospitalised and 40% less likely to die because of bleeding complications.

Other research has shown that regular prophylactic treatments to prevent bleeding episodes that start early, before age 4, preserves the ability to move joints properly.

However the two Queensland HTCs are in Brisbane, and people living in less populated places, often have to travel hundreds of kilometres to get proper care, especially in emergencies.

This is the situation that many of our regional members encounter, as most local doctors do not have the expertise that is required to take care of them on a day-to-day basis.

The Queensland HTCs increase access to care for regional patients by travelling to Cairns, Townsville, Mackay, Rockhampton, Toowoomba, Sunshine and Gold Coasts to run satellite clinics (as required) usually once a year - and by offering telehealth to people living away from Brisbane.

During the Covid pandemic, people found telehealth to be a wonderful support, and we hope to see it used a lot more frequently now that members are used to having video chats. You can even have the physical therapists assessing joints via telehealth!

Perhaps out of necessity, people who live in rural areas are remarkably independent and resourceful. We've always been impressed with these members who seem to have a backup plan for everything, but don't forget to connect with HFQ as well! We try to keep families connected through events and educational services and we act as advocates for the Queensland bleeding disorders community.

Edited for size and content from "Far and Away: Living with Bleeding Disorders in Regional and Remote Areas" by Linda Marsa. https://hemaware.org/life/far-and-away-living-bleeding-disorders-remote-areas

5 Minutes with James on Family and Friends

What type of Hemophilia do you have?
I have haemophilia A, severe and I'm treating with Hemlibra (and Eloctate), it's life changing really.

Do you experience any complications from Hemophilia?
Yeah. Plenty of different ones. Physical, mental, even down to my metabolism issues with normal factory products. I've got a high metabolism, so I have a very low Half-Life of about six hours. With hemlibra they are monitoring to see if I have any breakthrough bleeding or how much of the Eloctate I require. So far, I've had two ankle bleeds, but the Eloctate worked really well and I bounced back quickly.

With hemlibra, they seem to have quicker recovery time and they were less severe, and it's just taken away a lot of the aches and pains and my joints don't feel swollen. I don't know if it is all in my head. I've noticed things like my ankles are not as puffy as they used to be, and I have way less issues with them.

Did haemophilia impact on your decision to start a family?
As a young dad I wanted to make sure that I got in as early as was reasonable so that, if there was any joint degradation or mobility issues later in life, this was not going to impact on my ability to parent. I wanted to be able to run around with my kids. My Haemophilia was something I've always been very open with Brooke about, and she's always embraced it. And that's how she got into taking blood, from watching me do factor all the time. And so she's always been very involved and she's understood and been of a similar belief.

As the person with haemophilia it's a different set of odds, hereditary wise. We had a 50 percent chance of having a carrier. And looking at my life compared to my nephews, you know the next generation is going to have a different experience. It's completely different than even the generation before me. So you'd hope that if we had a girl and then she had a boy, 30 years from now, there will be significant advancements. Everything's exponential in medicine like that.

Has your bleeding disorder impacted on your ability to be a dad?
There are definitely some restrictions due to mobility issues. I can't run around the park with him, but I can kick a soccer ball back and forth with him. There's compromises that I have to make, but I can still ride a bike with him. And even if I have bleeds where I can't use my arm or I'm stuck in bed, or whatever it is, Brook's always helped me around it. So, it's definitely been a little bit of a struggle. But the support from Brook has been amazing and that is definitely what I rely on. And as a partnership you just sort of make up for it when you can.

What delights you in life?
Well, I definitely enjoy my family. Number one! Just seeing the two boys and Brook all together, the four of us. That definitely brings me a lot of joy. I love my cars and computers and learning about business and what the world is up to (Inventions and engineering and all different things). It all comes back into it. I'm always just mentally tinkering with things worth seeing if there's better ways to do things, and I think that's from being in hospital so much as a kid, you learn to do stuff with your head. Keep your mind active, while your body can't be.

How did you get involved with HFQ?
I've been around my whole life with the camps as a kid and my involvement started from when the camps restarted. I think a few of us naturally took that youth leadership role on. And then HFQ supported us with all that training, that was amazing. and that's helped us a lot to, you know, to what we do.

Do you think there's still a need for patient support, camps and for that sort of stuff?
There's definitely still unique parts about life with haemophilia, and they're not things that you can go through alone. You've got to have the community and especially for the mums. I find as patients we talk among ourselves, but the carers of the patients, they love to talk to us as well, because they've only got a three or four year old. They want to know what that adult perspective absolutely is. And it's great to speak to people and hear all the different stories in your network and you make great friends.

One of my best friends in life is Ian Zaro. And I met him through HFQ. He's in New Zealand at the moment and I don't think he wants to come back for a while anyway. He's got a few gigs going on over there, but we'll always be best friends.

Get the Most Out of you HTC or GP's Visit

Developing solid communication skills with providers can help them better manage you or your child's bleeding disorder. Follow these tips to get the most out of appointments with your haemophilia treatment centre (HTC) healthcare team.

Before Your Appointment

Know why you are going for a visit to the HTC. It may be for your annual comprehensive visit, for a mid year check-up, for evaluation of a bleed or for a follow-up after a bleeding episode.

For an Annual Visit

- During the year, keep a running list of questions you have for your healthcare team. Clinic visits can be hectic and you will see a lot of providers. Remember to bring the list with you!
- Track bleeding episodes using MyABDR or a treatment calendar etc. This information is key for your healthcare providers so they can assess your treatment plan and make changes if necessary.
- If you or your child has specific issues, write down when the problems occur, or if there is something that precipitates a problem. For example, do you or your child typically have bleeds on one particular day of the week, or following a specific activity?
- Keep track of any school or work days missed due to your bleeding disorder.

Bring with You to the Appointment

- A health history since your last visit. Bring any pictures you have taken documenting bleeding episodes, and don't forget your list of questions.
- Infusion logs for yourself or your child.
- Names of prescription and non-prescription medications you or your child takes. Include vitamins, herbal remedies and pain medicines.
- Names of medications and foods to which you or your child is allergic.
- Medical records, including X-ray films, test results or past doctor's records. If you have been seen at another HTC, bring a copy of the records from those past visits.
- A notepad to jot down information.
- If possible, bring a trusted family member or friend with you to the visit. This extra person will help you remember what was said, and he or she may ask questions you didn't think to ask.

Vale Rob Brooks

We wish to advise that Robin Francis Brooks (husband of Julie Brooks) passed away on February 15th, 2021, aged 72. Rob was the brother-in law to Robbie Weatherall and an advocate for HFQ and will be missed by all. Our condolences to Julie and her family.

Hemophilia and Tattoos

Most tattooists require you to sign a liability release saying that people with bleeding disorders (and a long list of other conditions) should not get tattoos. The problem with tattoos is the different healing experiences for each person and you need a plan for how to treat the "wound" caused by the tattoo.

Some health care providers caution patients to get tattoos at their own risk. And some providers will work with their patients to ensure a safe tattooing experience. If you are considering getting a tattoo talk to the HTC team and consider getting a tattoo on a prophylaxis day to maximise factor availability. You may need factor doses for a few days post-tattoo as well.

Some people think it is irresponsible and frivolous for a person with haemophilia to get a tattoo. The ones who label it irresponsible believe a tattoo isn't worth the risk of getting a bleed. Those who say it's frivolous think it is irresponsible to waste expensive factor to protect oneself while choosing to get a tattoo. A haemophilia diagnosis should not strip a person of the right to express themselves.

Edited for size from an article "I Have Hemophilia and Tattoos, and I Don't Regret It" by Shellye Horowitz.
https://hemophilianewstoday.com/2021/02/09/tattoos-hemophilia-no-regrets/

Where next for HIV vaccines and therapies?

In the search for an HIV vaccine and for other immune-based therapies, the last 12 months have seen a modest success when on 26 January it was announced that the AMP study the first-ever efficacy trial of a so-called broadly neutralising antibody (bNAb), VRC01, produced a modest reduction in HIV infections, but a 75% reduction in the class of viruses most sensitive to it.

Dr Mark Feinsberb, President and CEO of the International AIDS Vaccine Initiative, said that they were getting closer to the goal of an effective immune therapy against HIV, although he still don't know how long that journey would take.

One problem with vaccine development is that pre-clinical trials in animals often give results that poorly predict what eventually happens in humans. Although VRC01 could neutralise 85% of HIV viral isolates in a lab, it clearly didn't do this in practice. This may be because you need a relatively large dose; its IC_{50} – the dose needed to inhibit HIV replication by 50%.

The level of antibodies needed to completely annul the viability of HIV is over a thousandfold higher than achieved. If VRC01 was used by itself it would only neutralise 47% of a panel of HIV viral variants. But if combined with two other antibodies, PGDM 1400 and PGT 121, it would neutralise 94% of variants.

From notes taken at a plenary session of HIVR4P. From Research to Impact: https://programme.hivr4p.org/Programme/Session/36

Teaching Young Adults About Haemophilia

My adult son, Julian, does a wonderful job managing his haemophilia. He infuses twice a week per doctor's orders, and if he has a breakthrough bleed, he treats as needed.

Julian is extremely fortunate, because throughout his 24 years, haemophilia has not been the centre of his life. His journey with haemophilia has resulted in only one major muscle bleed and no joint bleeds. However, there are times when life gets busy, and he forgets to infuse as directed. A recent phone conversation led to a frightening realisation for me as a parent, and a lesson I taught him was not appreciated.

Julian recently had a procedure scheduled at the dermatologist's office. The night before his procedure, he called to tell me his appointment was early the next morning. I asked what his haematologist said concerning the dermatologist appointment. I assumed he reached out to the haemophilia treatment centre (HTC) because he had contacted his doctor before dental work a few weeks earlier. When the phone went silent, I was alarmed. Julian admitted he forgot to coordinate care with the HTC.

It was almost 10 p.m., and his appointment was before business hours. "You didn't tell Dr. Q you were having this [procedure] done? You can't do this until she knows!" It was not my finest moment. I panicked because my son was scheduled to have a scalpel put to his skin in several places, and his haematologist did not know. Julian perceived my anxiety as scolding, but I was scared.

My son immediately tuned me out, and thankfully my husband entered the conversation with a calm attitude and helped Julian develop a plan. I was out of my mind with worry. Not only did he not call to coordinate care, but Julian seemed to think that he was invincible. He looked forward to this procedure, and did not give a second thought to the details of his haemophilia.

I know that he understands the importance of being in touch with the HTC, but in this case, I realised Julian's disregard for the severity of his bleeding disorder.

Becoming complacent about haemophilia can give a person a false sense of security. In Julian's case, if he had experienced complications from the procedure, not coordinating care between the dermatologist and the haematologist could have resulted in a serious situation, especially since he is five hours away from the HTC. How much factor would he need to infuse if there was a complication? Who in his immediate vicinity would provide treatment if he needed help?

Fortunately, the procedure went well. Julian spoke to the HTC after the procedure. It was firmly impressed upon him always to inform the clinic when considering a medical procedure, especially one involving a scalpel. It was a good lesson for my son.

Letting children make mistakes is part of parenting. Standing by to watch them fail is never easy, but when an adult child makes a decision that may cause harm, it is important to speak up. Be patient. Stay calm. Try not to get emotional, and lay out the facts. It will probably be a difficult conversation, but hopefully the adult child will realise the importance of the issue when approached with concern and respect.

In the end, parents send their children out into the world to seek their own fortunes, hoping they take the lessons they've been taught to heart, and that they know that caring for their bleeding disorder is a top priority.

Edited for size from an article by Cazandra Campos-MacDonald in Haemophilia news Today. https://haemophilianewstoday.com/2021/03/03/teaching-young-adults-about-haemophilia-never-ending-process/

5 Minutes with Mike on Life and Retirement

What type of Bleeding Disorder do you have?
I've got Hemophilia A and I'm classed as severe. So that means a factor 8 deficiency. My first treatment was cryoprecipitate when I was 18, then haemophilia factor 8 followed by Advate. Currently I'm on Zinther and now I'm about to commence Hemlibra

Are you're looking forward to that?
I was only reading an article last night in the last Queensland H Newsletter that just came out about Hemlibra and a young chap aged 20, he has quite an amazing story in terms of how it has changed his life for the better. So yes, I am looking forward to it very much.

Have you developed any complications from having had haemophilia?
I've had two knee replacements and I've got arthritis in my right ankle but I have been quite lucky compared to most, given my severe haemophilia. When I had my last knee replacement in 2005 I had an infection and that resulted in my being in hospital for about six weeks. They had to open my knee up again. Fortunately, there was a doctor in charge of infectious diseases at RBWH, Tony Allsworth and he was brilliant. He persisted with it and successfully overcame the infection. Overall, I've had very few complications in life. I've been very lucky.

What did you do for paid work? Because you've had quite an interesting career, haven't you?
There was no haemophilia treatments for me until I was eighteen. So I didn't go to school until I was 10. My mother taught me via correspondence at home and then I went straight to boy's college in grade 4 and after graduating year 12 I did a university degree part time. I ended up as national accounts manager for Unilever based in Sydney which caused me to travel all over Australia. At the time I had a very young family and I spent so much time away, I decided to resign and brought the family back to Queensland where I was the national sales manager for Paul's Dairy Company. While I still travelled extensively around Australia and occasionally overseas I could manage this more effectively to enable me to spend more time with the family.

In the early days I used to find out which hospital had factor in each city. But as the years and treatments progressed I could carry the factor with me, however I still had to go to a GP and get it administered because I had not learnt to infuse myself. And that didn't happen until 2010 when I was going with a good mate of mine on a 4 wheel drive trip to Cape York which took us five weeks to the" Tip"

In order to do that, I knew that if I got into strife, I would have to give it to myself. Marie (my beautiful wife) and I went into the Haemophilia Centre at RBWH and Beryl and the others taught us to self-cannulate and then we taught my mate to assist me in administering Advate. I would put the needle in, but he'd give me the factor and I did that four times in the course of the five weeks. Since learning to self canulate, life has been so much easier for Marie and myself.

What delights you in retirement?
Over the years since I've been retired, I've been an active fundraiser for surf lifesaving due to my daughter Tara being in the Burleigh Heads Surf Lifesaving club. And I've always been interested in aviation, but that was just a hobby. When I was 20, I learnt to fly out of the Royal Queensland Aero Club at Archerfield but after being transferred to Townsville, I didn't keep up with the flying, and now it's a very expensive hobby, so I didn't bother pursuing it. Nevertheless I've always been interested in aviation plus Australian history and in painting (art)

I liked art when I was in school but with university and then work and family, I just sort of lost contact with it. I only took that up again after retirement and I find it a very enjoyable and relaxing hobby. I like painting landscapes and seascapes in particular. And of course now I've got twin three year old grandsons (miraculously not haemophiliacs) and they are a constant joy and keep life "far from being dull !"

Are you entering into WHD art competition again?
I entered the last one. That was in 2019 and providing Covid doesn't interfere again I am entering this one. Also there's some art classes planned that I'm quite happy to help with if Loretta wants any assistance. And yes, our family plans to attend the art show opening evening which was very enjoyable last time.

IS there still a need for patient support?
Yes, I do. And I'll tell you why, because I know Hemlibra might change things for the positive, but that's going to take a long time. And even then, you'll still need treatment and guidance with surgery (or some will) for affected joints from time to time plus other medical conditions as we age. So, I don't see the need of HFQ disappearing for quite a long time.

COVID-19 Vaccines

Individuals with bleeding disorders may have questions and concerns relevant to the new COVID-19 vaccines being ordered by Australia, including any implications specific to their conditions. The following FAQs are from a Q & A by AHCDO as well as other sources and if you have a question about your specific situation, be sure to discuss it with your healthcare provider.

FREQUENTLY ASKED QUESTIONS

These vaccines were developed very fast. Are they safe for a person with a bleeding disorder?

It is true that the vaccines have been developed very quickly, but the Australian Government has a careful and thorough process to check that the COVID-19 vaccines are safe and effective before it makes them available to the community. In general the COVID-19 vaccine is safe and effective for people with bleeding disorders.

Would I be in a priority group to receive the vaccine with a bleeding disorder?

Because people with bleeding disorders are not at a greater risk of contracting COVID-19 or developing a severe form of the disease, they are not considered a priority group. General selection rules will apply for those with a bleeding disorder. Information on the phases for the vaccine rollout is on the HealthDirect website - click on Who will get the COVID-19 vaccine first?

Is there a particular type of vaccine I should choose?

Currently there is no option to choose a particular type of vaccine, but if you are considering enrolling in a gene therapy clinical trial, you should avoid any vaccines that use a modified adeno-associated virus (AAV) since these viruses are used in gene therapy. No current vaccinations are using AAV viruses, although some vaccines use a different virus, adenovirus - but this should not be a problem with enrolling in future gene therapy trials.

Do I need treatment for my bleeding disorder before I have the vaccine?

If you have a moderate or severe bleeding disorder, such as haemophilia or VWD or a rare clotting factor deficiency:

- If you are on prophylaxis with clotting factor concentrate, time it to have it on the day of your vaccination before the injection
- If you do not routinely give yourself factor, please contact your HTC for advice
- If you are taking Hemlibra®, just follow your usual treatment plan.

If you have mild haemophilia or Type 1 or Type 2 VWD:

- You will not usually need any special treatment with factor concentrate or DDAVP before the vaccine (Please follow the general precautions for immunisations).
- However, if you have ever had a problem with bleeding from an injection in the past, please contact your HTC or haematologist for advice before you have the vaccine.

Will I have a bleed if I receive the vaccination?

The vaccination is administered intra-muscularly. As you would do with any immunisation, let the health care provider who is giving the vaccine know that you have a bleeding disorder and ask them to use the smallest gauge needle that is available for the vaccine.

Apply pressure on the injection site for 10 minutes after the injection and check the injection site several minutes and 2-4 hours after the injection to make sure bleeding and swelling has not occurred. You may have discomfort in the arm for 1-2 days afterwards. If it becomes worse and there is swelling, contact your Haemophilia Treatment Centre (HTC).

Any adverse events should be reported to your GP and any allergic reactions need to be reported immediately, or go to the emergency room straight away as it can be life-threatening..

Should I take the vaccination if I am pregnant or breastfeeding?

Currently, there is limited data on the safety of COVID-19 vaccines for women who are pregnant or breastfeeding. Individuals who are pregnant and considering vaccination for COVID-19 are encouraged to speak with their clinicians.

Do I need to have the Fluvax as well as the COVID-19 vaccine?

Current advice is that people should still have a Fluvax this season as well as the COVID vaccination. Ask your doctor about the timing of having it if you are also having the COVID vaccination.

If you have any questions about your bleeding disorder in relation to the COVID-19 vaccine, contact your Haemophilia Treatment Centre or your treating haematologist.

For more information see: https://www.ahcdo.org.au/news/covid-19-vaccinations-for-people-with-bleeding-disorders

Relieve Arthritis This Winter

Cold-weather months, even in Queensland can be a challenge for people with arthritis, so how can you go outside and face the elements while managing arthritis? Keep these four tips in mind.

Layer for Cold Weather

Be sure to bundle up any time you want to face the cold. As the temperature drops, so does barometric pressure. When this happens, tissue in the body expands and puts more pressure on your nerves, which leads to more pain.

Keeping warm improves circulation and relaxes joints and muscles, which reduces that stiffness and pain. So make sure you have some winter clothes handy, wear long sleeves, keep your extremities covered, wear insulating fabrics, such as wool.

Just remember that you could overheat if you're active for a long stretch, so use breathable materials for your outer layer and be prepared to shed an item or two.

Stay Active in the Cold - Don't Hibernate

Some might assume that exercising would be harmful to those with arthritis. However, regular exercise can increase strength and flexibility, reduce fatigue and alleviate joint pain, which is especially helpful in the winter as the cold weather puts more pressure on your body. When you build strength, your muscles will be better equipped to support your joints.

So don't stop exercising regularly once winter comes around. Want to get outside? Walking outdoors is an arthritis-friendly activity, as long as you stick to even terrain.

Before making any changes to your exercise regimen, consult your doctor, or talk to your haemophilia physiotherapist, to get a sense of what is appropriate for you.

Get Your Vitamin D

Make sure your body has what it needs to maintain joint health by getting the right amount of vitamin D. Studies show that reduced vitamin D intake can make people more susceptible to developing rheumatoid arthritis and can affect the severity of the disease.

Vitamin D helps keep your bones strong, reduces inflammation and improves muscle function. With the right intake, you'll be more prepared to manage your arthritis, even as you face the winter cold. There are a few ways to get more vitamin D, such as taking supplements, exposing yourself to sunlight and eating food with high levels of the vitamin.

Talk to your doctor about the recommended vitamin D intake for you.

Stay Hydrated

Dehydration is often associated with hot summer days, but winter also carries the risk of dehydration as sweat evaporates more quickly in the cold air, which causes dehydration. And lack of hydration is associated with joint pain, since you're not properly lubricating your joints.

Keep this in mind as you get ready to go outside in the winter. How much should you drink? An adequate daily fluid intake is about 10 cups of fluids a day for men and about 8 cups for women.

Edited for size and content from "4 Ways to Relieve Arthritis in Winter" by Michael Hickey. https://hemaware.org/mind-body/4-ways-relieve-arthritis-winter

Health Updates

Efanesoctocog alfa granted FDA Fast Track Designation for treatment of haemophilia A

The U.S. FDA has granted Fast Track Designation for efanesoctocog alfa (rFVIIIFc-VWF-XTEN), in patients with haemophilia A. Efanesoctocog alfa is designed to provide near -normal factor activity levels in a once-weekly prophylactic treatment regimen.

Efanesoctocog alfa represents a potential new class of factor VIII replacement therapies. The half-life of conventional factor VIII therapy is constrained by the von Willebrand factor's (VWF) chaperone effect, which is believed to limit the time the factor remains in the body. Efanesoctocog alfa builds on the innovative Fc fusion technology by adding a region of von Willebrand factor and XTEN® polypeptides to extend its time in circulation.
https://www.marketscreener.com/quote/stock/SANOFI-4698/news/Sanofi-nbsp-Efanesoctocog-alfa-granted-FDA-Fast-Track-Designation-for-treatment-of-hemophilia-A-32468400/

Postural Balance Sign of Joint Health in Paediatric Patients With Hemophilia

An observational cross-sectional study of patients with severe haemophilia who had haemophilic arthropathy in at least 1 lower limb joint was compared these patients without haemophilia.

Paediatric patients with haemophilic arthropathy were found to have more impairment in their bipedal stance and children with haemophilia were found to have more side-to-side displacement in their stance than front to back displacement.

The authors concluded that balance evaluations should be included in the assessment of paediatric patients with haemophilia. Impairments in static postural balance may be an early sign of a musculoskeletal system disorder.
From "Static postural balance evaluation and an investigation of the relationship with joint health in children with severe haemophilia: a controlled cross-sectional study. Haemophilia"; https://onlinelibrary.wiley.com/doi/10.1111/hae.14240

Free hemlibra to kids under 13. A different story to Aus

The Punjab state in India is providing free hemlibra treatment to haemophilia patients up to 13 years of age who are inhibitor-positive at all government medical colleges. This restriction is because of the cost of the treatments.

The state has around 450 haemophilia patients and 24 of them are inhibitor-positive.
From "A first: Free haemophilia cure at medical colleges". https://www.tribuneindia.com/news/punjab/a-first-free-haemophilia-cure-at-med-colleges-218878

Fitusiran Dosing in Trials Reduced to Lower Blood-clot Risk

The dosing of the investigational treatment fitusiran in clinical trials has been lowered to reduce the risk of blood clots. Fitusiran was previously placed on hold after reports of non-fatal vascular thrombotic events in trial participants.

Evaluation of these reports suggested that the risk of brain bleeding may be greater with levels of antithrombin. As such, clinical studies will now target antithrombin levels between 15% and 35%, and fitusiran's dose will be reduced to 50 mg every other month with further adjustments as needed on a case-by-case basis.

By blocking antithrombin, fitusiran is designed to enhance blood coagulation, and in doing so, prevent bleeding in haemophilia patients. The therapy is given via a subcutaneous (under-the-skin) injection.
https://www.hemophilia.org/news/sanofi-revises-fitusiran-dosing-regimen-to-mitigate-risk-of-vascular-thrombosis

Investment in liver cancer medicines

The Australian Government has listed atezolizumab and bevacizumab on the PBS to treat patients with advanced unresectable (inoperable) hepatocellular carcinoma; most common form of liver cancer with tragically one of the lowest survival rates of all cancers.

These liver cancer medicines are shown to increase survival rates, decrease disease progression, and provide more time with higher quality of life and physical functioning for patients.
https://www.hepatitisaustralia.com/Handlers/Download.ashx?IDMF=eb34be65-0dbf-4a87-b7d2-5bb8fa8182b8

New Guidance on COVID-19 and People Living With HIV

The US Department of Health and Human Services has recommended that all HIV-positive people should receive Covid-19 vaccinations, regardless of their CD4 count or viral load.

Early studies showed that people with HIV were not more likely to test positive for the COVID-19 or die from it. But more recent research has found that HIV-positive people might have a modestly increased risk for poor outcomes. This particularly applies to those with a low CD4 count or comorbidities.
https://clinicalinfo.hiv.gov/en/guidelines/covid-19-and-persons-hiv-interim-guidance/interim-guidance-covid-19-and-persons-hiv

Snack Attack

The school year is in full swing and you need to fuel your brain with important lessons and fun information. But what will you do to satisfy your appetite when you get home?

If it's been hours since lunch but dinner isn't ready yet, it's important to grab a snack. Snacks will boost your energy and help you stay focused for crucial things like homework later.

But after school, when you're studying, playing with friends or relaxing, it's easy to go for something quick and tasty, such as potato chips or cookies. These foods may taste great, but they aren't always good for your body. Ask your parents to stock up on good-to-eat and easy-to-prepare foods for these times. That way, when you need a snack, you'll have plenty of yummy, healthy things to choose from.

Hungry Hour
Eating good food is the best way to make sure your body gets all the fuel it needs to grow and stay strong, such as calcium, fiber and protein. These good components can be found in fresh fruits and vegetables.

Here are a few tips for what to grab when your next snack attack strikes:

- Stay away from fried snacks—no potato chips, french fries, or fast food. Instead, reach for baked snacks, such as pretzels, air-popped popcorn or rice cakes.
- Drink more water and milk. Juice and sodas may taste good, but they also have a lot of sugar. Water and milk will not only satisfy your thirst, but keep you healthy!
- Stock up on fresh foods from the grocery store or a farmer's market. Slices of fruit, vegetables, low-fat cheese, and lean meat and fish are all good for you.

Quick Bites

There are many healthy snacks you can choose, and some need to be fixed ahead of time. Ask an adult to help you get parts of some of these snacks ready so you can easily make them when you're hungry:
Slice up fruit and assemble it into a "kabob" that you can have later with yogurt dip.

Cut up fresh vegetables like carrots or celery into sticks so you can dip them in hummus or low-fat salad dressing.
Spread peanut butter, jam or vegemite on a rice cake.

Mix it up with a homemade trail mix of dried fruit, cereal, nuts, pretzel minis and yogurt chips.
Dip pretzel nuggets into honey mustard.
Layer low-fat granola or cereal and fruit together with yogurt or frozen yogurt for a parfait.

Eating these healthy snacks is another way to take care of yourself. They give you more energy to do fun things such as riding your bike or playing with friends. Save cookies, chips or pizza for occasional treats.

Change your snacks, too, and try different food groups—a glass of milk and whole-grain crackers, or spread peanut butter and raisins on celery to make ants on a log. By making your snacks interesting, it will be easier to pick healthy foods all the time.

Want to learn more about good-for-you snacks? Ask your teachers or parents for help in making these and other healthy food choices.

From: Snack Attack by Meredith Stanton
https://hemaware.org/life/snack-attack

Physical Education for Kids With Bleeding Disorders

At the beginning of every school year, many parents sits down with the staff at their son's school to review the list of PE offerings. Rugby? No. Too many kids still try to tackle. Hockey? Nope. Too many sticks flying. Soccer? That's fine. But he has to wear shin guards.

It's a balance that families of children with bleeding disorders have to strike when considering how - or if - their children can participate in physical activity at school.

The right to exercise

Despite the risks, physical education is an important part of growth and development for all children including students with disabilities and special needs participate in physical activities like gym class.

If your child has bleeds from certain activities, there should be a discussion with the school about other roles the child can play, those could include serving as equipment manager or referee. Children with bleeding disorders can and do excel in physical activities. Kids 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.

Getting the benefits without the risks

Because of the benefits of physical education, medical researchers have been looking into which activities are safe for young people with bleeding disorders. One Australian study looked at how much the risk of bleeding increased with vigorous exercise in boys aged 4 to 18 with moderate to severe haemophilia. The researchers monitored the boys' bleeds and physical activity for one year.

85 percent of participants had bleeding episodes, usually in the knees, ankles and elbows and most frequently before and after school. But researchers found that some sports were associated with a higher risk of bleeds, depending on the activity's intensity and how often the child played.

Activities were categorized by their likelihood of a severe collision, from category one activity (least likely) to category three where collision is inevitable. The study found that for a child who bleeds five times annually and is exposed on average to category two activities twice weekly, and to category three activities once weekly, exposure to these activities was associated with only one of the five annual bleeds, suggesting that kids with severe haemophilia could take a lot more in the way of impact sports than is often attributed to them.

Proceed with caution

The mindset surrounding letting kids with bleeding disorders participate in physical education and sports has shifted away from fearful exclusion toward enthusiastic, but cautious, inclusion.

The key is guiding parents and school staff toward the right activities for the child. The basis for the decision to participate in a physical activity should also include the child's age. 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. It's important to understand how the exercise is good for the child, how it can strengthen muscles around the joint so they are less likely to have a bleed and ultimately, for them to make the best decisions for themselves.

Edited for size from "Physical Education for Kids With Bleeding Disorders" by Kadesha Thomas. https://hemaware.org/life/physical-education-kids-bleeding-disorders

Important Dates for HFQ Members

Covid-19 is still a concern and all HFQ activities are subject to social distancing and other covid-19 restrictions that may apply at the tome of the activity.

OBE Men's Forum
First week of the Month
Call for details

Women's Brunch / Lunch
Sunday, 18 April 2021
Tingalpa Hotel

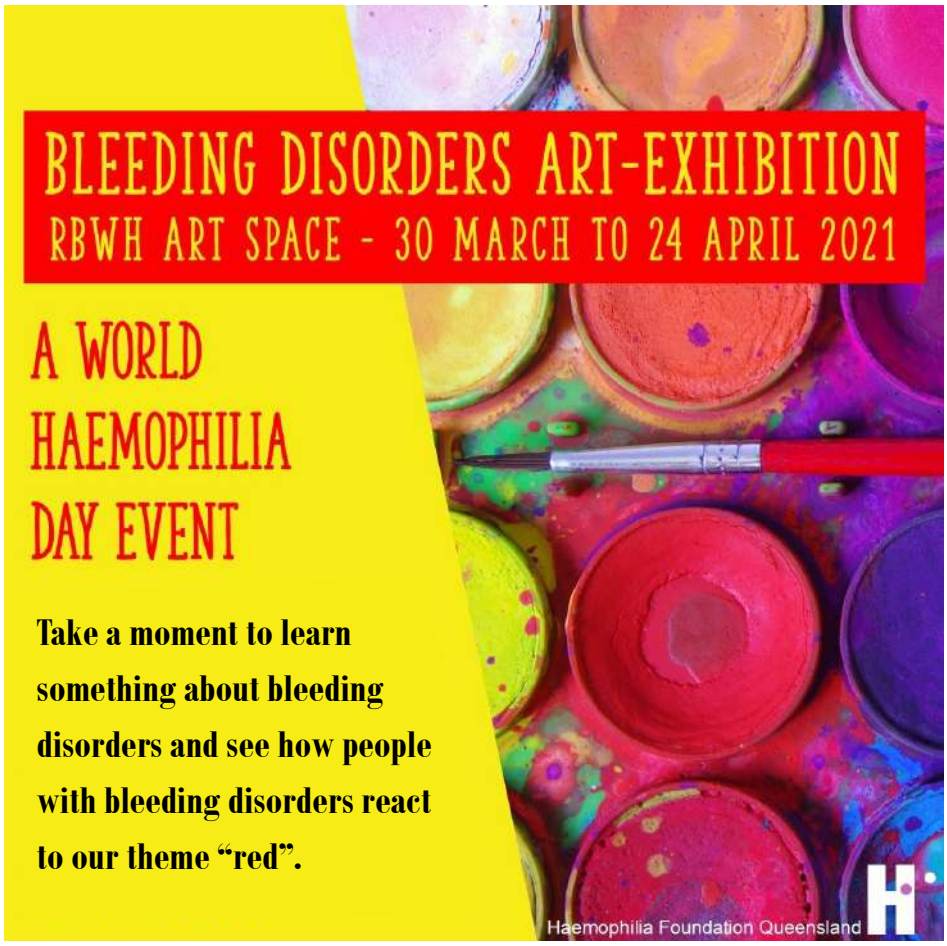
Bleeding Disorders ArtExhibition
5 - 30 April 2021

World Haemophilia Day
17 April 2021

Men's Health Week
11 - 20 June 2021

Please ask for events and activities happening in your area.

Please call Graham at the office on **0419 706 056** for more info on any of these events and other activities.



Throughout April there is an exhibit in the RBWH Art Space, of works by people affected by bleeding disorders. This is in the ground floor corridor between Ned Hanlon Building and the Joyce Tweddell Building.

Studies have shown that expressing yourself through art can help people with a medical condition and the beneficial effects of creating aren't dependent on a person's skill or talents. It's the process, not the product.

Decades of research has shown that creating visual art can reduce stress and promote relaxation in people who are hospitalised or homebound due to illness. Art also has an important role in helping people through particularly difficult times. Our exhibition features painting, photography and ceramics. If you are visiting RBWH in April, please take a moment to have a look.

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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