the H FACTOR

Haemophilia Foundation Queensland

SPRING EDITION

Issue 68

SEPTEMBER 2021

HFQ MEMBER MAGAZINE

FROM THE **PRESIDENT**

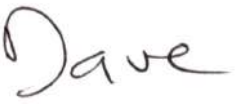
Hello everyone,

Hope you are all well. I continue to hear great personal comments from those who are on new treatments - Hemlibra and extended ½ life treatments, simply brilliant.

Around the world there continues to be research into newer treatment possibilities. I think most of us would have come across the term mRNA (messenger RNA) which is one of the mechanisms that is used in some vaccines for this pandemic, but in terms of haemophilia, mRNA is used in development of LNP (lipid nanoparticle), this is where mRNA is encapsulated into a tiny bubble of fat which is a way to efficiently carry the mRNA to its destination (principally liver cells). Testing this in mice did show the delivery to liver cells and effective factor production was happening as expected, but the levels slowly reduced over time. So the mice were given more LNP on a regular basis in immunocompromised mice – which resulted in consistent factor levels over time. So it's this sort of research that continues to investigate treatment options.

There are many others that are looking to prolong circulating factor (engineered factor concentrates), or to look at the balance between pro & anti-coagulant factors (rebalancing therapies), however the main one these days is to look at how to have the body automatically generate factor itself – gene transfer or gene editing. I believe there are still many scientific questions to be answered and that will take time, but once this is sorted I imagine it would open up great possibilities for those with haemophilia A & B as well as those with different clotting conditions.

Regards



David Stephenson
President HFQ
president@hfq.org.au

Many people with bleeding disorders still experience down time because of bleeds and some have joint problems and/or poor mobility.

Access to wheelchairs or walking frames; and good IT and data for video conferencing and telehealth can help, but they can cost money that some of our members can't afford from within their own resources.

HFQ has a Haemophilia Equipment Loan Program (HELP) for this situation. The program is open to everyone, but all users of HELP need to be endorsed by the psycho-social work staff at the QHC's as needing assistance from the program.

Please talk to your clinic psycho-social work staff member or call the office on 0419 706 056 and have a chat with us if this is something that might help you or your family.

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	... ...	Mr Tony Ciottariello
Treasurer	... ...	Mr Adam Lish
Members	... ...	Mrs Belinda Waddell
		Mr Charles Eddy
		Dr Jodie Caris
		Mrs Lauren Green
		Mrs Leanne Stephenson
		Ms Shannon Gracey
		Mr Shannon Wandmaker

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*

QLD 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 Jordan Staunton
Haemophilia Registrar – Dr Fiona Molloy
Joanna McCosker – Nurse Practitioner
Amy Finlayson / Salena Griffln – Clinical Nurse
Nathalie Holland (Mon, Tues) - Physiotherapist
Hayley Coulson (Wed, Thur, Fri) – 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)

Switch: 07-3646 8111

Dr Jane Mason - Haematologist	3646-8111
Dr Sally Campbell - Haematologist	3646-8111
(Page Dr's through switch)	
Haemophilia Registrar	3646-8111
(ask to page Haemophilia Registrar on 42177)	
Beryl Zeissink - Clinical Nurse Consultant	3646-5727
Alex Connolly - Clinical Nurse (Part time)	3646-5727
After Hours - Page Haematologist	3646-8111
Scott Russell - Physiotherapist	3646-8135

Contacting the Clinic Please telephone in the first instance. Appointments 3646-7752 or 3646-7751
For all non-clinical/non-urgent enquires please email RBWH-Haemophilia@health.qld.gov.au

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

Haemophilia/Orthopaedic Clinic — Dr Jane Mason and Dr Brett Halliday — 9am every four weeks

OUTREACH CLINICS

Gold Coast Hospital, Toowoomba General Hospital, Nambour Hospital, Cairns Base Hospital & Townsville Hospitals: For queries email *CHQ-Haemaphilia@health.qld.gov.au* at QCH or *RBWH-Haemophilia@health.qld.gov.au* at RBWH.

What's On?

MAKE IT YOUR EVENT

Sept to Dec 2021

Some of the HFQ programs and activities already planned

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

SEPT

- **OBE's Monthly meeting** 1st September Fernvale bakery
- **R U OK Day** 9th September
- **HFQ Youth Camp** 17th to 19 September Emu Gully
- **HFQ Board Meeting** 21st September (Virtual)

OCT

- **OBE's meeting** 6th October Mango Hill Tavern
- **20th Australian Conference on Haemophilia, VWD & Rare Bleeding Disorders** 8th & 9th October (Virtual)
- **Bleeding Disorders Awareness Week** 10th to 16th Oct
- **AGM & Member Info Night** 19th October RFQ Meeting
- **HFQ Community Camp** 29th to 31st October Noosa North Shore

NOV

- **OBE's Monthly meeting** Sunday 14th November The Glen Hotel
- **HFQ Board Meeting** 16th November 298 Gilchrist Ave, Herston
- **Women's Lunch** 21st November Tingalpa Hotel
- **World Hepatitis Day** 28 July

DEC

- **World AIDS Day** 1st December
- **International Day of Persons with Disabilities** 3rd December
- **OBE's Monthly meeting** 12th December Arana Hills Leagues Club
- **HFQ Board Meeting** 14th December 298 Gilchrist Ave, Herston

Go Red for Bleeding Disorders

It's time to start thinking about the other important event in the lives of people affected by bleeding disorders. 10 to 16 October is Bleeding Disorders Awareness Week this year. This week is an important opportunity to raise awareness in your own community about inherited bleeding disorders such as haemophilia and von Willebrand disease and related inherited bleeding disorders.

This year's theme is Embracing a Changing World. We're encouraging everyone to get involved and help us raise awareness about bleeding disorders, so why not **Go Red for Bleeding Disorders** + fundraise. It's easy and fun to get involved, so start planning now so that you can inform your friends and family with a fun red themed activity or a red cake day.

COVID-19 Myth Buster with Dr JANE Mason

Myth: "COVID is just a bad flu"

Here is a quick comparison that hopefully helps to get the message through. I'll use data from the 2017 Influenza season, which was record breaking in Australia.
In the 2017 Influenza season:

- 1255 deaths from 233,453 cases. That's a case mortality of 0.53%

In 2017 there was: No social distancing. No masking. No restrictions. No lockdowns. Despite that, case fatalities from influenza were 0.53% at most.

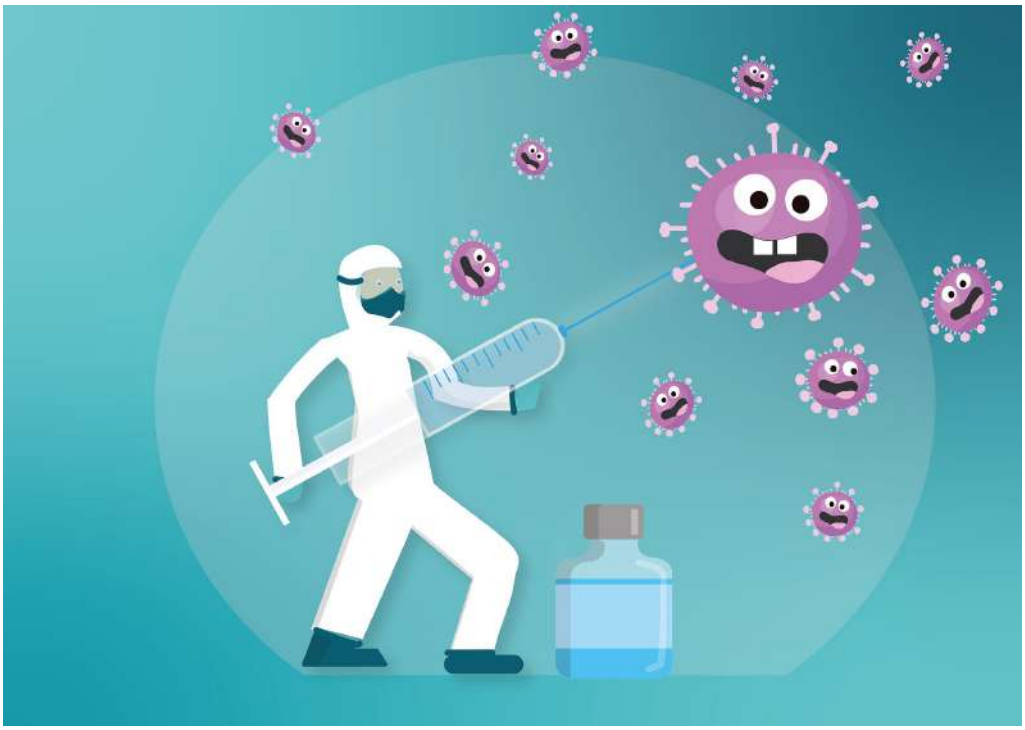
Then let's look at COVID from the 2020-2021 season:

- 967 deaths from 40097 cases. That's a case mortality of 2.4%

That's WITH social distancing, WITH masking, WITH restrictions and WITH lockdowns.

With ALL these measures, case fatality from COVID is still at LEAST 5x more deadly.

Furthermore the case fatality rate doesn't take into account the poor quality of life of people suffering from long haul COVID symptoms.



Myth: "Vaccination side effects are worse than getting COVID"

It's hard not to worry about side effects when you come across unsubstantiated social media posts about alleged adverse events that people experience post vaccination. These posts can be quite dramatic and confronting and are subsequently used to discourage others to get vaccinated. I think it's important to state that serious adverse events post vaccination still remain quite rare. While mild muscle aches, headaches and general lethargy are more commonly experienced, serious symptoms like the clotting syndrome TTS (after AstraZeneca vaccine) or heart inflammation (after Pfizer vaccine) are extremely rare.
But you need to remember that even if a vaccine has a one in a million risk of a serious adverse event, by virtue of the fact that 3.64 BILLION doses have been given worldwide, you will see 3,640 such events from that population even at that very small risk.

Even if the risk of serious adverse event from vaccinations was one in ten million, you would still see 364 such events from that vaccinated population. While we obviously empathise with anyone who may experience such an adverse event, it's important to realise that if 3.64 billion unvaccinated people contracted COVID, what we would see is catastrophic levels of death. The benefit of vaccination against the risk of COVID infection is overwhelmingly in favour of vaccination. Unfortunately there are real risks associated with everything in life, whether it's

crossing the road, swimming in the ocean or driving in your car. That is undeniable. But don't be swayed by online spreaders of misinformation who vocally promote the extremely rare cases of vaccine adverse events as being a tragedy, while ignoring the more than 4 million people who have died of COVID. These individuals are not qualified to provide scientifically robust advice nor to interpret public health data.

Myth - "People with bleeding disorders are at higher risk of contracting severe COVID-19"

People with bleeding disorders are not at greater risk of contracting COVID-19 or developing a severe form of the disease, and are thus not considered a priority group for vaccination. However when persons with haemophilia do happen to develop severe COVID-19, it is important to acknowledge that ICU transfer, ventilation, and general management are very complex due to the meticulous balance between bleeding and clotting risk in this situation. I hope for all of my bleeding disorder patients to be vaccinated in order to avoid these challenging (and heartbreaking) ICU admissions with severe COVID-19 infection.

Myth – "People with bleeding disorders are at higher risk of vaccine side effects"

There is currently no reason to select a particular type of vaccine for bleeding disorder patients. Specifically - the very rare side effect of TTS (thrombosis with thrombocytopenia syndrome) that has been rarely reported after AstraZeneca vaccine is NOT more common in people with inherited bleeding disorders. This includes those people with inherited platelet disorders. The vaccine does need to be administered intramuscularly, so there are some precautions that need to be undertaken that are well-documented in the HFA COVID-19 FAQ handout *https://www.haemophilia.org.au/publications/news/covid-19-vaccine-faqs-updated*

In short – the smallest gauge needle available should be used, pressure should be applied to the site for at least 10-minute post-injection to reduce bleeding and swelling. Additionally, self-inspection of the injection area several minutes and 2-4 hours later is recommended to ensure that there is no delayed haematoma. Persons with moderate/ severe bleeding disorders who routinely self-administer factor products at home should time their usual dose to be given on the day of vaccination. Persons who are receiving prophylaxis with Hemlibra do not require any additional factor replacement. If you have a mild/ moderate bleeding disorder and don't usually self-treat, but have had previous significant haematomas related to intramuscular vaccination you should contact the HTC for specific advice.

Bleeding disorder patients can receive their vaccine in the standard venues/ locations. See: *https://www.healthdirect.gov.au/covid-19-vaccination/getting-the-covid-19-vaccination* for details about how to confirm your eligibility and find clinics near you/ book your appointment. NOTE that the Haemophilia Centre is not involved in vaccine administration.

Note that the Astra Zeneca vaccine uses an Adenovirus vector. This is unrelated to adeno-associated viruses (AAV) and is not being used in haemophilia gene therapy, thus there is no contraindication for using it in the bleeding disorders population. People with haemophilia and other bleeding disorders who have had a history of allergic reactions to blood products, including plasma and cryoprecipitate, but have not had reactions to previous vaccines, are at no greater risk than the overall population for a reaction to a COVID-19 vaccine. Persons with a history of serious allergic reactions to extended half-life clotting factor concentrates containing polyethylene glycol (PEG) should discuss vaccine choice with their doctor as some vaccines (Pfizer and Moderna) contain PEG.

If you find your GP is reluctant to vaccinate you due to your bleeding disorder, the QHC have developed a vaccine clearance letter for adult patients, so that hopefully any unnecessary delay is avoided. Contact the QHC nursing staff on 36465727 if you are experiencing any hesitancy from your local doctor to provide you with a COVID-19 vaccination (despite otherwise being eligible) and we will arrange a letter.

Get vaccinated. It's the only way we can live with COVID.

Acknowledgements: Dr Sara Marzouk, for her excellent evidence-based COVID-19 resources

The QHC experience **Transitioning Patients** to **Hemlibra**

On the 2nd November 2020 The National Blood Authority (NBA) announced Hemlibra had become available to people with severe and moderate Haemophilia A and patients with inhibitors to factor VIII. As soon as this announcement was made, both the Queensland Children's Hospital (QCH) and Royal Brisbane and Women's Hospital (RBWH) started making plans to roll out Hemlibra to all the eligible patients.

The Australian Haemophilia Centre Directors' Organisation (AHCDO) provided guidance to all the Australian Haemophilia treatment centres (HTC) regarding prioritising which patients to change over. Both centres were asked to assess individual circumstances for their patients e.g. does the patient have an inhibitor or breakthrough bleeds on their current treatment? does the patient have a CVAD? does the patient have adequate venous access and does this affect their ability to maintain regular treatments? All this information was carefully evaluated by the HTC to determine whether the patient would benefit from changing to Hemlibra.

Another important consideration prior to the change in treatments was patient factor stock levels at home. Both centres had to check how much clotting factor was remaining for each patient to ensure this was used up. This involved a lot of talking to patients to check stock amounts at home and providing them with additional stock (if needed) prior to coordinating the start date for Hemlibra. Once eligibility was established for Hemlibra, the next step was planning the appropriate education and support for those who wished to transition to Hemlibra and their carer's.

Both the QCH and RBWH provided education to medical, nursing, pharmacy, and laboratory staff both locally and regionally. Education was provided over Microsoft TEAMS and Telehealth to other hospitals around the state such as Toowoomba, Sunshine Coast, Gold coast, Townsville, and Cairns. The RBWH team provided education in collaboration with patients and their GP's via video link in local and rural areas.

QCH team also provided education and supervision to patients via Microsoft Teams and Telehealth to Hervey Bay and Bundaberg hospitals.

Prior to changing treatment products each patient needed to come to the Haemophilia treatment centre or their local hospital for a discussion with their Haemophilia health care professionals. In this initial appointment we discussed what Hemlibra is and how it differs from factor VIII (8) concentrates. This was also an opportunity for patients to ask questions and make an informed decision about their treatment options in the regional areas. This process proved quite challenging and time consuming for HTC staff in both centres, however, both centres have great connections with regional centres thus no patient missed their opportunity to transition to the new treatment.

Based on the evidence from the research studies, we know Hemlibra takes 4 weeks to reach a steady state. This involves four weekly injections known as the loading doses and week five is the start of maintenance doses. HTC staff were heavily involved in the communication, coordination, prescribing and administration of Hemlibra in the loading phase.

Following the announcement from the NBA late last year, both centres decided Hemlibra would only be available through Queensland Health pharmacies. The rationale behind this decision was that the processes for ordering products and professional relationships already existed between the HTC and QLD Health pharmacies. The process of ensuring that patients receive their Hemlibra involved multiple steps. These steps included education to pharmacists, completing new prescriptions, scanning, emailing, and posting the original prescriptions to the pharmacy or hospital, this was time consuming and stressful! We were very conscious that this was a new product with new processes to learn and didn't want any mistakes along the way.

Today with most of the patients now transitioned onto Hemlibra, the centres are spending a lot of time setting up HEMLINK (community pharmacy program) so that patients and families can

Continued on next page ⟶

collect their Hemlibra from their local pharmacy. This is a new program for both centres to navigate and involves a substantial amount of communication between the HTC, patient and the HEMLINK coordinators. Ongoing scripts will continue for those who are collecting through the current hospital arrangements.

Another big change for both centres and patients was the recommendation from the NBA that the Australian Bleeding Disorders Registry (ABDR) and the MyABDR App should be used to record the use of Hemlibra by patients in Australia. The NBA utilise data recorded in the MyABDR for supply planning, utilisation, and finances to better assess and evaluate the benefits of the therapies over time. Some patients needed to be educated on setting up MyABDR and others needed to be directed on how to re-access their accounts.

The nursing team at both centres are committed to transitioning all eligible and willing patients onto Hemlibra as soon as possible and have now transitioned between 80 – 90% of patients since November last year. This doesn't mean that the nurses now get to sit back and have cups of tea with their feet on the desk! (we wish).
There will always be an ongoing need to plan and provide care for all patients with inherited bleeding disorders including the newly diagnosed, carriers, acquired haemophilia, von Willebrand disease, platelet disorders and other rare factor deficiencies. There will always be the need for co-ordination of surgery and dental procedures, education, outreach clinics, outpatient appointments and patients presenting with bleeds who need our assistance. We continue to educate other health care professionals to ensure appropriate care and management is delivered across Queensland and within our own local hospitals here in Brisbane.

If you have any questions about your specific requirements, please send us an email on *QCH-Haemophilia@health.qld.gov.au* or *RBWH_haemophilia@health.qld.gov.au.*

Thank you to the community for your patience and enthusiasm as we continue to roll out new medications.

Beryl, Alex, Joanna, and Amy – RBWH & QCH

Welcome to **DR SALLY CAMPBELL** to the QHC at the RBWH

HFQ and the Queensland Haemophilia Centre (QHC) welcomed Dr Sally Campbell (Staff Specialist Haematologist) to the RBWH team this August. Dr Campbell is an experienced Haematologist from Melbourne with considerable Haemophilia / bleeding disorder experience, She trained here at UQ before going on to do a master degree in inherited bleeding disorders in Melbourne.

We are both pleased and excited to have her on board. She will be doing a half day on Tuesdays and every Thursday.

Dr Campbell's appointment represents the first increase in specialist Haematologist funding at the QHC in over 30 years. Our current QHC Director Dr Jane Mason wears many professional hats at different locations in the Haematology clinical, laboratory and research space and many people are not aware that her clinical appointment to the QHC is part time. The addition of this extra dedicated QHC funding for Dr Campbell's position will allow improved clinical cover of the growing service and will ensure there is specialist continuity during periods of leave.

Talking about LONELINESS

According to the Australian Loneliness Report, loneliness is experienced by 1 in 4 Australians and people under the age of 65 report experiencing higher feelings of loneliness. Even though we might associate loneliness with growing older, an article I read recently explained that loneliness is not just something experienced by the elderly, who in fact report to feel the least lonely in society.

How do we define loneliness? It can be defined as the feeling or perception of being alone and separate from people. In contrast, social isolation is defined as physically being apart from people. Thus, loneliness is unique to every individual. You can physically be alone but not feel lonely, or you can be surrounded by many people and feel lonely.

Research shows loneliness focuses on the quality of relationships we have and not the quantity. A quality relationship is a meaningful connection where the individual feels understood by others.

Some facts about lonely people:

- Lonely people report having poorer health, both physically and mentally, than those who feel more connected.
- Lonely people have increased levels of depression and anxiety regarding social interactions.
- Additionally, higher levels of loneliness are associated with increased levels of social interaction anxiety, reduced social interaction, poor mental wellbeing and a poorer quality of life.

STRATEGIES FOR CONNECTION

So, with all this loneliness, doom and gloom, how can one feel less lonely and more connected?

Think positively and do not worry or overthink social interactions. Try to shift your focus from how you are being perceived to what you are discussing and the person you are talking to.

Stop comparing yourself to others and how many friends they have. Remember, it is about the quality of relationships and not the quantity.

Change is a normal part of life. Accepting change or welcoming it means that you are prepared or can adjust to moments when you lose significant individuals from your life, which is inevitable.

Contextualise discomfort, as social interaction anxiety may stop you from socialising. The feeling of awkwardness does not mean you have done something wrong. Continue to reach out to people, and over time your skills will improve.

Preparation can be useful for when the conversation slows down. You can prepare questions or discussion points for this moment, for example, what movie has the person recently seen, have they travelled or been to a museum lately?

Actively listen to the person you are speaking with. Listen to the person's response when you ask them a question, rather than waiting for your moment to speak. Paraphrase what they have said to you, as this will ensure the person is aware you are genuinely listening to them. Focus on your posture, facial expressions and the words you say. Say their name while speaking to them or anyone else in connection to them, such as their mother's name or pet name. Once again, this highlights that you care and have been paying attention.

Take a rest from social media. This might be a great way to feel instantly connected to people. Social media can be a way of focusing on the quantity of relationships and not quality. Try to create and maintain a healthy offline life. It might be an idea to arrange a meet-up with trusted online friends.

Explore unexpected moments of social interaction, smile at a stranger or make eye contact with people a little more often. Unexpected social interaction can be a way to improve your mood instantly.

Help someone out, or ask for help if you need it. Join in a local community group, volunteer or attend your next local haemophilia event. Helping someone out or sharing an activity with someone is an instant way to feel connected.

Reconnect with people from your past. Most people will welcome this reconnection and feel that you care. It might be an idea to meet at a place that has significance or where you shared fun experiences.

Stress management is key. Figuring out a way to manage your stress, such as deep breathing or mindfulness, can help you through stressful moments.

Spending time with pets can also be a way to reduce or ease feelings of loneliness. If you do not own a pet, arrange to spend time with a neighbour or friend's pet.

Chat with your HTC social worker or psychologist if you are worried or anxious about social interactions as we can help support you and assist in building up your social skills.

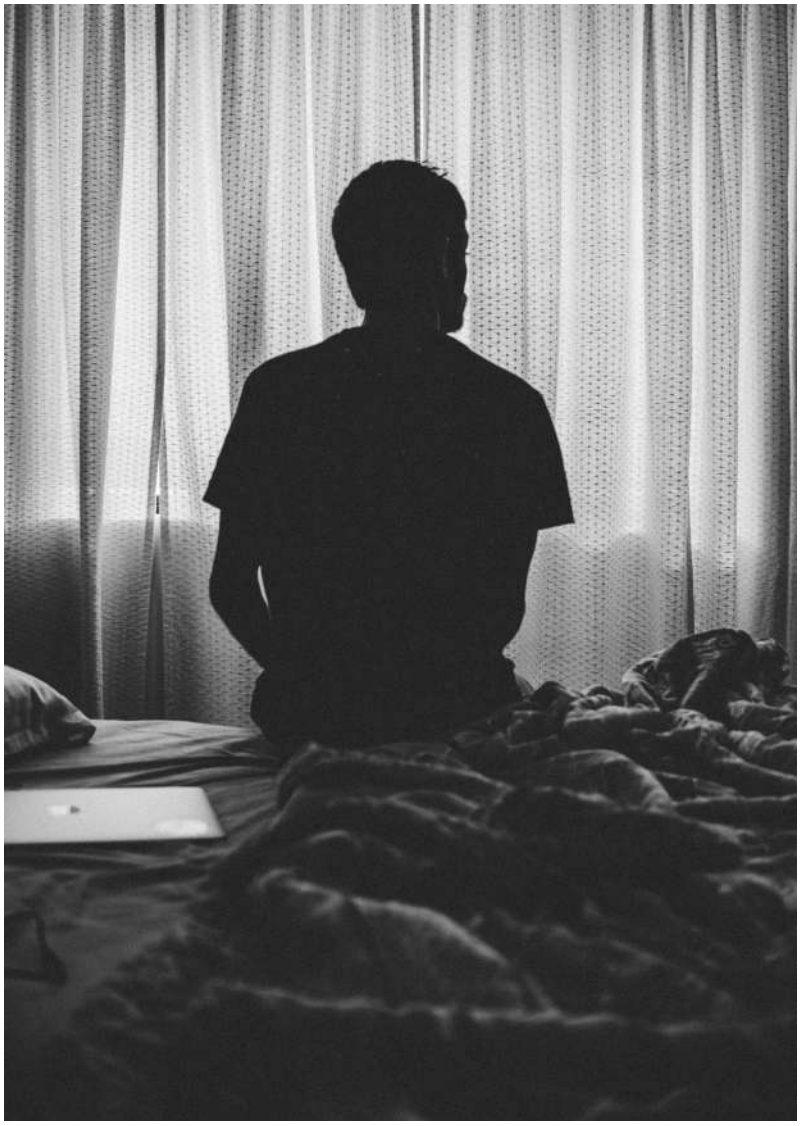
Loneliness might not be specific to the haemophilia and rare bleeding disorder community; however, it is something we all experience. Having the knowledge and ability to identify and respond to feelings of loneliness can have positive impacts on our physical and mental health that are instantaneous.

REFERENCES

Australian Psychological Society; Swinburne University of Technology. Australian loneliness report: A survey exploring the loneliness levels of Australians and the impact on their health and wellbeing. APS; SUT: Melbourne, 2018.

Lim, M.. The young Australian loneliness survey: Understanding loneliness in adolescence and young adulthood. Victorian Health Promotion Foundation: Melbourne, 2019

Article by Nicoletta Crollini (Haemophilia Social Worker, Royal Prince Alfred Hospital, Sydney). First published in National Haemophilia, March 2020 and reprinted with permission



5 Minutes with Brett

This month Brett sat down with Michael and Andrew to see what it was like growing up with haemophilia in another country and then migrating to Australia. (For Andrews story see page 16)

Talking with Michael on moving to

Tell us about growing up in China?

I was born in Guangzhou, the capital city of Guangdong in the southern part of China. I started as a computer engineer and now work in the trading and logistics industry. I am married with two daughters. My older daughter is in Guangzhou, and the little one is with us here in Brisbane.

When I was six months old a neighbours little girl was cuddling me and had a seizure which threw both of us heavily to the ground. I ended up with a big swelling and blue face. As my two cousins had Haemophilia, it is not difficult for my parents to work out that I had it too. However, I wasn't officially diagnosed with Hemophilia A until 2001, when I was in my 30s. My severity is moderate.

What level of health support did you get for haemophilia?

I developed severe arthropathy in my knees, hips and elbows joints due to a lack of proper treatment. When I got a bleed I had to stay in bed until the bleeding stopped. This would take up to 2-3 days and sometimes it could last for weeks. The first night was always harrowing, my parents could only hold me in their arms, patting my back to relieve a little bit of my pain.

In my early childhood my therapy was a daily bowl of peanut skin soup. Drinking such a bitter and astringent soup (with eyes closed!) made me tremble. I was also given a mix of chive roots and rice wine to apply to my swollen joints which didn't help at all.

One time I got severe bleeding in my gums and my parents thought I might not survive, so they cooked a bowl of chicken soup for my last supper with the only hen we had and a small Ginseng piece. Surprisingly, I woke up the following morning, and the bleeding had stopped.

In the mid-1980s, cryoprecipitate was used for the first time in China to treat haemophilia A.

Dad asked his friend, who was a bulk carrier captain, to buy 6 bottles of cryoprecipitate when he next sailed to Shanghai (the distance from Brisbane to Melbourne). These bottles had to last for 6 months or longer so I kept them in the fridge and only used them for emergencies.

In the late 1990s a haemophilia treatment centre was opened in Guangzhou and recombinant Factor VIII was also introduced in China. Although my joint damage was irreversible, with the new medication, I could control my bleeding much better. In 2010, I had replacement surgery for my right hip and left knee. The procedures went quite well, significantly reducing my bleeds and improving my mobility so that I could travel overseas myself.

How long have you been in Australia?

I went to Vancouver in 2008. To my surprise, it was still snowing in late April. I also like Singapore; it is beautiful but too small and too hot for me. Guangzhou and Brisbane are on a similar latitude, just in the opposite hemispheres.

I came to Australia in early 2012. It didn't feel too difficult to settle down in Australia. Most of the local people are nice and friendly. The weather is terrific. It is good to embrace the challenges in

a completely new environment, otherwise life is too boring.

From a busy city with more than 15 million population, I prefer to live somewhere quiet and cool. My family and I love almost every aspect of this charming garden city. We are adapted to the Aussie lifestyle, whether driving into the Outback during the school holidays or spending a casual Saturday afternoon at the riverside. We have many friends here. They are friendly and warm-hearted, always willing to give a hand when needed.

My parents and my elder daughter are still in Guangzhou. Because of the Covid pandemic, I haven't seen them for nearly two years and I miss them terribly. I also miss the traditional local dishes in my hometown where there is a saying; 'Eating should be in Guangzhou'.

I hope my daughters can live in Australia, free to pursue their interests and chase their dreams. For myself, I would like to go to uni when I retire. Although I got pretty good results in my University entrance exams, I was not allowed to go due to my disability.

Are you covered for your Bleeding Disorder, do you need to pay for health care here in Australia?

I have been waiting for my permanent residency for six years, now hopefully, it will be finalized soon. My experience is patience, patience, patience. I have Medicare (interim) and private health insurance in Australia, but I have a long-standing arrangement to obtain my Factor VIII from the Hemophilia Treatment Centre in Guangzhou. I usually travelled to China for work two or three times a year and brought back the Factor. I would declare it on my arrival through customs and because the prescription is in my name and I have a travelling letter from the doctor, I never had any issues with this. Due to the COVID -19 travel restrictions, my stock has nearly run out. So I will need some local supplies soon.

Has anything disappointed you about health care in Australia?

Health care costs increase all the time. From my point of view, some of them might not be essential. For example, private health insurance entitles you to a pair of new glasses every year, but I think we're being fleeced.

What could people do to make it easier to settle in?

Australia is a multicultural society, and immigrants played an important part in its modern history. The beautiful land attracts many people from all over the world. Help them settle into their new lives, build their connections to the local communities. In return, they will contribute to the society. This will benefit Australia in the long term.

COMMUNITY Camp is on again

YOU are invited to attend the 2021 HFQ Community Camp at Noosa North Shore Retreat on the beautiful Sunshine Coast. Our 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.

This year's camp is on Halloween Weekend which is also the deferred Ekka public holiday so you are welcome to arrive earlier on the Friday and we hope to have a Halloween based activity on the Saturday night

You might think of camps in terms of kids and action-based activities and it's true to say we'll try to have lots of activities across the weekend to build resilience, confidence and self-worth but there are much deeper outcomes that we gain from attending. You might also think of camps in terms of being under the stars and in tents, but we are all accommodated in self-contained motel style units and we have a dedicated function area we can use.

Our community camp is highly subsidised and is for all members of the bleeding disorders community in Queensland to connect, support and empower themselves and each other. There are many families with grown up children, singles and couples that can attend and benefit from the social connection we make with each other. Regional families are also welcome to join us. Please call the office if you need financial assistance to make this happen as we have some funds available for getting regional members to camp.

At camp you have your own accommodation, but we encourage you to mix with others and share experiences with people who will soon become friendly faces. 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 new, challenging but fun activities that will help us improve our spirits and learning as well as expand our own capabilities and expectations.

It can be a relaxing weekend away, you can sit back and enjoy the quiet, connect with others and reflect. At the end of camp, it will be time to say goodbye, but we think everyone will leave with a smile and a real sense of achievement. Going home with newly found confidence and readiness for the future we face!

It can be easy to dismiss the camp saying, "It's not for me", but it is for you and for every other member of our community. We all benefit from the experiences and support of those around us, so if you haven't been to camp yet, if in the past you have thought it's not for me...think again and let this be the start of a new and more fulfilling activity with others from the Queensland bleeding disorders community. If you haven't booked yet and want to attend, please call the office ASAP on 0419 706 056.

EMPLOYMENT and career planning for people with bleeding disorders

From May to July this year Sarah Drobczyk a master in social work student did a literature search and research for HFQ on the needs and aspirations of people with bleeding disorders in Queensland in regards to employment and career planning opportunities.

Four female participants and nine male participants from 23 to 52 were interviewed. Eight participants were in the Greater Brisbane area and five participants lived in regional Queensland. Four participants were employed full time, four were working part time hours, three were unemployed, one was a full-time student, and one was medically retired.

Most participants said that haemophilia has had a negative impact on their employment and career choices. Several participants stated that "haemophilia makes things more complicated" or that they would have liked to choose a different career path. However, they felt unable to do so because of their haemophilia. Half had made a conscious decision to get office-based jobs due to their bleeding disorder. But 30% of all participants had fallen into the job, rather than actively choosing or pursing a career.

Most participants shared a mindset of "get on with it" and "push through" which highlights their resilience and strong will. Participants also voiced a range of feelings from needing to "play down" their condition to actively hiding their bleeding disorder due to discrimination and stigma they experienced in the workplace.

Three young people reported difficulties to find employment that did not involve heavy and repeated lifting and some adult participants had needed to change jobs or retire due to haemophilia related issues. This was mostly related to pain and arthritis.

Overall, participants seemed to find it easier to gain employment when they had a postsecondary qualification such as a degree.

70% of participants had experienced depression or anxiety due to experiencing many uncertainties, not knowing when they would have their next bleed and not being able to plan ahead. Another issue raised was adherence to routine treatment. Non-adherence can increase the risk of joint bleeds which might require time of work.

Most participants voiced concerns about being disadvantaged and discriminated against because of their haemophilia; due to a lack of understanding from employers and also their colleagues. 40% of participants reported that they had experienced discrimination in the workplace directly related to their haemophilia.

However, providing full disclosure seems to create an ethical dilemma. Wanting to be honest and safe in case an emergency situation arises, versus wanting to protect themselves from discrimination. Participants also noted that there are risks involved with non-disclosure which means the employer does not know about what the employee needs, and legal issues could potentially follow if their condition is affecting their performance or requirements of the role.

With regards to future directions, participants voiced interest in a variety of support options and HFQ is considering offering workshops, mentoring focused on career planning, employment, disclosures in the workplace and transitioning between different positions and work environments. This is likely to be in small groups or one-on-one mentoring situations so that the workshop addresses their individual needs rather than being generic.

5 Minutes with Brett

Talking with Andrew on moving to

Tell us about growing up in the UK.
I grew up with standard issue parents, identical twin brother and a younger sister. It was a happy healthy childhood. No big dramas apart from haemophilia. My brother and I were diagnosed at six months and that was a bit of an eye opener for my dad.

I've been treating prophylactically since diagnoses. We lived 40 minutes drive from one of the main centres which was very well connected in terms of research and staff. But we had to drive up there every time there was an accident and initially on a weekly basis until my mother learned how to do injections.

Did the HIV and hep C crisis impact on you?
Yeah, I went through all that and I'd tried the earlier treatment for hep C but it put a lot of strain on the relationship with my wife as I couldn't sleep and basically had an instant urge to rip somebody's head off for no particular reason.

Then at the same time as I was moving over, I was offered another treatment, with the new 99% effective drugs. It was one pill a day for three months. Deanna and the kids had already gone and I was packing up the house when the nurse says she's got approval to give me the new hep C treatment: take the pills with you, don't lose them and send us the results. So the week before I got on the plane, I started hepC treatment. I actually had my fourth one on the plane. Took them for three months with no real side effects, sent the test results back to UK from the blood sample. Got a message saying Congrats, you're clear and I went, bloody bonza! thanks for that.

Tell me about shifting to Aus?
Initially, I came on a three-month tourist visa as a mature aged backpacker. And I met a girl and reimported her back into the UK for ten years. And then she said, stuff this rotten weather, I want to go home. And so we moved after ten years to Grafton. I don't miss the weather. I love the space out here. I love the outdoor lifestyle out here. The most difficult thing about leaving was friends and family really. But I'm long term committed here. I'm literally finishing off my citizenship application this week.

What made you decide to go to Australia instead of somewhere else?
I was in a pub in London with lots of Aussies and Kiwis who I was working with at the time, and the lovely Natalie Umbrugglia came on the TV with her song, Torn. And I thought, I wouldn't mind one of those so I'll go and have a look. That, plus the fact that I spent quite a few years working with Aussies and Kiwis; they were always generally in a good mood and were always having a good time.

How has the citizenship process gone?
I was married to a fifth generation Aussie so we decided to do the citizenship application thinking, I'm married now, it should be alright. We had to have a health check, had to declare everything and then (because of my haemophilia) had to do a financial calculation before the whole application got sent off. And then, after four years, we got a response that basically said it has been decided that you can sod off because you are too expensive to the Australian community.

But my wife Deanna talked to her mother who wanted her to come home as well, and she spoke to her local MP. Deanna's mother explained the situation and the MP says, I know the immigration minister, I'll sit him down in the Canberra canteen and we'll have a chat. So as far as we know, she literally nobbled him in the canteen in Canberra and he said, yeah, we are about to get voted out so why not?

So of the whole shenanigans regarding moving to the other side of the world, all the packing up, all the immigration, all the saying goodbye to family and organizing jobs and all the rest of it,

the most seamless bit of the whole transition was the medical transition; It was basically a smooth handover from one doctor to another.

Has the New South Wales, Queensland divide caused you any problems?

I had one session down at the Prince Alfred in Sydney, and they said we are happy to see you and get you into the system, but you live in the top half of New South Wales, the closest centre is Brisbane. So I go there and we had a bit of a joke about them prescribing me expensive drugs that NSW has to pay for.

What was your biggest challenge or your greatest joy adjusting to life in Australia?

Well, I was really relieved that it was so seamless. The same medication that I had in the UK was the same medication that I received here in Aus when I arrived.

I went straight on to the family farm for the first couple of years. I was still doing work in Ireland, because I had this solar company in Ireland that's still going and twice a year I could go back to UK. But then about four years ago I got approached to do a job over here, which I did. I was fairly gob smacked how much Australians get paid, because when I started the job in Australia the salary package was double what I'd been paid for a similar job in the UK.

But the real thing is that Australia is a much more expensive country to live in. Taxes are generally higher because you get taxed for everything and that's the scariest thing about Australia, apart from the snakes, the spiders and dentists.

What were your hopes for living in Australia?

Good weather, happy people, reasonable job prospects, nice outdoor lifestyle, great environment for bringing up kids on a farm. Those were the main wishes, so despite what's happened with my relationship, I've actually met most of those. So I'm quite grateful for that. I'm also grateful for the fact that up until now, Australia's ridden out this pandemic pretty well. I've been in regular contact with the Poms over the last 18 months and they are really, really miserable, they've been in lock down for 17 months.

Is there anything you wish people knew more about migrating?

I believe that the emphasis is on the immigrant to make the effort to the incoming community they're moving to. So, if you're going to get off the plane, go and sit in a rented flat in the middle of Sydney and expect everybody to turn up at your door and offer you X, Y or Z, then don't bother. I think the immigrant has to make the initial effort.

Andrew chilling out with his daughter Eva.

Overcoming Stress

Stress is a potentially damaging force, which can occur in response to perceived or subconscious danger, or to changes happening in or about you. It stimulates all senses. When stress gets too much it turns to distress, and this affects your physical and mental wellbeing.

Stress affects the body's immune system and can lead to susceptibility to ill health and disease progression. It may also be linked to heart disease & cancer. If you are coping well you should have;

- An alert and creative mind.
- A keen memory
- A spectrum of emotions and feelings
- Easy and painless body cycles such as appetite, going to the toilet and sleep.

Living with a bleeding disorder is stressful, and we sometimes forget this. Stress can manifest in a number of ways.

It could be that you are sleepless, short tempered, have mood swings, have headaches and migraines, or drink or smoke more than usual.

Perhaps you sweat, stammer, become miserable and depressed, have muscle cramps, lower back and neck aches, get butterflies in your stomach or sweaty palms.

It also shows when you cut yourself off from other people, have difficulty making decisions, have memory lapses or changes in appetite.

You might feel tired all the time, out of sorts, have nightmares, blurred vision, heartburn and indigestion, acne, diarrhoea, or feel overwhelmed.

Stress Strategies

Learning to manage the effects of stress and developing strategies to cope is vital. It is important for you to develop self-awareness and recognise when your stress turns to distress. Remember that others may be able to see the effects of stress on you, but they can't feel it. Only you can bring about the changes to reduce stress.

Plan to set aside some uninterrupted time and space every day for relaxation (say 10 minutes). You need to find something that you can really enjoy, reading, meditation, sitting in a garden, creative visualisation, listening to a relaxation tape – until your mind is clear.

To combat stress

- Take time out to define what stresses you out
- Assess what you are able to cope with
- Attempt to relieve the stress. If it fails, try something new.
- Don't tackle too much at once.
- Keep fit through exercise, eat well., reduce sugar, salt, alcohol and saturated fats – a poor diet can affect your mental wellbeing.

- Rest when you feel tired, and make sure your bed is a comfortable space.
- Say what you think, talk and share your concerns.
- Be assertive and say 'no' to unreasonable requests. You are more important than your job or relationships.
- Find someone who can listen to you impartially, and then let rip – it is proven to be good for you.
- It's pointless listening to friends who want you to do things you are not up to doing – it only adds to your stress.

Muscle Relaxing

Progressive muscle relaxation is a good technique everyone can do. Tense, hold, and then release each major muscle from your head to your toes for about ten seconds each. This is an effective way to release stress.

Visualising

If you have a mind that seems to be in overdrive, try visualising a blank blue screen, or picture a scene/place that is calming to you. Do this for a

Continued on next page ⟶

minute. Remember your brain needs down time too.

Another effective relaxation technique combines both muscle relaxation and visualisation. Lie down in a quiet room and relax. Start your visualisation by picturing all the stress and bad energy moving out of your brain and flowing out to your extremities. Feel it leaving your head and flowing down the neck. Imagine that as it goes through the neck it collects the soreness stored there and it moves down your body and out through your toes or fingers. Follow them as they flow out of your body. After they are gone, lie quietly for a few minutes before getting up.

Some meditation and relaxation apps will guide you through similar relaxation techniques.

Breathing

Deep breathing exercises can also calm you and help you relax. Start by breathing in for four seconds, then release for four seconds. Do this for a whole minute.

Humour

Watching comedies and having a laugh are good ways of reducing stress because they release endorphins. These are the bodies natural painkillers.

Massage

Massage can feel good and it is safe for those on prophylaxis and those not at risk of spontaneous bleeds - however any pain, swelling or bruising afterwards would prompt a call to the HTC. If you like it, plan to have one regularly. It doesn't have to be a registered therapist; you can practice with a friend, but please note; those individuals not on prophylaxis who are prone to spontaneous bleeds should exercise caution with massage.

Complementary Therapies

Many complementary therapies work for relaxation, but some can be costly. Here are some that people have found work for them: Aromatherapy – Back flower remedies – Hypnotherapy – Massage - Meditation – Reiki – Traditional Chinese Medicine – Yoga

Stress can lead to anxiety or depression. If you are not able to relieve your stress talk to your doctor or the QHC psycho/social worker and seek professional help before it takes a bigger toll.

Our Bleeding Experience weekend meeting

The last weekend OBE's (Our Bleeding Experience) was cancelled because of Covid lockdown so we have booked a *NEW* date and venue.

Sunday 14th November 2021 at The Glen Hotel - Eight Mile Plains.

OBE's is an enjoyable social gathering for Men in the Bleeding Disorders Community.

So, if you are male who has a bleeding disorder, or maybe a Dad who has a child with a bleeding disorder, please feel free to come and join us for a meal, beer, coffee and a good old yarn.

For more information or to RSVP please call 0419 706 056.

Haemophilia, VWD & Rare Bleeding Disorders conference

This years 20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders is a virtual conference due to the uncertainty of the pandemic and at HFQ we are very excited about the opportunities this provides to our members. Without the requirement to travel many more people may be able to participate and contribute to the discussions. We expect the virtual conference will attract more delegates than usual and create innovative learning opportunities and discussion for everyone.

The October conference will run over Friday and Saturday between 9am – 5pm. There will be keynote presentations for everyone, followed by concurrent sessions for you to choose from, and there will be breaks in between so you can plan your days. If you miss a session, you can playback later that day and all sessions will be as part of your registration for 6 months, you can log in anytime.

Focusing on the theme, Embracing a Changing World, there are a range of topics including:

- Managing bleeds
- Treating and diagnosing VWD
- Specific issues for women and girls
- Bleeding disorders and young people
- Understanding and managing pain
- Getting older
- Living with hepatitis C/HIV
- Mental health
- Managing change
- Optimising peer support

You can attend from the convenience of your home or office, because the 2021 conference is the most accessible yet. All you need is access to the internet and a computer, smart phone, or tablet / iPad. Watch sessions, participate in Q&As, speak with industry experts, attend social events, and meet friends – old and new.

This year's conference will bring together people with bleeding disorders, family, carers, health professionals and stakeholders in a brand-new way.

What's Included?

All registrants will have access to the entire two-day event, including all sessions, extra activities and social events, private rooms with Gold Sponsors, Remembrance Service and a conference pack with abstract book and information.

Only $50 per user access for people with a bleeding disorder, family and carers

If you have ever wanted to attend a conference and couldn't because of time constraints, travel or costs, this is the perfect time to do so! And if you require assistance with your registration, please let us know as HFQ is offering funding and subsidies that could cover you registration and/or internet data so you can attend, please contact us on 0419 706 056 or email info@hfq.org.au for further information.

Website link *www.haemophila.org.au/conference21*

Registration link *www.haemophilia.org.au/registration*

Ensure you don't miss out on this major event. Register now for the 2021 conference.

Health Updates

Resubmits Roctavian Gene Therapy for EU Approval

The European Medicines Agency has validated BioMarin's new application for approval in Europe of its experimental gene therapy Roctavian for severe haemophilia A. If accepted, Roctavian will be the first gene therapy approved in Europe for haemophilia.

Last year, Roctavian's applications got rejected both in the EU and in the U.S., with health authorities requesting more data.

BioMarin's resubmission showed that Roctavian was generally safe and significantly increased FVIII levels, while reducing bleeding rates and the need for replacement therapy.

The latest data demonstrated that a single dose of the gene therapy continued to safely and effectively prevent bleeds after four to five years.
https://www.prnewswire.com/news-releases/european-medicines-agency-validates-biomarins-marketing-authorization-application-for-valoctocogene-roxaparvovec-to-treat-severe-hemophilia-a-301334635.html

Extended Half-life Products Linked to Fewer Infusions, Low Bleed Rates

Switching to EHL's is linked to a reduced number of infusions and a sustained low rate of bleeds, according to a Canadan study published in the journal Haemophilia. Notably, a significant drop in the annualised bleeding rate (ABR) was observed with EHL products in children with haemophilia A.

The results showed that there was a significant reduction in the prescribed weekly prophylactic dose after the switch to EHL products. Switching to EHL was also associated with a stabilisation of actual annualised factor use.

The most common reasons cited for the product switch, according to researchers, included the need for fewer infusions to reduce the patient's treatment burden. Other cited reasons were patient/family preference, high ABR, poor adherence to standard half-life products, and improved quality of life.
www.https://onlinelibrary.wiley.com/doi/abs/10.1111/hae.14369

Quality of Life Benefits Seen With Long-term Hemlibra Use in Trials

Preventive treatment with Hemlibra improved physical health-related quality of life and led to fewer missed workdays among people with severe haemophilia A without inhibitors, an analysis of two clinical trials published in the journal Hemophilia found.

Extended data from analysis of HAVEN 3 and 4 focused specifically on adults with haemophilia A without FVIII inhibitors, since they were the majority in both trials.

Before enrolling in the study, 70% of patients had one or more target joints. 54% of patients experienced clinically meaningful improvement in the physical health domain. Participants with a lower HRQoL showed the highest improvements in physical health once Hemlibra was started., these improvements are complementary to demonstrated efficacy of Hemlibra in bleed prevention.
https://onlinelibrary.wiley.com/doi/full/10.1111/hae.14363

BioMarin's troubled haemophilia gene therapy continues to fade.

The effects of BioMarin's gene therapy for haemophilia A are continuing to fade in the earliest treated patients, renewing questions about the long-term prospects for a drug the company had billed as a one-time cure.

At the International Society on Thrombosis and Haemostasis 2021, BioMarin announced that, after five years, the first seven patients treated with the therapy's high dose expressed a median of just 8.2% the amount of factor VIII that a healthy person would. That's a small fraction of the 60.3% expression patients saw one year after receiving the therapy, known as valrox.

Despite the waning levels of protein, patients were still largely symptom-free. The therapy reduced the annualised bleeding rate by 95% among six of the patients, and even in year 5, six of the seven patients had no bleeding events at all.

Durability of the treatment is a concern as patients receiving this type of treatment can receive a dose only once. Last year, the FDA asked the company to complete more research before it would allow the company to market the therapy. This new data is expected in November of this year.
https://www.biospace.com/article/new-trial-data-call-into-question-long-term-efficacy-of-biomarin-s-hemophilia-a-gene-therapy/

Patients' Priorities for Gene Therapy: Durability and Bleeding Control

Effectiveness in controlling bleeds and the potential for less frequent use of a treatment are two priorities people with haemophilia place on a potential gene therapy, and both ranked slightly higher than safety according to a study published in the journal Haemophilia.

A hypothetical gene therapy's ability to lower bleeding rates ranked highest in priorities by the largest proportion (31%) of respondents, followed by treatment burden, or its dosing frequency and durability (26%). Other commonly valued attributes of a therapy were its potential safety (17%), and its affects on daily life and physical activity (11%).

The researchers also noted that whereas efficacy at preventing bleeds was the most valued attribute among haemophilia A patients, those with haemophilia B were more likely to value treatment frequency of use and durability.
https://onlinelibrary.wiley.com/doi/10.1111/hae.14383

GreenGene F, Next-gen Hemophilia A Treatment, Approved in China

GreenGene F (recombinant factor VIII), has been approved in China for use in treating haemophilia A. GreenGene F was approved in Korea to treat haemophilia A in 2010.

GreenGene F's approval was based on a Phase 3 clinical trial in China, which showed the therapy's efficiency in easing symptoms in about 80% of haemophilia A patients.

The study also achieved key secondary goals, with GreenGene F effectively showing a 94% reduction in annual bleeding rates and annual joint bleeding rates. Patients treated with GreenGene F in the trial also reported a better quality of life.

The company focused on haemophilia patients in China, because about 60% of the people with haemophilia A in that country are not being treated properly or not using any disease-specific treatment.
https://www.businesswire.com/news/home/20210811005949/en/GC-Pharma-Announces-GreenGene-F-Approval-in-China-for-the-Treatment-of-Haemophilia-A

AGM and Member Information Night

This year's Annual General Meeting and Member Information Night (AGM) will be on Tuesday 19th October 2020, at 7:00pm. It will be held in the Richmond Fellowship Meeting Room, ground floor at 298 Gilchrist Avenue, Herston (below the HFQ office). There is free parking available at the front of the building, but because of current Covid-19 restrictions RSVP's are required. You can also zoom in on-line for the meeting.

Ever popular and informative, this is your chance to hear from all areas of the foundation, from President David Stephenson and board members to manager Graham Norton delivering their review of the last year updating on progress and forecasting for the year ahead. As always, both the AGM and Members' Information Night offer you the chance to ask your questions of the foundation, feed in your opinions and be fully updated on the work we do.

The meeting will conclude with the presentation of reports for the 2020/21 year, an amendment to the constitution, and the election of board members. Financial members can also nominate to positions on the Board of the foundation. The total board membership can be eleven including 4 office holders and 7 ordinary members.

Nominations, declarations and proxies relating to the AGM close on Tuesday 28th September 2021. To RSVP for the meeting, or if you want to renew your membership, or nominate for a board position (or have any other questions), please contact Graham Norton, our manager on mobile 0419 706 056; or email *info@hfq.org.au*

World **Hepatitis** Day 2021

World Hepatitis Day is marked globally on 28 July. In 2021 we joined the global community in the message of Hep can't wait!, reminding us that we need to be proactive and act on viral hepatitis.

Hepatitis C has had a profound effect on our community. In Australia many people with bleeding disorders acquired hepatitis C from their plasma-derived clotting factor treatment products or other blood products before 1993. Several safety measures were introduced by 1993 and the risk of bloodborne viruses from plasma-derived clotting factor products in Australia is now considered to be extremely low. But many people in our community live on with the consequences of those early infections.

WHAT ARE THE KEY ISSUES IN 2021?

Revolutionary new hep C treatments are now available in Australia. They are easy to take – tablets not injections - with very high cure rates and few side effects.

Who is at risk?

If you had a blood product or a plasma-derived clotting factor concentrate before 1993, you could be at risk for hepatitis C.

Many Australians with bleeding disorders and hepatitis C have now had treatment and been cured – but some might not even know they have hep C. This could be the case for some women and men with mild bleeding disorders who may have had very few treatments in their lifetime and never thought of themselves as at risk for hep C. If this is you, don't wait to be tested – find out if you have hep C. Treatment is simple and hep C can be cured.

You have been cured – has your liver recovered?

If you don't know the answer to that question, don't wait to find out. Take the time to **contact your hepatitis specialist and check your liver test results.**

It's very important to check that you don't need ongoing follow-up with a liver specialist. For example, if you have cirrhosis or extensive scarring and have successful treatment, you will still need ongoing care of your liver.

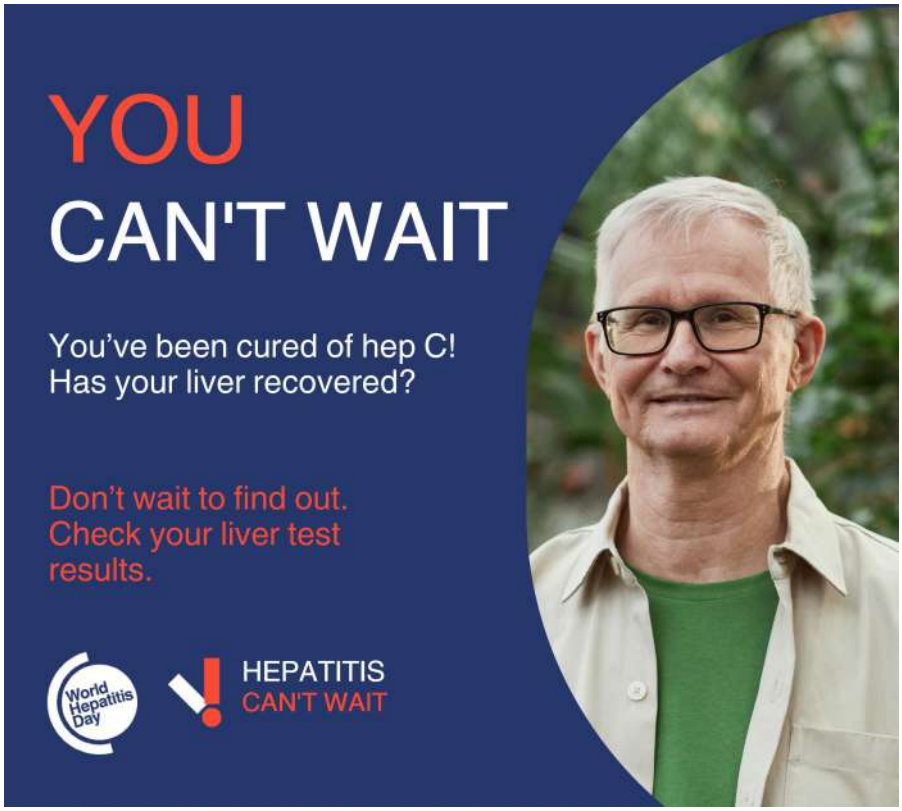
Sadly, some people with bleeding disorders and hep C have very advanced liver disease caused by long term infection. Close liaison between hepatitis or liver specialists and Haemophilia Treatment Centres is very important for care and treatment. Research is continuing into new and improved hep C treatments and management of advanced liver disease.

PERSONAL STORIES

We thank Gavin Finkelstein, HFA President, and Mary Jane for sharing their personal stories about living with hep C, treatment and being cured. Read their stories on the HFA website.

FOR MORE INFORMATION

Visit: *www.world.hepatitisday.org.au*
The HFA World Hepatitis Day page – *www.haemophilia.org.au/world-hep-day*



Important Dates for HFQ Members

Covid-19 is still a concern and all HFQ activities are subject to any restrictions that may apply at the time of the activity.

OBE Men's Meetings
Wednesday, 6th October
Mango Hill Tavern

Sunday, 14th November
The Glen Hotel

Women's Lunch
Saturday, 21st November
Tingalpa Hotel

Haemophilia, VWD and Rare Bleeding Disorders Conference
8th - 9th October

Bleeding disorder Awareness Week
10th - 16th October

AGM & Member Info Night
19th October
Richmond Fellowship Room
298 Gilchrist Avenue

Community Camp
29 - 31 October
Noosa North Shore Retreat

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.

After our research into the employment and career planning needs of members HFQ is considering offering small workshops and/or mentoring focused on career planning, employment, disclosures in the workplace and transitioning between different positions and work environments.

To do this we need stories of successful careers and to hear from people who might be willing to share that story and even spend some time mentoring workshop participants if they are interested in a career path like that one you have (or did). This is not a commitment on your part just an expression of interest in sharing your expreiencs in small groups or one-on-one mentoring situations.

If this is you please call the office on 0419 706 056 and let us know or email info@hfq.org.au

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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