

# the LIFE FACTOR

Haemophilia Foundation  
Queensland

## WINTER EDITION

Issue 71



JULY 2022

HFQ MEMBER MAGAZINE

# FROM THE PRESIDENT

Hello everyone,

I hope you are all well and enjoying the cold of winter. I must say I am not – having a bleeding condition when it's so cold can present real problems when trying to get a needle into a vein.



The smaller veins shrink in size with cold, making it a challenge. Some people target larger veins which is not such an issue but others like me use smaller veins on the hand and when it's cold the blood flow to the skin is reduced – a normal process which helps the body minimise heat loss to maintain internal core temperature.

Luckily, for those on Hemlibra this is no longer a problem, but for others it can be, so what can you do to make things easier to hit that vein. Firstly always seek guidance from your medical professional for any issues. In my personal experience there have been a few things that assists me .

Being adequately hydrated helps, using a head mount magnifier is great especially with aging eyesight, heat packs like a wheat bag, some exercise can assist if possible, vein training (ask your HTC team) and the last one is a dilation cream but you would have to talk to your medical professional about that as there can be side effects.

So there you go – not all is lost when accessing a vein is problematic, stay safe and keep warm.

*Dave*

**David Stephenson**  
President HFQ  
president@hfq.org.au

If you've been affected by the recent bad weather in South East Qld there is Government Financial Support available at <https://bit.ly/3uCDTEg> However, if you don't qualify for the payment or if there are any special issues impacting on you, then you can apply to HFQ in writing via info@hfq.org.au with your particular circumstances (no form required). Each application will be considered by the HFQ board on merit and a speedy response is guaranteed.

**WHEN FLOOD WATERS RISE,  
WE RISE UP AS A COMMUNITY**

**State Government Financial Disaster Recovery Payment**

[www.servicesaustralia.gov.au/south-east-queensland-floods-february-2022-australian-government-disaster-recovery-payment](http://www.servicesaustralia.gov.au/south-east-queensland-floods-february-2022-australian-government-disaster-recovery-payment)

# Inside this Issue:

From the President	2
Contacts and Information Page	4
Write for the H Factor or Volunteer for Us	5
AR Joint Scanner	6
World Hepatitis Day	7
Some Health Issues Men Should Know About	8
HFAQ Membership Renewal	9
New Resource on Female Haemophilia Testing	10
Running on Empty	11
Low Cost Health Services	12
Bridge to Brisbane and Bunnings Fundraisers	13
Financial Stress	14
More Health Issues Men Should Know	15
Getting in the Best Position to Find a GP	16
Breakthrough Bleeds on Hemlibra	17
Mood and Cognition Improve after Hepatitis C Cure	18
Health Updates	19
Damon Courtenay Memorial Fund Now Open	20

## 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](mailto: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 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: Her Excellency the Honourable Dr Jeannette Young PSM Governor of Queensland.

HFQ programs and services are funded by the Queensland Government.

HFQ is also grateful for the support it has received from the Prescott Family Foundation.

## Internet

Find us on the web at [www.hfq.org.au](http://www.hfq.org.au) or at our Facebook page at [www.facebook.com/HFQLD](http://www.facebook.com/HFQLD)

## OUTREACH CLINICS

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

## 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 Griffin – Clinical Nurse

Crystle Gambetta (Mon, Tues) - Physiotherapist

Elise Mosey (Wed, Thur, Fri) – Physiotherapist

Vacant - Psychosocial / Allied Health

**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](mailto: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](mailto: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 *On Maternity Leave*

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

Liam Ball - Physiotherapist 3646-8135

Vacant - Senior Social Worker

**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](mailto: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*

# What's On?



**MAKE IT YOUR EVENT**

## July 2022 to Oct 2022

Some of the HFQ programs and activities already planned

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

JULY	<b>OBE's Monthly meeting</b> Wednesday 6 July Old Fernvale Bakery	<b>HFQ Board Meeting</b> 19 July 298 Gilchrist Avenue	<b>National Pain Week</b> 26 to 31 July	<b>World Hepatitis Day</b> 28 July
AUG	<b>OBE's Monthly meeting</b> Wednesday 3 August Broncos Leagues Club	<b>Women's Lunch</b> 7 August Everton Park Hotel	<b>HFQ Board Meeting</b> 16 August Via Zoom	<b>Bridge to Brisbane</b> <i>Fundraising Fun Run/walk</i> 28 August
SEPT	<b>OBE's Monthly meeting</b> Wednesday 7 September Warwick Bus Trip	<b>RU OK Day</b> 8 September	<b>Youth Camp</b> 16-18 September Emu Gully	<b>HFQ Board Meeting</b> 20 September 298 Gilchrist Avenue
OCT	<b>Bleeding Disorders Awareness month</b> All October	<b>OBE's Monthly meeting</b> Wednesday 5 October Yeronga Services Club	<b>HFQ Bunning Fundraising BBQ</b> Saturday 8 October Bunnings Rothwell	<b>HFQ AGM</b> 18 October Nundah Library

## Write 4 the H Factor or Volunteer 4 Us

We are always eager to have member's contribute to our publications and activities. Maybe you would like to share a story about you or your experiences with bleeding disorders, or perhaps your experience at one of our events, fundraising, volunteering or something else entirely! If you would like to contribute and write an article for HFQ contact [info@hfq.org.au](mailto:info@hfq.org.au)

Right now we are also looking for fundraising volunteers. HFQ is Queensland's only organisation advocating for and supporting people affected by haemophilia and other bleeding disorders in this state. The organisation is run entirely by family members and friends of people living with a bleeding disorder. If you are active in our community (or want to be) and are willing to be an ambassador and advocate for the values and mission of HFQ, then consider becoming a volunteer. Volunteering for fundraisers can be fun.

With your help we can accomplish good things for the Queensland bleeding disorders community. Please talk to Graham at HFQ (0419 706 056 or email us at [info@hfq.org.au](mailto:info@hfq.org.au)) for more information.

# AR Joint Scanner coming to QCH

A new high-tech scanner is coming to the Queensland Children's Hospital that will give kids with bleeding disorders a glimpse into the future as a way to help them stay on track with their treatment.

The Haemophilia Treatment Centre team at the Queensland Children's Hospital (QCH) are expecting to receive the scanner in late-June from Sanofi. The scanner will be another educational tool to help children and their parents understand the impact of joint bleeds on their joints.

If treatments are sometimes missed, it can cause a "bleed" into the joint space, which can result in long-term, irreversible arthritic damage and it is hoped that the scanners visual representation of this possible future damage will help patients make informed decisions about managing their health condition and reinforce the importance of maintaining their regular prophylaxis but also to treat bleeds quickly.

The Joint Scanner, donated by Sanofi, uses a 3D camera to scan and map a person's hand when placed under the device. Then specially designed software overlays imagery onto the user's hand to replicate normal ageing and the impact of joint disease to show patients what their joints will look like 10, 20, 30 years into the future, both with and without treatment.

While the scanner uses only the patient's hand as its reference point, it can allow the user to expand the screen view beyond the hand to see what is happening elsewhere in specific joints known to be impacted by haemophilia such as the elbow, knee or ankle.

We hope this scanner will help the

HTC team further educate their patients, particularly the young teenagers, about why regular treatment is important! Even though they may feel fine in the here and now, they may be causing themselves long-term damage that will impact their lives in the future which is something no one at HFQ wants to see.

<https://www.hospitalhealth.com.au/content/clinical-services/news/haemophilia-support-ar-joint-scanner-unveiled-at-the-chw-1125557250>

<https://twitter.com/7NewsSydney/status/1530481432405364736>



# World Hepatitis Day

World Hepatitis Day will be marked internationally on 28 July 2022 and is one of the World Health Organization's seven official global public health days.

It is an opportunity to come together to step up national and international efforts to eliminate viral hepatitis, in particular hepatitis B and hepatitis C. The global and Australian theme for World Hepatitis Day 2022 is **Hepatitis Can't Wait**.

World Hepatitis Day is also a day to take stock of any progress we have made and what we still need to achieve. It's also an opportunity for us to increase awareness in our local community and online.

In Australia many people with bleeding disorders were exposed to hepatitis C virus through infected treatment products before 1993, by which time screening of the blood supply and viral inactivation manufacturing processes had been introduced. These treatment products were made from blood, and included blood transfusions or clotting factor products such as cryoprecipitate or concentrates made from the plasma in blood. Many people went on to develop hepatitis C and sadly, some died of the complications.

Most affected people with bleeding disorders in Australia today have now been treated for hepatitis C and been cured. However, some who have liver cirrhosis or severe liver scarring will still need follow-up for their liver health, even if they have been cured.

It is important for us not to miss reaching anyone in our community who could be at risk, so that they have the opportunity for testing, treatment and cure, and to follow up their liver health if needed.

Many people with hepatitis C do not have symptoms until they have liver damage and may dismiss the symptoms as just part of getting older.

Both men and women in our community could be at risk of having hep C if they have a bleeding disorder or carry the gene and ever used factor or had a blood product before 1993.

Do you think this might be you? Or someone you know?

By talking to our friends, family or a doctor about testing, treatment and liver health checks we can work towards the goal of viral hepatitis elimination by 2030.

On World Hepatitis Day we are reminded not to wait – know your hep C status, have treatment to cure hep C, where possible, and follow up on your liver health after treatment.

Keep an eye out on our website and social media for more information and activities in the week leading up to 28 July.

## FIND OUT MORE

Australian World Hepatitis Day website - [www.worldhepatitisday.org.au](http://www.worldhepatitisday.org.au)  
HFA World Hepatitis Day page - [www.haemophilia.org.au/world-hep-day](http://www.haemophilia.org.au/world-hep-day)



**YOU  
CAN'T WAIT**

You could be at risk for hepatitis C if you had a blood product before 1993.

Don't wait!  
Know your status.  
Get tested for hep C.

#WorldHepatitisDay | 28.07.2021  
[worldhepatitisday.org](http://worldhepatitisday.org)

# Some health issues Men should know

## Prostate cancer

Prostate cancer is currently the most common cancer in males, with incidences of prostate cancer continuing to rise.

In 2021 over 18,000 Australian men were diagnosed with prostate cancer, and almost one in 10 men are expected to develop prostate cancer during their lifetime.

Many prostate cancers have been known to develop without showing any signs or symptoms and early diagnosis by a GP or Urologist followed by appropriate treatment is vital in helping to reduce the severity of the condition.

Men who are in their 50's are encouraged to see their GP for regular prostate checks, particularly if there is a history of cancer in the family. If men of any age notice any unusual signs or symptoms they should consult their GP. (Source: The Australia Institute of Health and Welfare Report Australia's Health 2021 and from The Prostate Cancer Foundation of Australia)

## Diabetes

Diabetes is a condition where there is too much glucose (a type of sugar) in the bloodstream. Your blood glucose level is regulated with the help of insulin, a hormone made in the pancreas. Diabetes develops when the pancreas stops producing insulin or when your body does not respond properly to insulin. Diabetes is diagnosed by measuring the level of glucose in the blood. Diabetes can be classed as either Type 1 or Type 2.

Type 2 diabetes is the most common form of diabetes and develops when the body does not

respond properly to insulin. Type 2 diabetes usually occurs in people over the age of 30. This type of diabetes often runs in the family and can be triggered by eating habits and inactivity. People with Type 2 diabetes are more likely to carry excess weight and to have high blood pressure. They are also more likely to have raised cholesterol and heart disease.

Unless blood glucose levels are very high, symptoms of diabetes may not occur. This is why it is important to visit your GP for regular check-ups and to maintain a healthy and active lifestyle to help reduce the risk of diabetes developing. (Source: The International Diabetes Institute)

## Bowel cancer

Bowel cancer is the most frequently occurring form of cancer in men and women combined, and is the second most common cause of cancer-related deaths nationwide.



Commonly referred to as colorectal cancer, bowel cancer is generally seen as a slow-growing cancer, and people who have a recurrent history of bowel cancer in their family are normally considered to be most at risk. The chance of developing bowel cancer increases with age, and is usually found to be more common in people over 50.

Maintaining a healthy diet with plenty of regular exercise is important in keeping your digestion system working at its best, and one of the best ways to help prevent cancers and other lifestyle-related diseases and illnesses from developing.

Like with all cancers, early detection is vital and anyone who experiences anything unusual in relation to bowel symptoms and any irregular pain or cramping in their abdominal region should see their GP. (Source: The Cancer Council Australia)

# Membership renewal

HFQ annual membership subscriptions fall due for renewal on 1 July each year. Membership fees remain unchanged for the annual membership at \$20.00 per year but you can also pay a one-off fee for a lifetime membership. The fee was increased to \$200 from 1 July 2022.

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

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

We only have two part time staff members, so your fees are important to us. Over the past 12 months HFQ has continued to provide services to the bleeding disorders community in Queensland despite Covid-19 and we rely on your support in the form of membership to maintain these services.



Funding from Queensland Health provides us with some financial security and goes a long way in allowing us to deliver outcomes for our community, but there are several activities that we do, that require us to raise money elsewhere and independently of Queensland Health.

Community Camp, regional support activities, youth camp & mentoring activities, health & wellbeing seminars, welfare support for those in need, and a range of targeted services in partnership with the Queensland Haemophilia Treatment Centres addressing community needs could not be achieved on Queensland Health money alone and the fees you pay help make up the shortfall in the programs we currently provide.

Please go to our website where you can renew and pay on-line (<https://www.hfq.org.au/get-involved/memberships>). HFQ looks forward to your continued support and thanks in advance for your membership subscription.

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

Thank you

# New Resource from HFA

HFA has published a new education resource, **Haemophilia testing in women and girls: your questions answered**. It's a comprehensive booklet about genetic testing and factor level testing in haemophilia for women, girls and parents of girls.

There are often many questions and things to think about when checking to see if a woman or girl is affected by haemophilia.

- ❖ What is involved in genetic and factor level tests?
- ❖ Who should have them, and at what stage in their life?
- ❖ How is haemophilia passed on in a family – and what if there is no family history?
- ❖ And why do some women and girls have bleeding symptoms or haemophilia and others do not?

HFA developed the booklet to answer these and other questions in collaboration with women and parents in our community, HTCs and genetics and legal experts. It includes infographics, tables and personal stories.

You can download the booklet from the HFQ website - <https://www.hfq.org.au/publications/information-resources/women-with-bleeding-disorders/haemophilia-testing-in-women-and-girls>

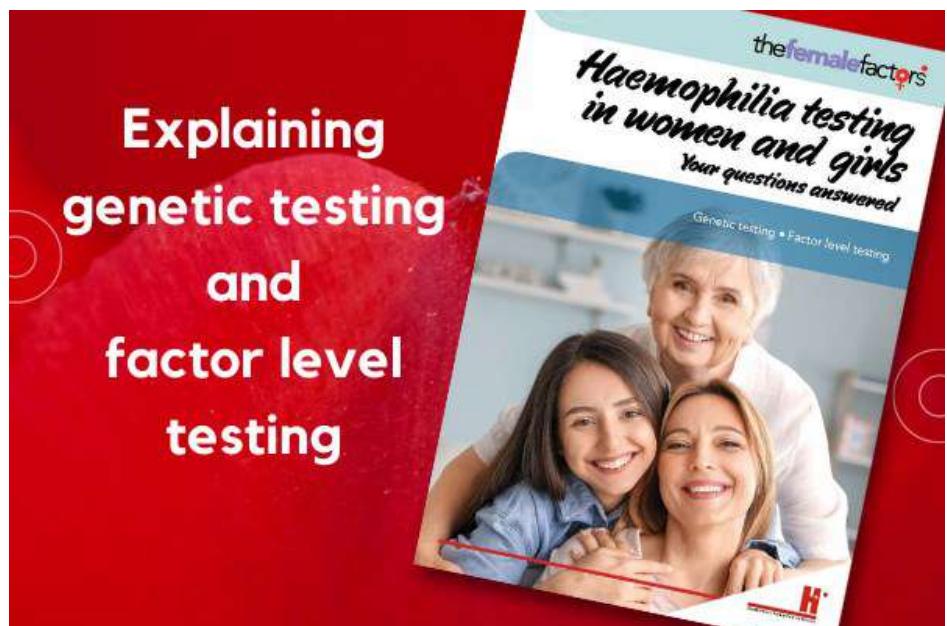
Or you can use the link to the HFA website - <https://tinyurl.com/haemophilia-testing-WG>

If you would like a print copy, email HFA at [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or call (03) 9885 7800 to ask them to post you a copy.

Thanks to everyone who contributed to the development of this resource, and a special mention of Jane, Sharri and Michelle for sharing their personal stories.

We invite you to take a look at the resource and pass it onto anyone you think would find it helpful.

And look out for the short and simple version which is coming soon!



# Running on Empty

Been going too hard for too long? If you are feeling as flat and depleted as the non-Energizer bunny, now is the time to get extremely serious about self-care. When feeling physically and mentally fatigued, some of the most effective ways to restore your health are extremely simple. You may however have to break some old habits, set some boundaries and place taking care of yourself to the top of your to-do list.

## **Rest**

When humans are run-down we tend to completely ignore our animal instincts, so we push on with work, study and all those other things which seem incredibly important. If we continually put rest last, we will start to fall apart, both physically and psychologically. Periods of big stress and big effort need to be balanced by big amounts of rest and recovery. Sleep has curative properties, so do whatever you can to get enough of it. While we may like to think of ourselves as indestructible go-getters, sometimes the only getting we should be doing is getting to bed. Early nights and nanna naps may seem a little lame, but they can play a hugely important role in helping us recover.

## **Do less**

The best antidote to doing far too much, is to do far less. Now is not the time to be a hero. Take off the cape and get super-realistic about what is achievable for you right now. Cut down your to-do list to the bare essentials and don't waste your energy on perfect when 'perfectly adequate' will suffice. To achieve 'less' we may need to set better boundaries and become a whole lot better at checking in on our own needs. When was the last time you asked "what do I really need right now?" A good start is to delay your 'yeses' and say 'no' to those activities that drain your energy and vitality.

## **Give your brain a break**

We have become accustomed to constant stimulation. Unfortunately, this isn't great for our brains. With our days spent multi-tasking and managing our social media and the multitude of open tabs on our internet browser, so our minds don't get the downtime they need. If you are

cognitively fatigued, you may start making uncharacteristic mistakes or finding it harder to concentrate. Taking regular time away from attention-draining activities and devices can be highly restorative. Try taking a walk without your phone or devoting some time to 'single-tasking', focusing on something you enjoy.



## **Listen to your body**

When feeling fatigued and run-down the answer is rarely what you see in self-improvement ads on TV. You will generally find the answer by listening to your body and giving it the simple things needed to nourish and restore it. Rather than truly support us, most wellness industry messaging tends to suggest solutions that set us up for failure and disappointment. When we are fighting fatigue and feeling flat, this can be particularly unhelpful. You don't need an enthusiastic celebrity telling you to unleash the power within. Good nutrition, good sleep and regular exercise are far more likely to yield results.

## **Have a plan**

If doing the same thing is leaving you more and more exhausted, it's time to do things differently. Instead of thinking about what's "normal" or "expected" of you, consider what is sustainable for you, what will keep you healthy and what a good life really means to you. Before you next have to go through a really tough period, plan how you will look after yourself during it and plan how you will recover after it. If it has been too long since you last truly rested, book in some leave and make sure you do something restorative. Having a plan can help us avoid a future filled with more exhaustion and help us walk a path to a far healthier and more enjoyable future.

# Low Cost health services from final year uni students

Many universities in Queensland offer low cost (about \$20 per session) client-focused health services to members of the public. In Brisbane this includes QUT and UQ who operate clinics at their Kelvin Grove and St Lucia campuses.

These health clinics have been set-up to provide senior students and post-graduate qualified students with hands-on experience in their chosen field while under the supervision of highly experienced and fully qualified practitioners.

All health degrees have a certain number of student-client 'contact hours' that are required in order for a student to complete their degree and become a fully-qualified practitioner. The health clinics give the students the chance to meet these requirements and helps them to develop the fundamental skills required to be successful health practitioners.

It gives you access to low cost, fully supervised allied health services. In Brisbane the health clinics include; Exercise Physiology, Nutrition & Dietetics, Dentistry and Oral Health, Paediatric services, Podiatry, Psychology and counselling, and Physiotherapy. These clinics usually have the most advanced equipment in each respective field and access to the latest research and understanding in each discipline.

Before treatment commences, your case will be assessed by highly experienced supervisors who will determine if you can be treated by a senior student. If your needs are deemed to be more complex in nature you will usually be referred to one of the clinics fully-qualified supervising practitioners.

For all other cases, the treatment you receive will be performed by senior students or post-graduate qualified students, who have had many years of study and research in their fields and most likely already have a considerable number of contact hours under their belt. This treatment will be performed under the strict supervision and guidance of highly experienced and fully-qualified practitioners who are leaders in their respective fields. An added benefit is that while you may be treated by a senior student, your case may be reviewed by a Professor or industry leading practitioner.

Universities invest heavily in their health clinics and they are usually equipped with the latest technologies, making them truly world-class. You will have access to technology that is not always available outside of Universities and research laboratories.

So rather than use up your limited allied health referrals from a GP that may have high co-payments consider accessing a university clinic to get the affordable health services you need. Premium health services that don't usually need a referral can be accessed in Brisbane via Queensland University of Technology (QUT) who offer clinics in: Eating Disorders; Exercise Physiology; Nutrition & Dietetics; Optometry; Paediatric; Podiatry; and Psychology & Counselling and University of Queensland (UQ) who offer clinics in: Audiology; Nutrition & Dietetics; Oral Health; Clinical Exercise Physiology; Physiotherapy; and Restorative Care.

UQ Health Clinics. Therapies Building (84). Slip Road. The University of Queensland, St Lucia. Phone: 3365 2232  
Website: [www.health-clinics.uq.edu.au](http://www.health-clinics.uq.edu.au)  
QUT Health Clinics. 44 Musk Avenue, Kelvin Grove. Phone 3138 9777 Website: <https://www.healthclinics.qut.edu.au/>



# Bridge to Brisbane and other fundraising

## Run to make a difference with Team HFQ

Please join HFQ for the BRIDGE TO BRISBANE this year on Sunday, 28 August 2022 and raise awareness for the Bleeding Disorders community in Queensland.

2022 is set to be another sell-out Bridge to Brisbane and people who run or walk with us will go the extra mile and raise funds for Queensland families affected by bleeding disorders. We would love for you to be one of them!

If you are interested in joining us to dress up and walk or run at this event, please let us know on 0419 706 056 or email us on [info@hfq.org.au](mailto:info@hfq.org.au) and talk to Graham or Sam.

Don't forget to talk to your friends and family and get them on board to help us get fit, or ask them for donations.

## Bunnings Sausage Sizzle Fundraising BBQ

The Bunnings Sausage Sizzle has been a popular and successful fundraiser for us in the past because they're low cost to set up, easy to organise and fairly straightforward to volunteer at.

Anyone who's visited a Bunnings on a weekend has no doubt seen a community group out the front staffing the sausage sizzle. The high volume of foot traffic usually leads to a high turnover of snags, drinks and dollars raised.

They are back on (after Covid-19 saw them stopped during 2021) and HFQ has their name down at Bunnings Rothwell and Bunnings Toowoomba.

It's an easy and fun volunteer roll and Bunnings provides the BBQ, gas, and marquees, so all we need to provide are the consumables and a good turnout in volunteer numbers.

The Bunnings BBQ is one of our key fundraising



opportunities and we'd like to know if you're interested in helping at either Rothwell or Toowoomba when we get our BBQ dates.

This is our chance to raise much needed funds for the things our government grant does not cover and we only want 2 hours of your time (we'll even take an hour if that's all you can spare as it can give one of the other volunteers a break).

We can give you a shift at any time that works for you, whether you're an early bird and want to help set up at 7.30am, or if you want a lie in and can help us pack up at 3.30pm, we need you.

WHERE: Bunnings Rothwell (Anzac Ave & Bremner Roads) & Bunnings Toowoomba North (239-267 Ruthven Street).

Call Graham or Sam on 0419706 056 or email [info@hfq.org.au](mailto:info@hfq.org.au) to volunteer. Your help will make these days a successful fundraiser for us!

# financial Stress

Inflation and interest rates are going up, and up to 90% of individuals say that managing money has an impact on their stress. Below are a few simple tips that may help to reduce financial stress and improve your overall wellbeing.

## **Pause before you make a purchase**

Before you make a purchase, mentally 'convert' any amount of money you are looking to spend into the time you would have to work to earn that money back. This helps you get a feeling for whether the service or product warrants that number of hours of your time and energy. If it doesn't, don't make the purchase. This mindset will help you walk away from impulse purchases that you might later regret.

## **Invite friends over to cook together**

Going out is great but not cost effective, you can reduce financial stress by cooking more. Sign up to a few cooking websites and blogs and start trying out new recipes. Invite friends over to do a cookout together, instead of going out to dinner. This allows you to still have a great time and socialise but without spending a lot of money.

## **Keep a monthly budgeting spreadsheet**

Keep an honest monthly budget and be diligent to ensure that all expenses are logged so that you can keep tabs on your spending. This also allows you to save for upcoming trips, events and occasions that you have planned. By keeping an eye on your finances you will feel more in control and be able to pick up needless spending quickly.

## **Schedule a financial planning day**

Book a financial planning day with yourself and your money. The act of doing this instantly makes you feel more in control and sets your mind to wondering instead of panic. There are some excellent online services (see box) to help you check your outgoing and incoming money and make a plan of quick wins and longer-term

goals.

## **Check in with yourself**

Reducing your financial stress may come down to your attitude towards money. If you feel anxious because you don't have enough money define what is enough. Compare your "enough" with your basic survival needs: Do you have a roof over your head? Do you have enough food? Do you have clothes? If the answer is yes to all those questions, then you are surviving. When you accept that basic truth, then your other expenses may be "wants" rather than "needs".

## **Keep a money journal**

You can focus on things like cutting out that \$5 coffee, keeping accurate records and doing financial planning, but you need to review your money myths and blocks too. Managing your money may be a misunderstood element of your life, rooted in things you learnt as a child, so write about your current relationship with money. What are your most traumatic money incidents? What are the emotions behind the way you

spend (or save) money? Try to learn what you actually believe about money and change your beliefs if they are not right for your current circumstances. It may open you up to more opportunities and less stress.

## **Make little spending swaps**

Spending less is great, but just cutting some expenses without adding anything new may feel like you are depriving yourself. Try adding one free or significantly cheaper item every time you cut something out.

# more health things Men should know

## **Weight and obesity**

Currently in Australia approximately one quarter of children and over half of adults are classed as being either overweight or obese, and this figure looks to be increasing. In Queensland alone, around 20 percent of adult men are obese and 47 percent are overweight.

The general causes of overweight and obesity are poor diet and lack of exercise. Queensland figures show over half of adults weren't doing enough physical activity to benefit their health.

Overweight and obesity can lead to serious, lifestyle-related conditions, including Type 2 diabetes, heart disease, depression, and some cancers.

To maintain a healthy weight try to stick to a well-balanced diet with regular exercise, and if you have any concerns about how to achieve this or about your weight in general talk to your GP. (Source: The Queensland Governments Eat Well Be Active website)

## **Skin cancer**

Over 800 Australian men die from melanoma each year, and Australia has the highest rate of cancer in the world.

Prevention is the key to minimising the risk of skin cancer, and all Australians are encouraged to protect their skin against sun damage through the use of a hat, protective clothing, and sunscreen at all times.

Melanomas in men are most common in the upper back area, which means you should ensure all of your body is protected and not just your face when you are out in the sun.

Try to remember to check your skin regularly for any changes, particularly moles, and if you find anything unusual or notice any abnormal symptoms on your skin have your GP check it out. (Source: The Cancer Council Australia)



## **Heart disease**

Nobody wants to get sick. So it's great when we know how to make lifestyle changes to prevent an illness occurring, such as heart disease.

Heart, stroke and vascular diseases are the leading cause of death (38%) in Australia. One Australian dies every 10 minutes from cardiovascular disease and men are more likely to die from it than women, as they are more likely to be overweight or smoke.

The easiest way to keep your heart and arteries strong is through a healthy lifestyle, healthy weight, and not smoking. Talk to your GP to find out how you can make changes to stay healthy. (Source: The National Heart Foundation Australia)

## **Depression**

Depression is more than a temporary low mood, and it generally lasts for more than two weeks. If you have lost pleasure in most of your activities, are feeling down, and have noticed negative changes relating to your behaviours, thoughts, feelings and physical symptoms, you should talk to your GP about what you can do.

A range of factors can contribute to depression in men. These can include employment and relationship problems, drug and alcohol use, physical health problems, and social isolation.

One in six Australian men will experience depression at some point in their lifetime. Depression is common, so there is no shame in talking about this with your GP. But if depression is not detected and treated, it could become serious and disabling and is a known risk factor in suicide.

The good news is that you can do something about it. There is treatment available and recovery is common. Have a chat with your GP about what your options are. (Source: beyondblue)

# Getting in the best position to find a GP

The relationship between patient and doctor can be a complex one, involving professional, personal and transactional aspects. A good relationship builds over time as GPs begin to understand the many factors influencing their your health & well-being.

The doctor-patient dynamic has shifted in recent years, thanks to emergence of patient centred care and health consumer movements. Doctors were once seen as all powerful holders of medical knowledge, patients can now readily access information online and you can get maximum benefit from your GP appointment by coming with the issues you want to raise clearly identified in your own mind.

This gives more time for the GP to build rapport with you, and ask questions that unearth your bigger medical picture.

The HFQ office often receives calls and emails from members looking for information that they haven't been able to find elsewhere or that wasn't provided (or understood) during a consultation with their GP or HTC due to embarrassment, a lack of time, or other factors.

While we're happy to share what information we have, we can't offer medical advice and it's important that people feel comfortable asking their doctors (GP and/or Specialist) about their specific health concerns. And if you're not happy with how you're being supported, you can seek a second opinion.

Some people have told us that they feel rushed or their questions were dismissed at a QHC consultation, but that can be because they do not work with non bleeding disorder related health issues. Others have said that they are conscious of the time and don't ask questions of their GP, or that the GP attributes most of their health issues to their bleeding disorder and dismisses any questions they have, so it is important that you have a GP you can confidentially raise your concerns with.

Many of us hesitate to move from one GP to another, even if we feel we aren't receiving the

support we want. This can be due to a sense of loyalty, a reluctance to repeat a full or sensitive medical history, or having to take time off work for a consultation.

Finding a GP for the long-term begins with taking a proactive approach. This means identifying a GP who has an interest in the types of health problems that afflict people like you and is up to date with relevant knowledge and best practice. It also means defining how you like to be treated by your GP. Do you like a doctor who lets you run the consultation, one who asks a lot of questions, or one who will raise their own concerns for your health based on their observations of you.

Finding a GP that's right for you will mean you are more likely to see them as often as is needed and that will help you experience higher levels of satisfaction with your GP's care and



communication as well as personally experiencing better health outcomes overall.

While time pressures, coyness and life in general, might make building a rapport with a GP difficult, it is possible to achieve success by doing some homework and with a little persistence. Keep at it until you've got the GP relationship you want.

# Breakthrough bleeds on hemlibra

## However that doesn't mean you need to increase your dosing!

Most people with haemophilia A on preventive treatment with Hemlibra (emicizumab) will experience spontaneous or traumatic bleeds at some point, according to a recent study published in the Journal of Clinical Medicine.

Results also indicated the risk of spontaneous bleeds while on Hemlibra is higher for older individuals.

Hemlibra is an antibody-based therapy that works by mimicking the activity of factor VIII, the clotting protein that is missing or is faulty in people with haemophilia A.

Dosing is highly prescribed based on the weight of the patient and because of the risk of clotting if you use more than the prescribed amount, dosage adjustments of Hemlibra are not recommended in the medical literature.

In the study "Real-World Data on Bleeding Patterns of Haemophilia A Patients Treated with Emicizumab"; researchers described the breakthrough bleeding patterns of 70 haemophilia A patients, who had used Hemlibra for at least 18 months. Prior to treatment start, patients without inhibitors had an average of four annual bleeds, while those with inhibitors had an average annual bleeding rate of six.

Over the 18 months of follow-up 51% patients experienced at least one spontaneous bleed, and 61% had at least one injury related bleed. Joint bleeding, or hemarthrosis, was the most common type of bleed seen in patients with spontaneous and traumatic bleeding episodes.

No significant relationships were found between the risk of bleeding and prior bleeding rates, or

the presence of inhibitors. However, being older was independently associated with an increased likelihood of at least one spontaneous bleeding episode within the 18-month period of Hemlibra treatment.

Notably, a subset of 24 patients who had been treated for at least two years had fewer spontaneous bleeds in months 18–24, as compared with months 12–18. However, the



researchers noted that this "may be explained by restrictions in mobility and fewer outdoor activities during the COVID-19 pandemic."

Hemlibra is not a cure for haemophilia and cannot be used as a treatment for breakthrough bleeds. Taking Hemlibra is like transforming a severe diagnoses into a mild one, but bleeds can still happen. If you use Hemlibra prophylaxis, you need to have a second therapy available, like a FVIII product, to treat breakthrough bleeds.

Talk to your doctor to develop a plan for managing breakthrough bleeds.

Carefully follow your doctor's instruction regarding when to use infused FVIII, and the exact dose and schedule you should use to treat bleeds.

It is recommended you keep track in MyABDR the bleeds that happen, the treatment doses, and when the doses were given to treat each bleed.

Edited predominantly from an article "Real-World Data on Bleeding Patterns of Haemophilia A Patients Treated with Emicizumab," published in the Journal of Clinical Medicine. September 2-021. <https://www.mdpi.com/2077-0383/10/19/4303/htm>

# Mood and Cognition Improve after Hepatitis C Cure

People who were successfully treated for hepatitis C with direct-acting antiviral (DAA) therapy experienced improvements in their mood and cognition, according to study results published in the Journal of Viral Hepatitis.

Over time, chronic hepatitis C virus (HCV) infection can lead to severe liver disease, including cirrhosis and liver cancer. It has also been linked to neuropsychiatric problems. For example, people with cirrhosis may develop hepatic encephalopathy, wherein toxins in the blood result in impaired brain function.

But sustained virological response (SVR) to antiviral treatment - an undetectable viral load 12 weeks after completing therapy, which is considered a cure - may positively impact neuropsychiatric conditions and quality of life. Harpreet Kaur, PhD, and colleagues conducted a study to explore this association.

The researchers studied 385 people with hepatitis C; of these, 59% had HCV genotype 3. Three quarters were men, and 21% had liver cirrhosis. Participants were between ages 18 and 65 years and most had acquired HCV via unsterile injections, surgery or injection drug use.

At baseline and at 12 weeks after completing antiviral therapy, the participants underwent a series of tests that assessed mood, anxiety and quality of life as well as other cognitive factors.

Irrespective of cirrhosis status, they showed significant declines in cognitive function at baseline compared with healthy individuals and those with non-alcoholic fatty liver disease (NAFLD).

Some 91% of participants achieved sustained virological response; 88% of people with cirrhosis and 91% of people without cirrhosis were cured.

Those who attained SVR had less depression and anxiety along with improved concentration, reaction time, processing skills and visual, short-term and working memory. People who were not cured, however, saw either no improvements or a decline in these cognitive and mental health measures. When the researchers compared cognitive function in people with HCV versus those with NAFLD, the former performed more poorly.

The researchers noted that given the cumulative evidence of the safety of DAs and the efficacy of improving cognitive and neuropsychological and quality-of-life outcomes (irrespective of age and gender) shown in their study, future recommendations should focus on integrated universal HCV care to enable HCV elimination.

*Journal of Viral Hepatitis. <https://onlinelibrary.wiley.com/doi/10.1111/jvh.13668>*

## SAVE THE DATE

Bleeding Disorders Awareness Month is an opportunity for everyone to take part in a campaign and activities that raise awareness about haemophilia, von Willebrand disease and related inherited bleeding disorders throughout Australia.



# Health Updates

## Blood Vessel Abnormalities May Explain Gene Therapy Limitations

The effectiveness of liver-directed, viral-based gene transfer — the most used experimental gene therapy approach for haemophilia A — is significantly reduced in mouse models of haemophilia A relative to healthy mice, a study shows.

These findings suggest deficient levels of factor VIII (FVIII) — the blood clotting protein missing in haemophilia A — result in structural changes in specialized liver blood vessels that limits their ability to deliver genetic material to liver cells efficiently.

Further studies are needed to understand how FVIII deficiency leads to such blood vessel abnormalities and whether these changes may also be limiting liver-directed gene therapy in haemophilia A patients.

<https://ashpublications.org/bloodadvances/article/6/12/3729/484960/Defenestrated-endothelium-delays-liver-directed>

## Gene Therapy for Haemophilia B, Gets Priority Review

The Food and Drug Administration (FDA) will decide by late November whether to OK an experimental gene therapy for haemophilia by CSL Behring and partner UniQure. The FDA had accepted their application for approval of etranacogene dezaparvovec, to treat adults with haemophilia B.

Etranacogene dezaparvovec uses a recombinant adeno-associated viral vector to carry the Padua gene variant of factor IX. Clinical testing showed that a single dose treatment generates factor IX proteins that are 5 to 8 times more active than normal. 98% of trial patients were able to stop using prophylaxis and the treatment was found to be well tolerated.

<https://www.prnewswire.com/news-releases/fda-accepts-csl-behrings-biologics-license-application-for-etranacogene-dezaparvovec-for-priority-review-301553420.html>

## Project GYM: Physical Fitness Improves Wellbeing in Young Men With Haemophilia

A haemophilia-specific fitness training program was shown to improve psychological wellbeing and self-confidence in young men with haemophilia aged 18 to 25 years.

All study participants were provided an activity tracker and gym membership, and

were randomized to “gym only” or “gym and personal trainer” groups.

After analysis, the researchers found that there was a significant difference in motivation to exercise and the psychological wellbeing of young men with haemophilia improved during this study.

The results showed that training with personal trainers led to greater gym attendance and participants felt more supported compared with “gym-only” intervention.

<https://www.hematologyadvisor.com/home/topics/bleeding-disorders/hemophilia-project-gym-physical-fitness-improves-young-men-patients-risk/>

## Next-Generation Viral Load Test Detects HIV at Lower Levels

HIV viral load levels are usually considered “undetectable” if they are below 50 or 20 copies of the virus per millilitre of blood and researchers assessed the impact of switching to a newer PCR test which can detect the virus at lower levels, according to a study published in the Journal of Antimicrobial Chemotherapy.

The researchers looked at people living with HIV who had a viral load consistently below 50 copies (undetectable on the older test) for at least three years and another group with confirmed low-level viremia when the new test was used.

For both groups, the newer test found that 25% of people considered “undetectable” according to the older test had detectable virus.

<https://academic.oup.com/jac/advance-article-abstract/doi/10.1093/jac/dkac174/6595592?login=false>

## Screening of behavioural disorders in children with haemophilia

In a study of fifty boys (6-18 yo) with moderate and severe haemophilia the patients' age significantly correlated with anxious/depressed behaviour, somatic complaints, social problems, aggressive behaviour, internalizing behaviour, and total behaviour problems.

The most affected scale was aggressive behaviour. The least affected scale was attention problems. Behavioural disorders

in children with haemophilia are influenced by the age of the patient, the severity of the disease, the number of joints affected, the duration of haemophilic arthropathy, and the Haemophilia Joint Health Score.

The researchers said that this study supports the “negative effect of haemophilia on emotions and behaviour in patients with haemophilia.

<https://onlinelibrary.wiley.com/doi/10.1111/1756-185X.14352>

## Snake Venom-based Gel May Rapidly Reduce Bleeding

Researchers at UQ have used two proteins found in the venom of Australia's eastern brown and scaled viper to develop a thermoreactive hydrogel. The hydrogel rapidly and effectively forms stable clots and reduces bleeding even in the presence of an impaired blood-clotting disorder, such as haemophilia, a preclinical study shows.

Results showed there is five times less blood loss, and clots form three times more quickly when the venom gel is applied, compared to the body's natural process. These findings support the discovery of a new class of haemostatic agents that achieve formation of rapid and stable blood clots even in the presence of blood thinners.

<https://www.uq.edu.au/news/node/132251>

## Long-Acting Lenacapavir Shows Continued Promise

Lenacapavir, a long-acting anti-HIV drug injected every six months is still at the research stage, but after one year of treatment regimens including the new drug seem to be as effective as conventional antiretroviral regimens, in terms of bringing viral load down to an undetectable level.

Lenacapavir works in a different way from existing drugs. It interferes with the assembly and disassembly of the HIV capsid. Lenacapavir's very long half-life in the body suggests it has the potential for long-acting treatment if the developers can pair it effectively with other drugs that also only need to be taken twice a year.

<https://www.aidsmap.com/news/feb-2022/lenacapavir-shows-continued-promise-first-line-treatment-and-highly-resistant-hivThe latest results from people taking a new antiretroviral medication called lenacapavir continue to show promise.>

## 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.

### **World Hepatitis Day**

28th July 2022

### **OBE Men's Meeting**

Wednesday, 3rd August 2022  
Broncos Leagues Club

### **Women's Lunch**

Sunday, 7th August 2022  
Everton Park Hotel

### **Bridge to Brisbane Fundraiser**

**Run / Walk**  
Sunday, 28th August 2022

### **Youth Camp**

16 - 18 September 2022  
Emu Gully

### **Bleeding Disorders Awareness**

**Month**  
October 2022

### **Bunnings Fundraising BBQ**

8th October 2022

### **HFQ AGM**

Tuesday, 18th October 2022  
Nundah Library meeting room

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

# Damon Courtenay Memorial Endowment Fund applications now Open

The Damon Courtenay Memorial Endowment Fund was established by HFA in 1994 with financial support from the late Bryce Courtenay and the late Benita Courtenay in memory of their son, Damon.

Small grants are available to individuals or patient support organisations for the care, treatment, education and welfare of people affected by haemophilia or related bleeding disorders.

Anyone with a bleeding disorder or affected by a bleeding disorder who resides in Australia can apply and funding can be used for projects, services and/or care, or an activity aimed at improving the physical and emotional wellbeing and independence of the applicant.

An amount of \$20,000 is currently available for distribution. Applications will be considered on merit and there is no limit on the amount that you may apply for, however activities up to the amount of \$2,000 are more likely to be successful.



Damon Courtenay Memorial Endowment Fund Awards Now Open



### **Applications close 30 August 2022**

Download the application form from:

[haemophilia.org.au/  
support-services/awards/  
dcmet](http://haemophilia.org.au/support-services/awards/dcmet)

or email to [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
or call 1800 807 173.

## 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](mailto:info@hfq.org.au). You can be removed from the list at anytime.

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