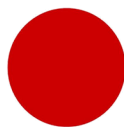


the

FACTOR



Haemophilia Foundation
Queensland

SUMMER EDITION

Issue 73



DECEMBER 2022

HFQ MEMBER MAGAZINE

FROM THE PRESIDENT



Hello everyone,

I hope you're all enjoying the warmer weather now.

My topic this time is ...**Hidden progressive liver disease.**

We have had several people recently with a bleeding condition, that have been cured of hepatitis C for some time, and have been shocked with the news their liver disease is at stage 3 or 4 (out of 5). Liver fibrosis or stiffness is where scarring of the liver has occurred - where changes in the microscopic structure of the liver has occurred because of inflammation.

These people felt well in themselves with no symptoms or abnormal physical signs. Since the news, they now understand the significant risk of further liver damage, and have chosen to abstain from alcohol and look into implementing a healthier diet.

These are great health choices as this may stop fibrosis progressing into significant fibrosis or cirrhosis and help prevent more serious complications and possibly cancer. So my message is - know your liver health today (even if you're now clear of Hep C and feel fine). Give your haemophilia treatment center a call and book an appointment.

To add to this important message - it's with great sadness to advise we have lost one of our members to liver disease. So don't be a statistic - **know your liver health today.**

Until next time...

A handwritten signature in cursive script that reads "Dave".

David Stephenson

President HFQ
president@hfq.org.au

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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 officer. 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
		Mr Engelbert Bets
		Dr Jodie Caris
		Mrs Leanne Stephenson
		Ms Shannon Gracey
		Mr Shannon Wandmaker

Acknowledgements

HFQ is grateful for the support of our patron: Her Excellency the Honourable Dr Jeannette Young AC 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 or at our Facebook page at 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 at QCH

QLD HAEMOPHILIA STATE CENTRES

CHILDREN'S CLINIC

PAEDIATRIC CLINIC STAFF (QCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown – Haematologist
 Dr Nathan Morgan – Haemophilia Fellow
 Joanna McCosker – Nurse Practitioner
 Tamara Shannen / Salena Griffin – Clinical Nurse
 Claire Bennett (Mon, Tues, Wed) - Physiotherapist
 Elise Mosey (Thur, Fri) – Physiotherapist
 Tiara Tan - Psychologist (Mon 1/2 day, Wed, Thurs)
 Lara Nicholson—Social Worker (Mon, Tues, Wed)

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 *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

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

January - March 2023

Some of the HFQ programs and activities already planned

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

JAN

HFQ Office Opens
Tuesday 3rd January

HFQ Summer Function
Sunday 22nd January
Venue TBA

Australia Day Public Holiday
Thursday 26th January

FEB

OBE's Monthly Lunch
Wednesday 1 February
Easts League Club

Women's Lunch
Sunday 5 February
Venue TBA

HFQ Board Meeting
Tuesday 21 February

Rare Diseases Day
Tuesday 28 February

MARCH

OBE's Monthly Lunch
Sunday 5 March
Fitzy's Waterford

HFQ Board Meeting
Tuesday 21 March

HFQ Community Camp
Friday 10th - Sunday 12th March
Sandstone Point Big 4

Bunnings BBQ
Saturday 25th March
Bunnings Ruthven St, Toowoomba North

WORLD HEMOPHILIA DAY
APRIL 17, 2023
#WHD2023

ACCESS FOR ALL

Prevention of bleeds

AS THE
GLOBAL
STANDARD
OF CARE

17th April 2023 is World Haemophilia Day. The theme of the event this year is “Access for All: Prevention of bleeds as the global standard of care”. Building on last year's theme, the call to action for the community in 2023 is to come together and advocate with local policy makers and governments for improved access to treatment and care with an emphasis on better control and prevention of bleeds for all people with bleeding disorders (PWBDs). This means the implementation of home-based treatment as well as prophylactic treatment to help those individuals have a better quality of life.

New Psych/Social Team at QCH

Welcome Lara

QCH has welcomed two new superstars to the psych/social team, Lara & Tiara.

Lara Nicholson is the new Social Worker and will be working Monday to Wednesday at Queensland Children's Hospital.

💧 Tell us a bit about yourself?

I'm a busy mum of two girls and love to travel, run, dance and stay active. I also love food and television, the beach and spending time with my family and friends.



💧 What do you do in your role at QCH?

I'm a senior social worker for Haemophilia and provide psychosocial support to children with bleeding disorders and their families, alongside the medical and allied health team here at QCH. The nature of support depends on a child and family's need and can change over time.

💧 How long have you been a social worker?

I've been a paediatric social worker here at QCH since 2015 and before that, worked with adults at a regional hospital for five years, so twelve years practice in total since graduating as a Bachelor of Social Work.

💧 Do you have a key message for children and families?

Living with a bleeding disorder, like any chronic potentially life-threatening medical condition, has an impact on a child and family. Families cope in all different ways and I continue to be inspired by you all. Even with advancements in medical treatment, children and families with bleeding disorders can face difficulty with various aspects of their lives and social work is here to help with this however we can - so just reach out.



Lara is available at Queensland Children's Hospital Monday 8am - 12.30pm, Tuesday 8am - 4pm and Wednesday 8am - 4pm. She can be contacted on 0438 792 063.

Welcome Tiara

Tiara Tan is the new psychologist at QCH

Tell us a bit about yourself?

I enjoy working with children, young adults and their families and supporting them through their life's journey.

On my days off, I love spending time with my family and friends, baking and crafting, volunteering at my kids' school canteen and school swimming.

What do you do in your role at QCH?

I am a senior psychologist on the Haemophilia Team at Queensland Children's Hospital.

I work alongside senior medical officers - haematologists, nurse practitioner, clinical nurses, physiotherapists, social worker and other allied health clinicians to support families who received a diagnosis of haemophilia via face to face, online consultation and outreach clinic. I work collaboratively with families to meet their needs and provide support accordingly.

How long have you been a psychologist?

I have been a psychologist since 2003. I am currently endorsed as a Educational and Developmental Psychologist. I was working predominantly in Child and Youth Mental Health though have experience also at Disability Services Queensland, Drug Diversion Program, Ed-LinQ and private practice.



Do you have a key message for children and families?

Living with a family member with chronic illness requires being flexible, adjusting and adapting to the new normal. I admire the resiliency and strength of families faced with health challenges. I have learnt a lot from them over the years. Some general tips could be:

- 💧 Taking care of yourself as a parent in order to have the ability to care for your child well.
- 💧 Having good supportive social network.
- 💧 Being open to the care and consideration of other professionals who can best support the family in their journey in navigating the best outcome for the family.
- 💧 Having the balance of taking one day at a time and being organised and planning ahead e.g.: utilise a visual calendar for medication, appointments etc.

Tiara is available at QCH Monday (1/2 day), Wednesday & Thursdays. She can be contacted on 0438 792 063.



Community Camp



Community Camp 2023 is shaping up to be the biggest and best one yet!

REGISTER NOW TO AVOID MISSING OUT!

Registration deadline: Friday 25th Jan 2023

An Update on Gene Therapy

New Gene Therapy Vectors Better at Targeting Liver: Hem B Mouse Study

Two new gene therapy vectors designed for liver diseases show promising effects in a mouse model of haemophilia B, according to a recent study.

The study, “Adeno-associated virus serotype 2 capsid variants for improved liver-directed gene therapy,” was published in *Hepatology*.

Hemophilia B is caused by mutations in the gene that provides instructions for making the clotting protein factor IX (FIX). The objective of gene therapy for haemophilia is to deliver a healthy copy of the mutated gene to cells in the body — particularly in the liver, which is where most clotting factors are produced.

Gene therapies use viral vectors to deliver genetic payload

To deliver the genetic cargo, gene therapies commonly use viral vectors — the viral envelope, called the capsid, is wrapped around the genetic payload, and when the capsid binds to a cell, it transfers the cargo inside. Most gene therapies in development specifically use vectors engineered from a family of viruses called adeno-associated virus (AAV).

In the study, a team led by scientists in Germany set out to create new AAV-based vectors that would be better at targeting the liver.

To do this, the researchers used a peptide display library approach. Put simply, they started with the capsid of the AAV2 virus as a foundation. Then, the researchers used genetic engineering to make a bunch of new forms of the capsid with slight differences in the molecular structure.

Finally, the researchers screened all the potential capsids in the library in a mouse model, looking specifically for vectors that could effectively deliver cargo to the liver, but not to other tissues. The mice had functional immune systems; an antibody-driven immune response against the viral vector can reduce the effectiveness of gene therapy.

“In our work, we looked for AAV variants that, on the one hand, target the liver precisely and do not stray into other tissues and, on the other hand, escape the neutralising antibodies,” Nadja Meumann, PhD, a postdoctoral researcher at Hannover Medical School and first author of the study, said in a press release.

From this screen, the researchers identified two candidate vectors, which they dubbed MLIV.K and MLIV.A.

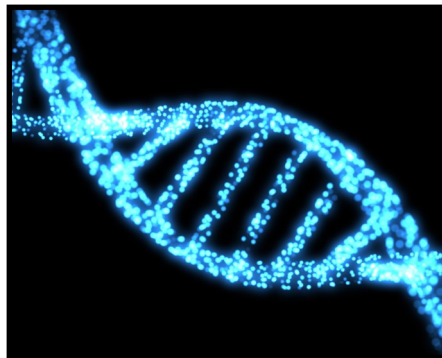
In a battery of experiments, the researchers demonstrated that these two vectors were better at delivering genetic material to liver cells than the unmodified AAV2 vector. Notably, the two vectors were able to effectively deliver cargo to mouse cells and human cells, both in cell experiments and in live animal experiments.

“This cross-species application possibility is very important for the development of new therapeutic strategies, because it enables the necessary preclinical trials in the mouse model and their transfer to the later clinical trials in humans,” Meumann said.

The scientists then tested these vectors in a mouse model of haemophilia B.

Results showed that an unmodified AAV2 vector could restore clotting activity, with FIX activity increased to 100% of the typical physiological range. The MLIV.K and MLIV.A vectors also restored clotting activity — but FIX activity was substantially higher, up to 400% of the normal physiological range at the same dose.

Although more studies are needed before therapies based on these vectors can be tested in people, the researchers said the development of these new vectors “may represent a valuable advance in the field of liver-directed gene therapy.”



Edited for size from <https://hemophilianewstoday.com/news/new-gene-therapy-vectors-promise-hemophilia-b-mouse-model/>

BDAM Recap

This year was the first year the 'Bleeding Disorders Awareness Week' was extended to the entire month of October. Here at HFQ, we held a few events to celebrate the month so here's a little recap of what we got up to.

Government House Event

Thursday 6th October

We were invited to kick off Bleeding Disorders Awareness Month with an event at Government House, which also presented



the opportunity to officially welcome Her



Excellency the Honourable Dr Jeannette Young AC PSM, Governor of Queensland as our new patron.

This year, we offered the opportunity for members to nominate their GP

to attend and we were thrilled to have several GP's in attendance who were excited to meet with other members of the community and hear of their personal experiences with a bleeding disorder. A fantastic night for all and we thank Dr Young for hosting us. They even turned Government House red for us!

Bunnings BBQ - Rothwell

Saturday 8th October

Another very successful BBQ at Bunnings Rothwell. Thank you to all our wonderful volunteers who attended and all those who popped in and bought a sausage.



'Blood Day' at Mother Duck Childcare

Wednesday 26th October

One of our members, Lisa Bowdler, organised a 'dress red day' at her son, Tommy's daycare for Bleeding Disorders Awareness Month.



They asked all the children to dress in red and had a donation tin at the front desk.

There was colouring in and the children made red cupcakes. The children couldn't pronounce haemophilia so they dubbed it 'blood day'.

RBWH HTC BBQ

Thursday 27th October

The treatment centre staff at RBWH invited us to help them host a fundraising BBQ at the hospital as a joint celebration of Bleeding Disorders Awareness Month and the treatment centre's 21st birthday. The hospital staff were all very excited for a sausage and to chat about all things haemophilia.

Remembrance Ceremony & Plaque Unveiling

Saturday 29th October

To round off BDAM, we hosted a ceremony to unveil the remembrance plaque we recently had commissioned. This ceremony allowed time for people to reflect on those in our community we had lost and share memories of their own experiences growing up with a bleeding disorder.

Nose Bleeds

Do's & Don'ts

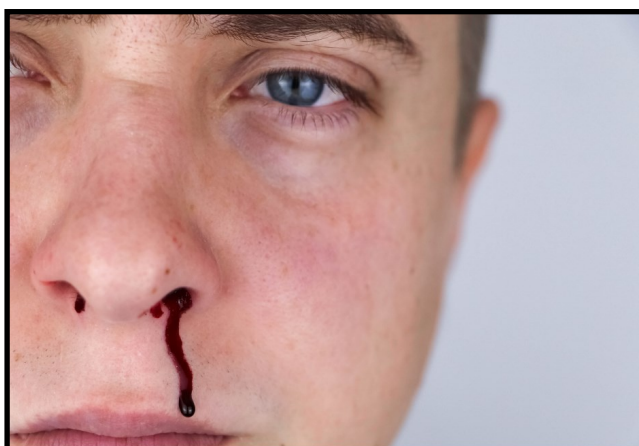
Nosebleeds can be annoying and sometimes scary, especially if you have a bleeding disorder. But they're seldom cause for alarm. With many tiny, delicate blood vessels, the nasal membranes are easily irritated. Allergies, certain medications and dry air can all aggravate those membranes and lead to nosebleeds.

Most of the time, nosebleeds don't require emergency medical attention and can be treated at home. However, you should seek medical care if you have a prolonged nosebleed—one that lasts for several hours and that does not respond to pressure or other home remedies—or frequent smaller nosebleeds that stop easily but return for weeks.

Here are a few tips on what to do if you have a nosebleed

DO:

- Pinch the bridge of the nose and lean forward slightly, holding pressure for a minimum of 10 minutes. You can use nose clamps to apply pressure, but you shouldn't leave a clamp on for more than 10 minutes.
- Time the nosebleed and record the information to share with your care provider.
- Talk to your medical care team about the best products for preventing nosebleeds. Options include saline sprays, creams or gels that prevent the breakdown of clots, and lubricating creams and ointments.



- Avoid secondhand smoke and other triggers, such as allergens, or hot, dry air. If dry air seems to be a trigger, you can counteract it by using a humidifier.
- Rest after a nosebleed to avoid a recurrence.
- You should avoid vigorous activities like sports, running, and other activities that cause your blood pressure to increase.

DON'T:

- Lie flat or recline during a nosebleed. Blood could run down your throat; swallowing blood can upset your stomach and cause vomiting.
- Pick or vigorously blow your nose. Both can irritate the delicate nasal passage. Blowing your nose during a nosebleed can make the bleeding worse or cause bleeding to restart after it's stopped.
- Bend over for a long period of time.
- Eat warm and spicy food—which can cause blood vessels to dilate—on the day of a nosebleed.

Edited for size from source: <https://hemaware.org/mind-body/nosebleed-dos-and-donts>

Hello from the new Manager

My name is Lauren Green (nee Albert) and I have recently stepped into the very big shoes Graham has left for me, as Manager of HFQ.



Winning the Matthew Schneider Youth Award in 2003

I have been involved with HFQ since I was a very young girl, doing fundraisers at my school from as young as 8 or 9, so to say, this is a dream come true getting to do something I've always been so passionate about as my day job is not understating things.

I first became involved with the haemophilia community when my younger brother was diagnosed with severe haemophilia A as a baby. This came as huge shock to our entire family as we had no knowledge of any family history.

My parents quickly spent the following months reading everything they could about the condition and, not long after, became active members of the HFQ board for many years, even serving as President & Secretary for a while.

We later discovered that my mother and I both carry the gene and I have since been diagnosed with mild haemophilia A myself.



My three daughters, Ruby (11), Layla (3) & Ivy (1) and I

I now have three beautiful daughters, two of which have mild haemophilia with varying levels.



I have served as a HFA Youth Delegate, Co-Chair of the HFA Youth Committee, general board member and board Secretary for HFQ before stepping into this role. So it's safe to say most of you are probably already familiar with me as I've been around a while!

I have always been a passionate supporter of raising awareness for all bleeding disorders, not just haemophilia, but have a special interest in busting the myths around women with haemophilia A.

I would like to take this opportunity to thank the members of the community who have taken the time to welcome me to the role so far. I am very excited to be working with Samantha, our wonderful Admin Officer, and together help bring awareness to our community and organize some fantastic events in the coming months.

On that note, please make sure to RSVP for our family camp in March 2023 as this one is going to be our biggest and best yet!

If you have any suggestions or feedback on how we can better connect with, or help support you, please do not hesitate to contact me at the office or on the HFQ phone 0419 706 056.



HFQ Youth Camp 2016 as a Youth Leader

Lauren

Iron Infusions for Women with Haemophilia

Iron deficiency is a common cause of anaemia. According to the Cleveland Clinic, *"If you have anaemia that is not treated, it could lead to an arrhythmia (irregular heartbeat), an enlarged heart or heart failure. You are also at greater risk of getting infections and becoming depressed."*

"Iron deficiency and bleeding both have underlying causes, which must be identified. One unifying diagnosis is an underlying bleeding disorder," Sandoval said. He stressed that a haematologist should check women with iron deficiency for a bleeding disorder.

Iron Pills

"My doctors prescribed me iron pills for iron-deficiency anaemia for much of my life. I wouldn't say I liked the pills. An upset stomach and constipation were just some of the side effects. I would take them three times a day, but they made very little difference. My ferritin level would stay between 1–10 mcg/L, which is below the normal range for women of 11–307 mcg/L."

When I switched haemophilia treatment centres in January 2020, my new haematologist suggested an iron infusion. My ferritin was low, and I was periodically anaemic, despite the iron pills. I was grateful for the suggestion and looking forward to trying something different."

The Iron Infusion

"An iron infusion delivers iron directly into your bloodstream.

At the first appointment, the nurses at the infusion clinic couldn't find a vein. Two nurses used me as a pin cushion and gave up. My tiny veins like to roll. Two other women were also designated a hard stick. We marched across the street to the radiology department, following the medical assistant like ducks in a row.



Besides being a little achy the following day, I had no side effects.

The best news of all? Since the iron infusions, I am not iron deficient for the first time in my life. My ferritin level has held above 50 mcg/L for two years, and I am not anaemic.



If you are a woman with a bleeding disorder and have anaemia or iron deficiency, I suggest you speak with your haematologist about an iron infusion. It certainly helped me."




Edited for size from 'Iron Infusions May Be Beneficial For Women With Hemophilia' - by Jennifer Lynne.

Source: Hemophilia News Today. <https://hemophilianewstoday.com/columns/iron-infusions-may-be-beneficial-women-hemophilia-iron-deficiency>

According to the 2011-2012 National Nutrition & Physical Activity Survey, 40% of women aged between 14 and 50 years of age have inadequate intakes of dietary iron.

The **estimated average requirement (EAR)** for iron, used to estimate the prevalence of inadequate intakes within a population group, is 8mg per day for females aged 14 to 50 years.²

While the **recommended dietary intake (RDI)**, used to evaluate whether iron intake in an individual's diet is adequate, for females is:

-  15mg per day aged 14-18 years
-  18mg per day aged 19-50 years
-  27mg per day during pregnancy

Source: National Nutrition & Physical Activity Survey 2011-12 <https://medicalrepublic.com.au/gettingenoughironisachallengeforwomen>

Famous People with Bleeding Disorders

Having a rare disorder like haemophilia means you don't often get to see people who share your condition in the news or the glossy magazine covers.

But did you know there is quite a few famous folks who have bleeding disorders from athletes, to movie stars, even a Queen!

Richard Burton



Although it was not widely known that Richard had haemophilia, he set up the Richard Burton Haemophilia Fund in 1964. Richard Burton was a seven-time Oscar-nominated British actor and on-off husband to Elizabeth Taylor. During his career, he starred in 61 films and 30 plays. He died in 1984 from a stroke at the age of 58.

Alexandrea Borstein Best known for being the voice of *Family Guy*'s Lois Griffin, Alexandra is a carrier of haemophilia. She is an active advocate for the disorder. She has also appeared in films such as *Barbie*, *Casper* and *Power Rangers*.

Jesse Shrader Jesse was a professional baseball player with severe haemophilia A. Despite having to ice his arm after every game, he had a successful career at an elite level for many years.

Queen Victoria



Queen Victoria was a carrier of the gene for Haemophilia B. This was passed to two of her daughters and one of her sons.

This is why Haemophilia is often referred to as the 'Royal Disorder'. Prince Leopold, her son, died after a fall in 1884.

Barry Haarde is the only man with haemophilia, HIV & hepatitis C to have cycled across America... twice! He is a famous cyclist who spends his spare time raising awareness and advocating for those with the condition, as well as raising funds to support access to medication for those in developing countries.



Older Male Patients Report Higher Rates of Diabetes Depression & Anxiety

Older men with haemophilia report higher rates of anxiety, depression, and diabetes compared with the general U.S. population, a recent study reported.

However, rates of heart-related health problems, such as myocardial infarction (heart attack) and coronary heart disease, were lower in haemophilia patients than in the general population.

The study, "Prevalence of comorbid conditions among older males with haemophilia receiving care in haemophilia treatment centres in the United States," was published in the journal *Haemophilia*. With new advances in care, people with haemophilia are living longer, healthier lives than ever before. As more and more people with haemophilia reach older age, it is expected that there will be more haemophilia patients with age-related comorbidities (co-occurring health conditions).

Co-Morbidities in Older Patients

To learn more about comorbidities common in older haemophilia patients, a quartet of scientists conducted an analysis of data collected across more than 100 haemophilia treatment centres in the U.S.

The data were collected through a public health surveillance system called Community Counts, launched via a partnership between the Centres for Disease Control and Prevention (CDC), the American Thrombosis and Hemostasis Network (ATHN), and the U.S. Hemophilia Treatment Centre Network (USHTCN).

In total, the analysis included data from 2,237 haemophilia patients, ages 45 and older, who were seen at haemophilia treatment centres from 2013 through 2021. About three-quarters had haemophilia A, while the rest had haemophilia B. About three in four had a history of hepatitis C infection, while just over 24% had a history of human immunodeficiency virus (HIV) infection. All of the patients were male.

Depression & Anxiety

Compared with the general population of U.S. males, a significantly higher proportion of men with haemophilia had diabetes (24% vs. 15.8%),

anxiety (18.5% vs. 9%), or depression (21.9% vs. 11.2%). These trends were generally consistent in further analyses that divided patients by age into "middle-aged" (45–64 years) and "elderly" (ages 65 and older). In particular, rates of anxiety and depression were much higher in haemophilia patients, researchers noted.

"Males with haemophilia had a much higher prevalence of anxiety and depression in both age groups compared to the general population. The prevalence of these conditions was more than double among middle-aged and about one-

third higher among older males with haemophilia," they wrote.

The team added that the high rate of mental health problems "highlights the underlying psychological burdens" that come with living with haemophilia, and they called for further work to provide support to patients struggling with these issues.

Diabetes in Haemophilia Patients

Reasons for the higher incidence of diabetes among haemophilia patients are still unclear, though it may be potentially linked to a higher incidence of hepatitis C infection or obesity. Researchers said they are not aware of any prior research linking haemophilia and diabetes.

"Additional investigation is needed to understand why the haemophilia population has a higher rate of these comorbidities and how they affect overall health and wellbeing," they wrote.

Edited for size from Hemophilia News Today
<https://hemophilianewstoday.com/news/older-male-patients-report-higher-rates-diabetes-depression-anxiety-hemophilia/>



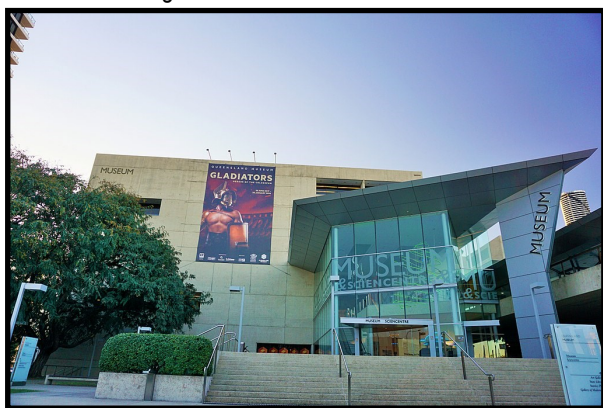
5 Boredom Busting School Holiday Ideas

School holidays are fast approaching and soon the house will be filled with the chorus of 'I'm BORED!'

Finding activities that are not only safe to do with haemophilia but also fun for the kids can be tricky so we've included a few to help cure the holiday boredom.

Visit a museum or library

The State Library of Queensland and the Queensland Museum, both located in South Brisbane, host a range of free school holiday activities for all ages.



The State Library puts on free workshops including craft, STEM, music and performance so there is something for everyone.

The Queensland Museum is also host the SparkLab at the Science Centre. Although there is a cost included with this one, it's a great way to expand little minds. Why not make a day of it with a picnic by the water afterwards.

Bricks 4 Kidz

If your kids are Lego mad, the Bricks 4 Kidz is the place to be to get those creative minds working! Bricks 4 Kidz operate all across Queensland and locations can be found on their website at www.bricks4kidz.com.au



Play Centres

A play centre is a great way to beat the rainy day boredom when the kids are stuck inside and driving you mad.

Boasting something for the babies all the way up to tweens, it's the perfect gloomy weather solution. Most include cafes so it's a great way to sit and have a moment of peace with a cup of coffee while the kids run wild. The added bonus of lots of soft play and padding makes it a safer option too.



See a Show!



There is an extensive list of shows catered to families available on both the QPAC and Brisbane Arts Theatre websites.

<https://www.qpac.com.au/>

<https://www.artstheatre.com.au/>

Local Council Activities

Local councils put on a range of school holiday activities. Brisbane City Council currently have over 225 local activities planned for the holidays. Check out your local council's website or social media for a great list to start planning your holiday adventures!

Managing Bleeding Disorders Requires Attention To Mental Health

It's easy to spot physical damage, such as swollen joints, nosebleeds, limps, and bruises, when one suffers from a bleeding disorder, but the psychological and emotional damage that may result is not as easy to see or treat.

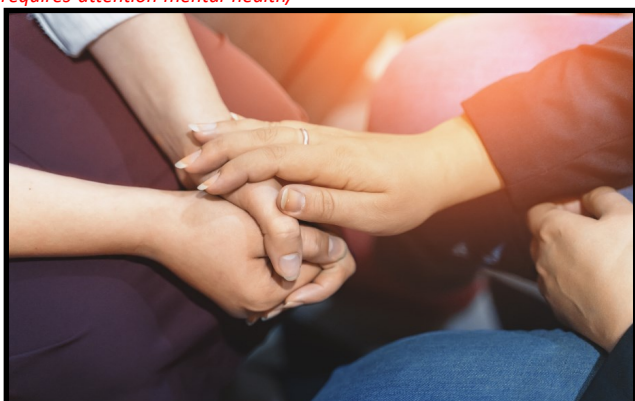
A U.S. survey of haemophilia patients, published a few years ago in the journal Patient Preference and Adherence, concluded that *93% of survey participants experienced depression, while 92% had anxiety*. Additionally, *28% reported having moderate to severe depression, and 13% had moderate to severe anxiety*.

Post-traumatic stress disorder

In the '70s and '80s, something our community refers to as the "haemophilia holocaust" changed the lives of everyone who experienced it. In a recent interview, bodybuilder L.A. Aguayo, who has severe haemophilia, told me, "Those that lived through the '70s and '80s and were diagnosed with AIDS and hepatitis from contaminated blood products went through the hardest time. We have a responsibility to keep pushing and sharing with others and creating change. There are still so many resources that we need as a community to live a fulfilling life."

Dr. Eric Russ, a clinical psychologist with expertise in assessing and treating traumatic stress, recently held a webinar on trauma and PTSD for the Hemophilia Federation of America. According to Russ, healthy ways to cope with stress include breathing deeply, taking breaks, and setting boundaries. Other tactics include creating routines and schedules, connecting with important people in your life, seeking help when needed, and building "meaning-making" into your day in the form of advocacy or education.

Edited for size from Hemophilia News Today. Article by Jennifer Lynne. <https://hemophilianewstoday.com/columns/managing-bleeding-disorders-requires-attention-mental-health/>



9 Strategies to manage stress and anxiety

Slow breathing. When you're anxious, your breathing becomes faster and shallower. Try deliberately slowing down your breathing. Count to three as you breathe in slowly, then again as you breathe out slowly.

Progressive muscle relaxation. Find a quiet location. Close your eyes and slowly tense and then relax each of your muscle groups from your toes to your head. Hold the tension for three seconds and then release quickly.

Stay in the present moment. Anxiety can make your thoughts live in a terrible future that hasn't happened yet. Try to bring yourself back to where you are. Practising meditation can help.

Healthy lifestyle. Keeping active, eating well, going out into nature, spending time with family and friends, reducing stress and doing the activities you enjoy are all effective in reducing anxiety and improving your wellbeing.

Take small acts of bravery. Avoiding what makes you anxious provides some relief in the short term, but can make you more anxious in the long term. Try approaching something that makes you anxious, even in a small way. The way through anxiety is by learning that what you fear isn't likely to happen – and if it does, you'll be able to cope with it.

Challenge your self-talk. How you think affects how you feel. Anxiety can make you overestimate the danger in a situation and underestimate your ability to handle it. Try to think of different interpretations to a situation that's making you anxious, rather than jumping to the worst-case scenario. Look at the facts for and against your thought being true.

Get to know your anxiety. Keep a diary of when it's at its best – and worst. Find the patterns and plan your week – or day – to proactively manage your anxiety.

Learn from others. Talking with others who also experience anxiety – or are going through something similar – can help you feel less alone. Visit our Online Forums to connect with others.

Be kind to yourself. Remember that you are not your anxiety. You are not weak. You are not inferior. You have a mental health condition. It's called anxiety.

Edited for size from <https://www.beyondblue.org.au/the-facts/anxiety/treatments-for-anxiety/anxiety-management-strategies>

Natural Remedies for Chronic Pain

Living with a bleeding disorder often comes with chronic pain. Over the counter medicines such as ibuprofen are effective pain relievers, but long-term use can cause side effects. Prescription medications may be addictive and have even more adverse side effects. So what are the best natural ways to relieve pain?

Hot & Cold Therapy

Hot and cold therapy is a common and safe technique to reduce pain.

Heat can help relax the muscles and dilate the blood vessels. It can also promote healing after an injury.

Cold therapy reduces blood flow and reduces inflammation that causes pain. It often involves applying an ice pack wrapped in a towel to the skin.

Ginger

Ginger, or *Zingiber officinale*, is a root that shows promise as a natural pain reliever.

A 2015 systematic source found that ingesting 2 grams of ginger per day modestly reduced muscle pain from resistance exercise and running when people took it for at least 5 days. The researchers also suggest that ginger may accelerate recovery and reduce inflammation related to exercise.

Always talk to a doctor before taking any new supplement. Dietary supplements can have side effects and may interact with existing medication.

Acupuncture

Acupuncture is an alternative therapy that advocates believe can help reduce pain. Recent research supports these beliefs.

The National Centre for Complementary and Integrative Health (NCCIH) Trusted Source state that acupuncture can help with certain types of pain, including:

- low back pain
- neck pain
- osteoarthritis or knee pain

CBD Oil

Medicinal cannabis and cannabidiol (CBD) are increasingly common pain treatments.

A 2017 study states that cannabis may ease neuropathic pain, but not pain due to fibromyalgia, headaches, or rheumatoid arthritis.



In addition, cannabis for medicinal purposes may not be legal everywhere. High doses can trigger side effects, so it is best to check with a health professional before using cannabis CBD for pain relief.

Massage

Massage is a type of soft-tissue manipulation. People may benefit from this technique when used with other pain management treatments, such as physical therapy and pain medication.

The benefits of massage include:

- relaxation
- increased flexibility
- reduced inflammation
- improved posture
- improved circulation
- reduced stiffness

A 2007 study on massage found that it may be effective for lower back pain. However, there is mixed evidence from examining its benefits for other chronic pain types.

Edited for size from <https://www.medicalnewstoday.com/articles/pain-management-techniques>



Health Updates

Pregnancy & Childbirth in Women with Bleeding Disorders

Reproductive-age women with bleeding disorders (BDs) are underdiagnosed and understudied, despite their increased risk for adverse health outcomes and pregnancy complications. This study examines pregnancy outcomes and obstetric complications of Utah women with BDs

<https://onlinelibrary.wiley.com/doi/full/10.1111/hae.14688>

Proof of Concept and Feasibility of a Blended Physiotherapy Intervention

Mim8, an investigational next-generation therapy to prevent bleeding episodes in people with haemophilia and administered as an under-the-skin injection, is safe and well-tolerated at multiple doses, according to data from the Phase 1/2 FRONTIER1 trial presented at this year's International Society of Thrombosis and Haemostasis Annual Congress, held July 9–13, in London,

Exercise therapy, including resistance exercises, isometric exercises, bicycle ergometry, treadmill walking and hydrotherapy, seem to have a positive effect on several clinical outcomes, but a preferred exercise intervention for persons with HA is still undecided.⁵⁻⁷ We developed a blended physiotherapy intervention for persons with HA: e-Exercise HA.⁸ Blended physiotherapy integrates face-to-face physiotherapy with a smartphone application.⁹ It has the potential to support behavioural change and creates the opportunity to reach patients who have limited access to (specialised) physiotherapy. Furthermore, it could be used to support primary care physiotherapists, who are less experienced in treating persons with HA. <https://onlinelibrary.wiley.com/doi/full/10.1111/hae.14690>

Haemophilia: Training the immune system to be tolerant

Hemophilia A patients have a defect in a protein that is important for blood clotting: factor VIII. Most patients therefore receive an intravenous injection of the functional clotting factor every few days as treatment. But frequently, and especially at the start of treatment, the immune system recognizes the injected agent as foreign to the body and attacks it. This is the most serious complication of haemophilia treatment because factor VIII can then no longer work.

<https://idw-online.de/de/news803606>

Tribunal on Ireland's infected blood scandal led to treatment 'culture change'

A landmark tribunal into the use of contaminated blood products in Ireland led to a "culture change" in how patients were treated, the UK inquiry has been told.

Brian O'Mahony, chief executive of the Irish Haemophilia Society, said Ireland's Lindsay Tribunal was also "hugely important" in advancing the general public's understanding of what had happened to people treated with infected blood.

<https://www.independent.co.uk/news/uk/ireland-irish-patients-infected-blood-inquiry-theresa-may-b2220506.html>

Therapeutic joint aspiration relieves pain significantly in acute haemarthrosis of knee Joint

Hyaluronic Acid Eases Joint Damage of Haemophilia

<https://medicaldialogues.in/orthopaedics/news/therapeutic-joint-aspiration-relieves-pain-significantly-in-acute-haemarthrosis-of-knee-joint-101847>

Report Details Rare Case of Acquired Haemophilia A Secondary to Immune Checkpoint Inhibition

A case report published in *JTO Clinical and Research Reports* chronicles a patient who acquired haemophilia A during treatment with an immune checkpoint inhibitor (ICI). This rare immune-related adverse event (irAE) has only been previously reported 4 times in the context of ICI treatment.

Acquired haemophilia A (AHA) occurs when a patient develops clotting factor VIII (FVIII) autoantibodies but has no history of bleeding disorders. Haemophilia is characterized by spontaneous bleeding events that may be life threatening, and up to half of AHA cases may have unknown origins.

While it is rare, AHA has been associated with autoimmune or inflammatory diseases and other conditions. The case report marks the fifth time AHA in the context of ICI use has been documented.

<https://www.ajmc.com/view/report-details-rare-case-of-acquired-hemophilia-a-secondary-to-immune-checkpoint-inhibition>

Marstacimab Reduces Patients' Bleeds, Even With Inhibitors

Treatment with marstacimab, an experimental antibody-based therapy that binds to and blocks the tissue factor pathway inhibitor (TFPI), reduced the number of bleeds in patients with severe haemophilia regardless of whether patients had haemophilia A or B, or had inhibitors. These results were reported in the British Journal of Haematology.

Two patients experienced side effects that were sufficiently severe that they left the study (one had high blood pressure, the other had a large drop in their levels of fibrinogen).

Blood tests revealed both TFPI and peak (highest-level) thrombin increased with the treatment, suggesting effective targeting of TFPI which could make Marstacimab a possible alternative to replacement therapy.

<https://onlinelibrary.wiley.com/doi/10.1111/bjh.18420>

Important Dates for HFQ Members

OBE's End of Year Lunch

Sunday 11th December 2022
Yellowfin Restaurant

HFQ Summer Function

Sunday 22nd January 2023
Venue TBA

OBE's Monthly Lunch

Wednesday 1st February 2023
East's Leagues Club

Women's Lunch

Sunday 5th February 2023
Venue TBA

OBE's Monthly Lunch

Sunday 5th March 2023
Fitz's Waterford

HFQ Community Camp

Friday 10th - Sunday 12th March
Sandstone Point Big 4

Bunnings BBQ

Saturday 25th March
239-297 Ruthven St
Toowoomba North

Please call HFQ on **0419 706 056**
for more info on any of these
events and other activities.



The HFQ office staff are taking a break from the office over the holiday period but you can still get in touch if you need us, via the office mobile 0419 706 056. Our last day in the office will be Wednesday 22nd December 2022 and we will return to the office on Tuesday 3rd January 2023.

We wish all our readers a safe and happy holiday and would like to thank you for your ongoing support in 2022. We look forward to seeing you at our events coming up in 2023.

*Merry Christmas & Happy New Year
Lauren & Samantha - HFQ Staff*

About The 'H' Factor

The 'H' Factor is published four times each year by HFQ by the HFQ manager. 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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