



From the President



Hi everyone, time is flying with Christmas and the New Year almost on us (a special time for those with Christmas disease- Haemophilia B).

This edition I wanted to bring you

up to date on what has happened in Fiji. You will recall the generosity of the Qld bleeding disorders community, where sufficient funds were raised to provide a fridge and generator to store the donated factor from America. This has now happened, and to the great astonishment of the local Fiji haemophilia foundation. They are eternally grateful and asked me to pass on a great big thank you - so well done to all. This has already been effective as there have been several power outages - one affecting all of the main island for a significant time.

In addition to this I met with the local president, several doctors as well as attended a rotary

event. Much discussion was had re the Fiji community and the myriad of issues facing this 3rd world country. It was clear that more education for medical staff as well as other government organisations is badly needed. One disturbing story was of a donated factor delivery being held by local customs - where they would not release the factor as they thought there was something dodgy going on like the foundation selling the factor - regardless of all the evidence presented to them.

Last year when I was on holidays in Fiji there was talk of World Federation Of Haemophilia coming to register the country and start work to improve things.

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Presidents Message *continues*

Asking a few questions about this kicked off some action and now there is a delegation coming in December which is great. I also attended a meeting of their foundation and provided a detailed summary review document they can use - listing community, foundation and other issues / ideas which is assisting their thinking / planning.

Make no mistake - behind the 5 star resorts there is significant poverty (with just under 1 million people ~28% live below the poverty line), where the wages are in the order of \$1.8 to \$5 an hour, where some are paid for 8 hours but have to work 12 or more hours. Life is tough, so thank you again to the Qld Community for making a difference to those with bleeding conditions in Fiji.

See you in the next addition, have a safe Xmas and new year.

David Stephenson
President HFQ
president@hfq.org.au

Your Fundraising Dollar at Work

Virtual reality experiences may help reduce procedural anxiety at the Queensland Children's Hospital.

There are now several research trials using immersive virtual reality experiences played on Oculus headsets that show the efficacy of therapeutic virtual reality (VR) as an effective, non-pharmacological treatment modality to help treat anxiety disorders, support physical rehabilitation and distract patients during factor infusion and wound care.

Recently the QHC asked HFQ for help in purchasing one of these headsets and the research proven software to help kids with procedural anxiety. Virtual reality creates an immersive distraction that changes the way the mind experiences pain, offering a drug-free supplement to traditional pain

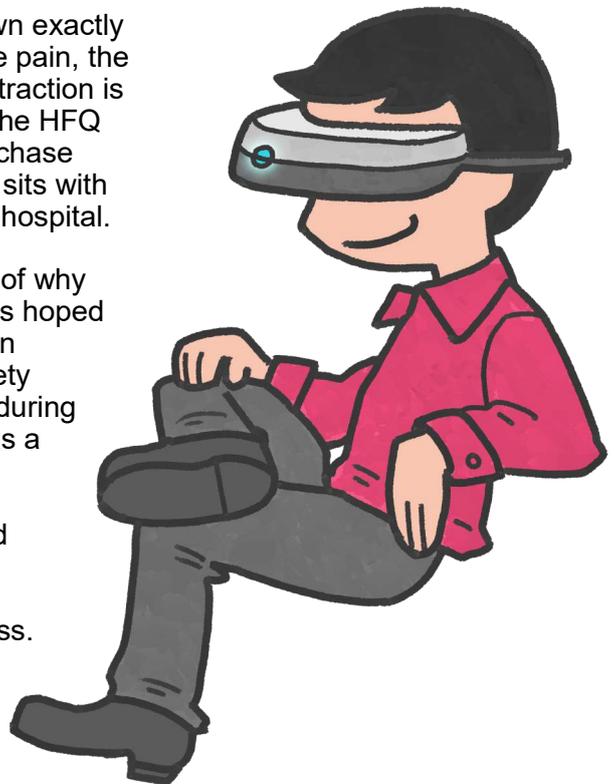
and anxiety management techniques.

While it remains unknown exactly how VR works to reduce pain, the benefit of immersive distraction is sufficiently proven that the HFQ board approved the purchase and the equipment now sits with Moana at the children's hospital.

This is a great example of why we fundraise money. It is hoped that children with or even without procedural anxiety may find the use of VR during port or venous access as a fun and positive pain management tool to ultimately help them and their parents to manage the factor treatment regimen with less distress.

Please contact
Moana at the QCH

if you would like further information.



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

ABOUT HFQ

The Haemophilia Foundation of Queensland Inc. (HFQ) provides representation, health promotion, education and support for people in Queensland affected by inherited bleeding disorders. The Foundation receives a grant from Qld Health and employs a part time manager and an administration assistant. It is guided by a Board of Directors which meets monthly.

We can be contacted on mobile 0419 706 056; or via email (info@hfq.org.au) or post at PO Box 122 Fortitude Valley, Qld 4006

HFQ provides financial members with support and benefits, including subsidies on:

-  **Medic Alert bracelets (50% discount)**
-  **Electric Shavers (up to \$75 off)**
-  **Supportive footwear (75% off)**

HFQ Management Committee

President	Mr David Stephenson
Vice President	Mr Robert Weatherall
Secretary	Ms Lauren Albert
Treasurer	Mr Adam Lish
Members	Mrs Belinda Waddell
			Mr Charles Eddy
			Dr Jodie Caris
			Mrs Leanne Stephenson
			Mr Mike O'Reilly
			Mr Mike Holloway
			Ms Shannon Gracey

HFQ Delegate to HFA

Mr Adam Lish

Acknowledgements

HFQ is grateful for the support of our patron: His Excellency the Honourable Paul de Jersey AC .

HFQ programs and services are funded by the Queensland Government.

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

Internet

Find us on the web at www.hfq.org.au or at our Facebook page at www.facebook.com/HFQLD

QUEENSLAND HAEMOPHILIA STATE CENTRES

CHILDREN'S CLINIC

PAEDIATRIC CLINIC STAFF (QCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown – Haematologist
 Haemophilia Fellow — Dr Antoinette Runge
 Haemophilia Registrar – Dr Chintaki (Chinithi) Jayasekera
 Joanna McCosker – Nurse Practitioner
 Amy Finlayson / Salena Griffen – Clinical Nurse
 Stephanie Manning – Physiotherapist
 Dr Moana Harlen - Senior Psychologist

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

For all non-clinical/non-urgent enquires please email LCCH-Haemophilia@health.qld.gov.au

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

Appointments — Outpatient Bookings Office on 1300 762 831 or email LCCH-Outpatients@health.qld.gov.au

Your health care team does not make these bookings or any changes to your appointments. Referrals can be sent to the Referral Centre Fax Number 1300 407 281

Haemophilia Outpatient Clinic — Dr Simon Brown — held in 2e outpatients Level 2, Thursday afternoons 1.00 – 3.30pm

ADULT CLINIC

ADULT CLINIC STAFF (RBWH)

Dr Jane Mason - Haematologist	3646-8111
	(Page through switch)
Haemophilia Registrar	3646-8111
	(ask to page Haemophilia Registrar on 59716)
Beryl Zeissink - Clinical Nurse Consultant	3646-5727
Alex Connolly - Clinical Nurse (Part time)	3646-5727
After Hours - Page Haematologist	3646-8111
Scott Russell - Physiotherapist	3646-8135
Loretta Riley - Advanced Social Worker	3646-8769

Contacting the Clinic Please telephone in the first instance. Appointments 3646-7752 or 3646-7751

For all non-clinical/non-urgent enquires please email RBWH-Haemophilia@health.qld.gov.au

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

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

OUTREACH CLINICS

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

How Can Loretta Support You?

As I write this, it is the start of December and I am beginning planning for 2020 and I wanted to give you enough notice to prepare for the upcoming year. I did promise Graham an article on pain – but that will held over until 2020!!!

Art Exhibition- 30 March to 24th April.

With World Haemophilia Day Event at the Exhibition – RBWH – 17th April 2020

As a follow-up to this years event, we are again going to hold an Art Exhibition in Art Space at RBWH, which will again be shared with Suzette (the Cancer Care Social Work Team Leader). This coming year we will have a theme "RED" and welcome art work to be displayed in this space. We have limited space for ceramics/woodwork/ other items which are unable to be hung, but plenty of wall space for art to be hung.

Please contact me (Loretta at the QLD Haemophilia Centre – 3646 8769 or

loretta.riley@health.qld.gov.au or via RBWH-

haemophilia@health.qld.gov.au

with Attention Loretta in the subject line) if you would like to exhibit work. All art work will need to be with me by the 23rd March 2020. We will send out more information in January. This year, we are also looking for some musicians to play at the opening event on Friday 17th April. Please contact me (3646 8769) if you are interested in being involved in this event.

Pain Education/Workshops

Discussions occurred in 2019 around providing pain education in a way which enables people from the community across the State to attend. We held one workshop in Brisbane, which wasn't able to be video conferenced, however in 2020

there are plans to hold 2nd monthly sessions which can be attended in person or via videoconference. At this stage, they will be shorter (1-2 hours) and we will grow the program throughout the year, dependent on interest. Please let me know if you are interested in attending and what day/s and times are most suitable and we will design a program around the days/times which suit most people. We have also been able to purchase some workbooks through the Hornery Foundation and Cancer Care



Services for anyone who attends.

Well-being

This years well-being workshop was unfortunately postponed. It will be run in 2020, with funding for resources obtained through the Hornery Foundation and Cancer Care Services. This workshop will tie in closely with the pain workshops/education sessions and if people from outside Brisbane are interested in being involved I can adapt the workshop to enable some of the workshop to be video-conferenced. This workshop will be practical and give opportunities to hear about activities which enhance well-being and participate in different activities. If you are hoping to attend via videoconference, please contact me as early as

possible to assist me with organising resources to be sent in the mail to you.

World Café or 'we would like to hear your thoughts and ideas' on a number of topics.

2019 saw this workshop also postponed due to lack of numbers, however I think maybe this was because I didn't explain the event well. This event will be a way of collecting your thoughts and ideas, with discussions guided by a number of questions which are posed to you during the day. It is about what works well for you, sharing ideas and challenges in a safe environment, where the aim is for the community to share their wisdom. By the end of the day, we will have an action plan, perhaps ideas to improve services, and a better idea of what the community's needs are. In addition, we will also have some fun, share stories, eat some delicious food and drink tea and/or coffee.

There has also been some interest in learning skills and strategies for **Self-Advocacy** and I ran a workshop in the world café style at the 2019 HFA conference, which I am more than happy to run in Brisbane in 2020. Please let me know if you are interested in improving, enhancing or sharing your experiences of self-advocacy and would like to participate in a self advocacy workshop during 2020. If you are interested in attending and you live outside Brisbane area, please let me know and we can adapt it to be able to run it via videoconference or teleconference.

Future Planning for Ageing

Following from HFA's Ageing Project Worker visit during 2019, there has been requests for further information being provided around Wills, Advanced

HFQ Have Moved Office

HFQ have moved into Herston Health medical rooms which are located in a beautiful heritage building, adjacent to RBWH, at 298 Gilchrist Avenue. We are nestled between the Herston Busway and the Cornerstone Carpark.

The office is on the 1st floor and has good natural light and a wheelchair lift. The building itself was originally the clubhouse for The Victoria Park Golf Club and was designed in Spanish Mission style.

It opened in September 1931 and predates the neighbouring UQ Mayne Medical School (1939). The clubhouse site was chosen to allow golfers an easterly walk at the end of their round and close proximity to the existing tram line.

When the gold club moved to its current location the building fell into disuse until it was tenanted in 1978 by the Lone Parent Club of Qld. In the 1980s it became a disco and affectionately became known as "The Pink Palace" or "Lonely hearts" nightclub. The disco hosted both blossoming and unrequited love of many hospital staff.

It was then abandoned and occupied by squatters. Thankfully the building was restored by Brisbane City Council because it was very close to following the sad history of Cloudland, et al. We are very pleased to be in the building as its close location to RBWH makes it easier to work with members visiting the hospital.



RBWH New Email Address

The RBWH Haemophilia Centre have a new generic email address, which all team members have access to. A letter will be coming to you soon with further details.



The address is RBWH-haemophilia@health.qld.gov.au

The aim of this email address, is to allow further flexibility with contacts, and ensures emails aren't missed when team members are on leave.

This is for non-urgent contacts. If you have a clinical issue that needs discussing please still ring 3646 5727 and state who you are, and what your matter of concern is.

Loretta continued...

Health Directives, Enduring Powers of Attorney and services/ supports to assist you living at home or looking at Residential Aged Care options. Please let me know if you are interested in learning more and I will keep you informed of the dates for this discussion.

Wives and mothers of adult children day/s

Graham and I plan to run more "nurture days" for wives and mothers (of adult children) in 2020. Although we had small numbers for our first day, I

understand that the day was enjoyable and I hope we can grow this event, which will encourage more women to attend. These days are for you, to recognise the support you provide to your partners and children.

There may be other opportunities for discussions/workshops throughout 2020. Please let Graham at HFQ or I know what topics you are interested in and we will do our utmost to provide this during 2020 and 2021. Or come to the 'World Café event'

and share your ideas there.

Please keep an eye out on your mail box, H Factor and HFQ for further information about all of these events. Looking forward to a busy 2020 and interesting conversations, workshops and events.

May you and your family/friends have a peaceful and joyous Christmas and New Year.

Loretta

Loretta Riley
Advanced Social Worker
3646-8769

Randall Climbs a Rock

Randall Parker is one of the regular OBE men's support group participants. He was born in Sydney NSW at the end of the war.

Randall has Haemophilia A (factor 8), at 1% level, but with an unusual form of wound healing that requires extended treatment of factor otherwise his wounds can take 6 to 8 weeks to heal.



Randall is an active community participant within his local community. He teaches computer classes for the excitement of helping someone understand a complex task or topic they never understood before. He finds it rewarding to see the look on students' faces when the penny drops (and the rare box of chocolates helps).

Randall also drives a taxi because it's a way of meeting people, having some great conversations and getting paid for just driving around!! Again, he's very community minded and does it to help people stay safe. With his tips he covers the cost for riders who can't afford the fare but have to get to a hospital courthouse, or just home safe if they are under the weather. If given a career choice Randall says he'd like to be President of Australia

Randall loves travelling, making model aeroplanes - mostly helicopters and working on machinery. As well as volunteering for the rural fire service, fishing, playing in band pub gigs etc. So what made him choose to play the bag pipes? He went to a concert in Brisbane in 2000 - a Tattoo and he heard a piper play Highland Cathedral and decided then and there to learn to play. Turns out that after searching war records in the UK, he found that his real father was born near the Scottish borders so it's quite a fitting (if loud) instrument for him to play.

Unfortunately Randall was in hospital three times this year with pneumonia. When combined with a 3 year old chest infection that he picked up in France 2016 after playing bagpipes in a Tattoo, it has resulted in heart damage from straining to breathe. For a while Randall had to give up piping, taxi work, helping around the house, rural fire service etc. It was an effort for him just to walk to the front gate.

Randall drove past Ayres Rock in the sixties on a trip round Australia and just before the Uluru-Kata Tjuta National Park Board closed the climb to the top of Uluru Randall and his wife Jenny decided to revisit the rock and joint the traffic jam of people climbing the rock because, as he says; "It's what humans do - sail to the end of the world or go to the moon, climb the highest mountain or go into caves. It's human instinct to test your limits. Driving a fire truck down a road consumed by fire - you have to see yourself on the other side. And go for it."

And go for it they did. When Randall and Jenny set out on their trip to the Rock & Alice Springs, the first day at the Rock was very hot - too hot for the Rock climb to be open!! The climb is closed when the temperature reaches 36C, or it is too windy. They had limited time in each tourist site so had to leave the Rock unassailed. They flew to Alice Springs the next morning and saw as much of the township as was possible as they were returning home the next day. Literally a flying visit.

Randall says Alice Springs is an interesting place, they enjoyed their time there, but once home he couldn't settle and made the decision to revisit Ayers

Rock, choosing the weather more carefully, thanks to Willy Weather. Randall set off again on the Monday of Queen's birthday holiday on his own, sleeping in a hire car at the caravan park and was successful at twice getting his feet onto the climbing track of the Rock!!!

He almost made it to the chain, but the group in front of him suddenly stopped and he lost my momentum. He came down onto on his hands & knees taking some skin off in the process and then turning to sit down he started to slide down the track!!! Randall says; 'There was nothing to stop me except the fast-approaching low rocks. Wow, what an experience! I shredded the seat of my trousers, luckily not my underpants and thanked my lucky stars that I could stop. No breakages, just slightly rattled but just so pleased to have accomplished my dream. You really have to see the Rock to appreciate its magnificence and size.'

So despite many setbacks Randall has achieved one of his bucket-list aspirations. Our congratulations to Randall on his adventures. He tells us he still wants to travel back to the USA, see the Spruce Goose and fly over the Antarctic.



New Gene Therapy Resource

Do you have questions about gene therapy for haemophilia?

We are pleased to announce the release of HFA's new resource Gene therapy for haemophilia, which was developed to answer the questions from our community:

- What types of gene therapy are used in haemophilia?
- How does gene therapy work?
- Is it a cure?
- How safe is it?
- Who can have gene therapy?

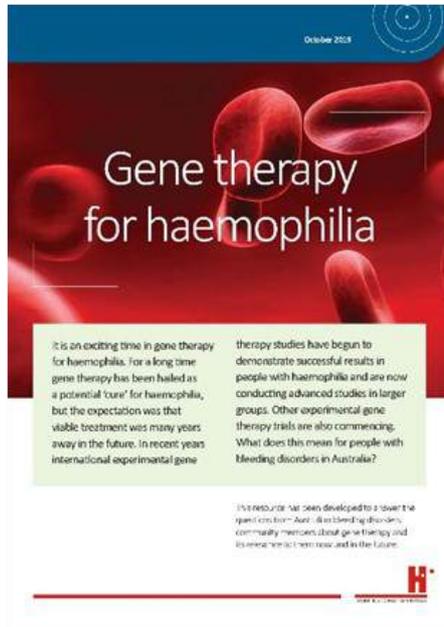
The information includes diagrams to explain simply how genes and gene therapy work.

HOW TO ACCESS IT

Gene therapy for haemophilia is available in multiple formats:

As a downloadable PDF on the HFA website under PUBLICATIONS (<https://tinyurl.com/HFA-gene-therapy-pub>)

As web pages under ABOUT BLEEDING DISORDERS (<https://tinyurl.com/HFA-gene-therapy>)



Print copies are also available from the HFQ office, HFA, and your Haemophilia Treatment Centre.

A print copy has been included in this issue of 'H' Factor.

OUR THANKS

We would like to thank the bleeding disorders community members and expert reviewers who made valuable contributions to this resource, and to our designer, Ray Hehr, for his clear and thoughtful diagrams.

In Dec 2018 - Jan 2019 HFA conducted a national community survey to find out what questions the bleeding disorders community would like to have answered. This resource was developed to answer those questions.

This resource was funded by an education grant from BioMarin.

MORE INFORMATION

To find out more about Gene therapy for haemophilia or to order copies, contact HFA:

E: hfaust@haemophilia.org.au
T: 1800 807 173
W: www.haemophilia.org.au

Alex Dowsett - Super Haemo!

Alex Dowsett, a British professional road racing cyclist, visited Australia earlier in the year to participate in the Tour Down Under in South Australia and the Cadel Evans Great Ocean Road Race. As much as many Australians admire Cadel, as a community of people affected by bleeding disorders we were more excited to see Alex participate in this event because he has severe haemophilia A. Despite his haemophilia he has had major wins in Grand Tours, Stage Races, One Day Races and Classics and holds the World Hour Record.

A few months after his visit down-under, Alex accomplished something not many people have done, especially with haemophilia.. The 30-year-old pedalled his bike onto Paris's streets, raced up and down the famed Champs-Élysées and then crossed the finish line of the 2019 Tour de France.

Years of hard work had gone into the achievement, but in the afterglow Alex informed his Instagram followers he'd gotten there "because I'm lucky." He was lucky, he said, to have good healthcare, access to the latest medication and knowledgeable healthcare providers, and lucky that his schools and racing teams respected and wanted to know everything they needed to know about his condition but didn't treat him any differently to others.

If Alex can do it, we all should be inspired to be more active. Alex had to sit out rough-and-tumble sports as a boy, but he found his passion, lets all take up a passionate activity in 2020



Photo: Alex Dowsett Katusha Sports limited edition jersey for haemophilia-via www.katusha-sports.com photo c. Laura Fletcher / the peloton brief

What's On Over the Next Few Months?



January to April 2020

Some of the HFQ programs and activities already planned

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

MAKE IT YOUR EVENT

JAN	New Years Day Make you new years resolutions stick	OBE's Monthly meeting 8 January TBC	Australia Day Event 26 January Archie Brothers Cirque Electriq	
	OBE's Monthly meeting 5 February Everton Park Hotel	Women's Wellbeing workshop 8 February	HFQ Board Meeting 18 February Toombul Library	Get you work ready for ArtEx in April Theme = RED
	Women's Lunch 1 March at 11:30 Tingalpa Hotel	OBE's Monthly meeting 4 March Toowoomba (TBA)	HFQ Board Meeting 17 March Toombul Library	St Patricks Day 17 March
APR	OBE's Monthly meeting 1 April Old Fernvale Bakery Cafe	HFQ Community Camp 3 - 5 April 2020 Noosa North Shore Retreat	World Haemophilia Day 17 April	ArtEx Display of members artwork at RBWH during April. Theme = RED

Protests over Lack of Action for HepC

Greg Ball, an HFQ member and Charles MacKenzie (NSW) were two tainted blood campaigners who protested outside the 19th Australian Conference on haemophilia, VWD & rare bleeding disorders at Manly on the Friday, saying that HFA had failed to strongly advocate for the kind of support some victims needed, or for an inquiry into decisions by authorities in the 1980s that led to thousands being exposed to hepatitis C.

Greg and Charles are probably not alone in their concern and the Newcastle Herald ran an article saying this concern is shared by Queensland federal Labor MP Shayne Neumann, who described the tainted blood scandal as "a terrible tragedy" and "a stain on us". Mr Neumann says the isolation that some tainted blood victims felt was real, and the threat of litigation was most likely the best explanation for governments over the years refusing to respond to calls for an apology and compensation.

The Australian Red Cross estimates between 3500 and 8000 Australians were infected with hepatitis C from blood products before 1990. However, the true incidence remains unknown due to the absence of a formal reporting system. A 2013 Victorian study of 700 haemophilia patients found 219 had hepatitis C. The study found it quite concerning that a proportion of these patients remained untested for hepatitis C and that patients with mild bleeding disorders "may not present until end-stage consequences develop".

Continues on next page →

Roll Up! Roll Up! Australia Day Family Fun

Are you feeling lucky?

Archie Brothers Cirque Electriq is the newest old school venue in town! They are Upstairs at Toombul Shopping Centre with unlimited free parking.

We have booked with them for a fun time on Australia Day, they are airconditioned and have arcade and ticket games, virtual reality rides and dodgems. We've got an hour of free Archie brothers electriq circus entertainment available to us after we gather at 11:30 for pizza and chat in our own function space

This Australia Day give the excitement of arcades a new life! Run yourself ragged around the arcade or sit back and let the children do it in a safe controlled space.

It's usually \$25 or more for an hour of games and food, but we are offering it to all members for only \$15 per person up to a maximum of \$50 per family.

It's a really fun place with lots of old and new arcade games. There must be 12 or more pinballs from Evil Knievil to Indiana Jones (Williams) and lots in

between. There are also 60ish? arcade games from the original Space Invaders upwards.

Finding the place. Its not like a KFC that sticks out, its on the roof of Toombul Shopping centre so head to the roof top parking, but once inside it has great atmosphere and feels safe and fun.

If you'd like to come please call us on 0419 706 056 to register you or your family's place or email us on info@hfq.org.au

UNLIMITED PLAY HOUR
AUSTRALIA DAY FUN DAY
 @
Archie Brothers
 • CIRQUE ELECTRIQ •
HFQ Fun Day for all the family
 One hour of air-conditioned arcade games and Pizza at Archie Brothers (Toombul Upstairs 1015 Sandgate Road, Toombul)
Free parking, free food and subsidised games
11.30am on Sunday 26 January
 RSVP's essential on 0419 706 056



The few thousand Australians with hepatitis C because of transfusions or blood products for haemophilia were "the forgotten people", Mr Neumann said. He had "high hopes" a decade ago that the federal Labor government would deliver a formal apology to tainted blood victims and act on Senate inquiry recommendations from 2004, but it did not happen.

Mr Neumann said he would speak with shadow health minister Chris Bowen in light of comments by the UK Infected Blood Inquiry chairman Sir Brian Langstaff, of UK health authorities' "lack of attention" to its tainted blood victims.

Current treatments for hepatitis C have cure rates of more than 95 per cent, and everyone known to us in Queensland with hepatitis C from infected blood products has taken up the treatments and had an effective cure. Rates of liver cancer have also gone down considerably.

However we acknowledge that for members exposed to HIV there is no cure and having a cure for hepatitis C does not make it less egregious for some members that they had to go through this experience in the first place and an apology by the government is not just a symbolic thing. A formal apology is a recognition by government that this actually happened.

If this has raised issues for you that you would like to discuss, please talk to Loretta Riley, the Advanced Social Worker at the QHC on 3646-8769 or call the office and talk to Graham on 0419 706 056

To read the entire article by Joanne McCarthy of the Newcastle herald, please go to: <https://www.newcastleherald.com.au/story/6429153/peter-dutton-in-act-of-grace-payment-offer-to-tainted-blood-victim/>

Advances in Gene Therapy. What does it

The goal of Gene Therapy is to provide lifelong curative therapy

There are 16 Gene Therapy Products Approved so far in USA for different diseases. As early as 1996 a study used stem cells (skin cells) in two haemophilia B patients. The transgene expression was not long lasting and lost expression after 15 months. However in the last ~10 years – considerable improvements in gene therapy for both haemophilia A and B, have shown much greater effectiveness. Patients with a severe forms of haemophilia have been shown to change to mild or even normal. The number of gene therapy clinical trials inched up by 10 from the 362 recorded as of the end of 2018. More significantly, the number of clinical studies jumped 17% year-over-year from the 319 trials in progress as of the first three months of 2018

Transport vector issues

- ~40% of the general population has a pre-existing immunity for some viral vectors used to insert gene therapies.
- Immune reactions were generally resolved with a short round of steroid therapy, Unfortunately, steroid therapy is not successful in all patients, this needs to be better understood and overcome?
- Most clinical trials avoid participants who have been exposed to the viral vector used and who have antibodies to it/them. The safety profile of different AAV's are further study areas.
- Potential genotoxicity derived from integrating gene delivery vectors should not be underestimated...

How close is Gene Therapy registration for Haemophilia

One US drug company UniQure in May this year presented updated clinical data showing that clinically significant elevations of Factor IX (FIX) activity were sustained in all three patients up to six months after a single administration of AMT-061.

The first patient achieved FIX activity at 51% of normal. They have now enrolled, all patients planned for the study, and no patients have been excluded because of pre-existing antibodies. Previous studies by uniQure suggest that the AAV5 vector may be viable for 97% of all severe and moderately severe patients. Subjects will be followed for five years after treatment.

There are Many Important Unknowns:

Question - Why is there such a large variance in expression of factor? What does this mean – unpredictable but if >5 or 12% will this do?

Question – Some evidence of genetic integration into genome? Are there any long term issues – unknown

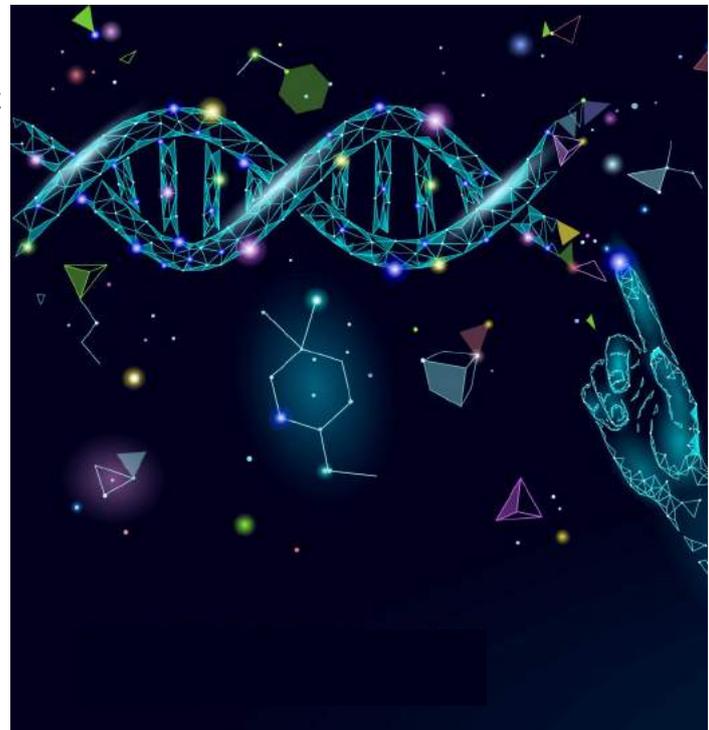
Question – How long will treatment last:

- There is some evidence of dropping levels of Gene Therapy treatment
- Some evidence indicating yes but will this apply to all treatments – some early

adopters still producing now approaching 10 years out. Even if a drop occurs it's still a positive if levels remain into moderate or mild - from severe??

Who has the better treatment & is there framework to evaluate:

- CorHem project is setting core outcome measures to evaluate efficacy, safety, comparative effectiveness & value (49 people made up of community, clinicians, researchers, regulators, research agencies, health



technology assessors, payers, drug developers)

Question – Who will qualify for treatment here in Australia?

- Will it only be made available for those with severe haemophilia?
- At what age?
- Will those with inhibitors be first?

Cost / Benefit for Government:

An Example Over a 10-year time horizon, total per-person gene therapy costs were

mean for you and me?

estimated to be \$1M and resulted in 8.33 QALYs (Quality-adjusted life-years), whereas prophylaxis cost \$1.7M and resulted in 6.62 QALYs.

Thus, gene therapy dominated prophylaxis (costs less and was more effective). Gene therapy remained dominant unless initial costs exceeded \$1.6M.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6058236/>

What should the government consider before approving Gene Therapy and new extended half life therapies?

- Will extended ½ life products 'factor in' – for mild /



- moderate?
- Burden of treatment with existing replacement therapy is significant.
- Adherence to treatment plans are poor with existing replacement therapies, Gene Therapy will resolve this.
- Breakthrough bleeds still occurs on current replacement treatments adding to cost & damage.
- Issues of disability, time off work /school, poor QOL,

hospitalisation costs (~\$1200/day), orthopaedic & other significant medical costs, psychosocial costs to patient & their supports, and cost of replacement factor.

We must remember this is a new science, still in trial phases, and much is still not understood. Some trialists have found their thinking changes and they no longer have to mentally note where their factor level is at in relation to any planned activities / prophy – Gene Therapy has removed their need to consider this

Some trialist say that any factor levels over 12% mean that they would be unlikely to have any spontaneous or true bleeds. It also removes the 'forward thinking' that was ever present in their minds before Gene Therapy. Prior to going onto a Gene Therapy trial many study participants report that they have exhausted all their annual leave and sick leave, and many have spent at least 3 weeks in hospital which has a large cost implications (3 weeks hospital =

\$25,200). If your self-employed or running a small business, the implications are huge.

So far anecdotal reports suggest that Gene Therapy has changed the lives of study participants for the better – I wished them good luck for the future lets see how it goes with the factor level. However, there are still questions – if / when will Gene Therapy will be appropriate for

children as joint damage still occurs in youth. Even if children who may qualify at say 10 or 15 (or whatever age it turns out to be) arthropathy will still have to be managed. Once these new treatments are approved clinicians will have to look at a lot of factors to determine the best treatment based on age, severity & number of bleeds.

What does it mean for you & me?

Gene Therapy is curative – not a cure! – we need to change the language \ conversation

Not everyone will benefit

Will non Gene Therapy treatments 'factor in'

Cost – a little 4 letter word with big implications

Still many questions with no answers – still early days

Community expectations – a need for education / perspective

I think we are justified to be optimistic as gene therapy, accelerated by scientific progress and clinical successes, one day may see long lasting, safe therapies for haemophilia management. BUT ... this rapid progress has not left enough time for patients and clinicians to understand deeply and completely the consequences (safety, longevity & economics) New trials are emerging with the use of powerful and flexible vehicles such as lentiviruses which shows high efficiency of gene transfer and a capacity for stable transgene integration in the genome of target cells stay tuned.

David Stephenson
President HFQ

Robbie's School Days

Starting School was a serious decision for my parents. The fear of not being able to prevent bleeds by restricting me and my activities like they did at home was frightening. But an education was the right thing. So we played it safe and I started at the age of five, doing Home Schooling. My only teachers were my mother and sister Julie and resources for home schooling was very limited.

At the age of seven the doctors discussed alternative ideas for my education. My parents had many concerns because back then, there wasn't enough treatment if something was to happen whilst I was at school.

After much deliberation they placed me at Montrose Home a type of boarding school and home for crippled children. I stayed there for 4¹/₂ years as a resident from Sunday afternoon till the following Friday afternoon.

All meals were supplied, but Mum liked to send some snacks or treats along with me to store in my locker. My favourite treat was 'Iced VoVo's'. But somehow my supposedly locked locker had a resident gremlin and my stock of treats diminished quicker than I could bear without me even laying a lick on them.

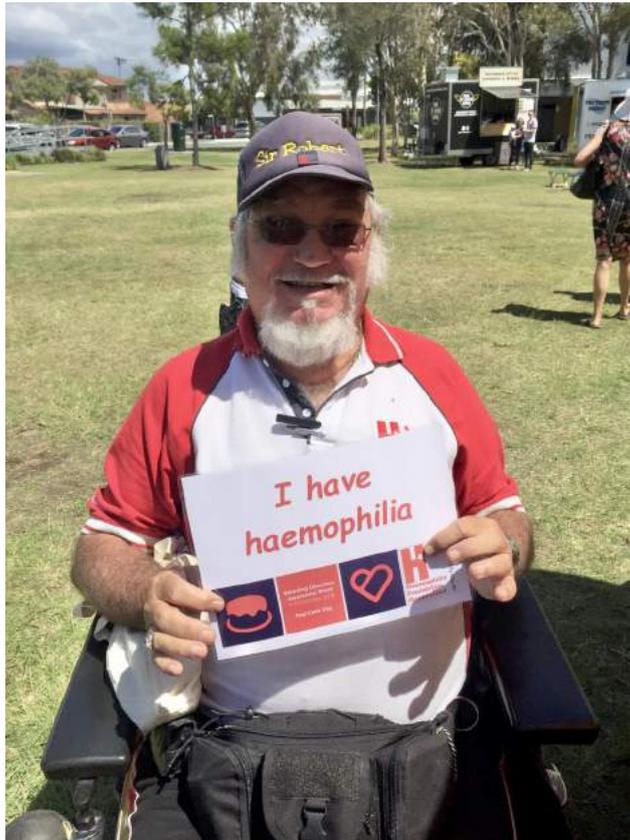
Dinner would be in the Mess Hall. We would all be responsible for setting up and putting away the tables and chairs. We had rostered turns of Mess Hall and Kitchen chores and I enjoyed that. After dinner we could watch about 1 hour of TV, and then it was off to bed in the dormitory.

Of an afternoon, we played ordinary school yard games. It was a time where we learnt to tolerate others and be creative in adjusting how games were played to make allowances for each other's abilities and limits, so all could join in and have fun.

Some of my favourite afternoons were when we would go swimming

in the Home's pool (not heated) for exercise/physio and fun! Mr Watson ran Montrose at the time. He was a good, approachable man I thought he did a rather good job looking after the home and caring for us.

While I was staying at Montrose, my brother Wayne was born and I started to get homesick. I heard of how Wayne was crying and



getting bruises and felt a real need to be with him. I wanted to protect him more than anything in the world. I missed Ian too and I couldn't handle being away from my family anymore. It was making me so sad and even mad sometimes because of my frustrated feelings and I asked if I could come home. I just wanted to be there as my brothers and sister grew up. The next time I went back to Montrose was to pack my things and say goodbye.

In my younger life, I felt very alone in my struggles. I wasn't neglected, but at times if people felt awkward about my condition, they would avoid me. I think all people especially those with disabilities, strongly feel that

same need to be accepted. I always try to say hi to another person in a wheelchair, those who can respond sound so excited to get an acknowledgement.

There have been quite a few very special people who have looked beyond my disabilities and cared very much. My family was very close and struggled alongside me, but it takes a lot of effort, perseverance, patience and a confident personality to be the best that you can be. In some way, I'm very glad I had my time at Montrose.

Leaving Montrose left the dilemma of what to do about school. Lucky for me, a new state school was built in Nashville – one that Ian went to. It was only five minutes away from home and my parents and I decided to give mainstream school a go and I enrolled at Nashville State Primary School.

Though I was twelve years old, I was placed into grade four as I was so far behind, due to all the time I spent with going back and forth to Hospital. I was sometimes teased by other kids at school because I was older and I had troubles walking.

However, I was never at school or participated in schoolwork at full time capacity. Trying to do schoolwork while I was in pain from a bleed made it awfully confusing and concentrating while in pain was near impossible. It turned out that unfortunately year four was as far as I could go because I had some very long stays in hospital, including a head injury and had to go through intense rehabilitation.

My brothers were more fortunate. They got to finish their schooling. When Ian and Wayne had a bleed, and it was very painful, they didn't understand why they couldn't play football like their brother Barry. They were able to handle life much easier because of the

Getting a Diagnosis

It doesn't matter if someone is diagnosed at birth or in their 40s: Getting a haemophilia diagnoses is a whirlwind.

As a child, I struggled with pain and the limits it imposed on physical activity, but it became even more complicated when I was diagnosed in my 40s with factor levels below normal, suggesting I had haemophilia, and was not just a carrier.

For years, when doctors when they told me that women do not get haemophilia, I believed them. That a women's "good X chromosomes" compensate for their bad ones." Their claims gave me a false sense of security.

Receiving a haemophilia diagnosis as an adult was both liberating and terrifying. I was glad to know I hadn't imagined years of pain and symptoms that were minimised or ignored. But I came face to face with the fragile reality of life.

My bleeds has gone untreated for years. I was in a terrible car accident and wasn't given factor when I suffered a head injury. What if I had died? Looking back, there were many moments in my

life when I did not have access to the factor I needed to treat bleeds. My paradigm shifted. The stitches I



needed multiple times as a child were a result of haemophilia, as were the nosebleeds. The pain I felt while doing PE at primary school was not laziness. The swelling in my ankle was a result of untreated bleeds. People told me to run through the pain. I just had to build up my muscles. But physical exertion only made it worse. I thought it was my fault, but the truth is that none of it was my fault. Haemophilia was treatable!

What would happen if I was in an accident, I wondered? The thought was scary! Of course, I could have bled to death my entire life, but the difference was that now I knew I could. I didn't know what the future held. My comfort levels changed completely.

A proper diagnosis gave me the opportunity to partner with health care professionals to create an appropriate treatment plan. It took quite a while to find a team that understood how to treat haemophilia in women, but eventually I did.

Thanks to factor, I healed from injuries in days instead of weeks. What a relief! I no longer fear my new known status.

As scary as the journey has been, I'm so thankful to have the correct diagnosis. Access to appropriate haemophilia treatment has changed my life.

Edited for size from an article by Shellye Horowitz that appeared in Haemophilia News Today. <https://hemophilianewstoday.com/2019/10/22/fear-comfort-zone-loss-known->

- Robbie's Story continued

advances in treatment. With clotting Factors – cryoprecipitate and A.H.F. from a young age, they were able to attend School more than I ever could. But they still had times in hospital too.

Over the years, I spent so much time in hospital that I would have to do my schoolwork there which was difficult. The hospital had its own school room to which I would often have to be carried to in order to attend. Otherwise I would have my schoolwork brought up to my bed by a teacher. It was very hard to do work in bed, when my arms or legs were in splints or traction and in pain. I spent most of the time in hospital doing my schoolwork in a bed lying on my back.

When I was fourteen, I went to

Taringa Rehabilitation Centre to be trained for work. It had different classrooms for different training. Some were manual arts/ labour training, others were clerical and tutoring. I tried for the P.M.G. (Postmaster General) shop, where I fixed telephone wires. I was doing quite well until I cut my finger. After that I was sent to the pottery shop, learning how to lay tiles. They thought that to be to risky too.

While I was there, I learnt a lot. With the knowledge and skills that I was taught, it helped me with some home renovations of my own. However, because there weren't any more options for me there, I was told to go home and from there I was to be put on a pension for the rest of my life.

Now that quite a blow. I felt useless and there were people saying it to my face. The real hurt was when they said I was incapable of any employment. That was heart breaking to hear and even worse to accept. The bottom of my heart fell out. The 'fallout' from this lasted for quite some time. This feeling, however, was recognised by the family and the encouraged me to take up the strength and determination within me to get on with finding a favourite interest. I'm sure there were plenty of special prayers for

This is part 5 of Robbie's self-published story "Injection of Life" and if you'd like to read the full story please contact the office on 0419 706 056 and we can lend you our copy of the book.

Hep C and HIV News.

Elimination of HCV in People with Bleeding Disorders Surpasses WHO Goals

People with bleeding disorders such as haemophilia are more susceptible to diseases acquired by exposure to contaminated blood, as was the case of HCV infection.

In 2015, direct acting antiviral (DAA) therapy was approved as treatment for HCV infection. Due to these drugs having a 95% cure rate, the World Health Organisation set targets to eliminate HCV infection by 2030

Researchers in Belgium reported the effectiveness of DAA therapy eliminating HCV in a sub-group of Belgian patients with chronic bleeding disorders. Their retrospective study looked at 153 patients with a bleeding disorder and chronically infected with the virus.

By the end of the follow-up period in 2019, only 14 patients were still infected by HCV and the researchers say this is better than the elimination target of 80% set by WHO. This study shows that it is possible to eliminate HCV in a well-defined subgroup and underlines the need for monitoring tools in order to reach every patient

Edited for size from an article in *Haemophilia news Today*: <https://hemophilianewstoday.com/2019/10/25/study-daa-therapy-eliminate-hcv-bleeding-disorders/>

Major progress toward HIV treatment with antibodies,

A cure or prevention of HIV infection is looking complicated but more feasible, according to two scientific articles published last week by San Diego scientists and Scripps Institute researchers.

According to one article; the development of powerful “broadly neutralising” antibodies against HIV means that progress in treating and preventing HIV appears close at hand.

These antibodies constitute a new class of HIV therapy. They can be given directly to prevent or treat infection; and indirectly to guide vaccine development.

These antibodies inactivate a broad range of HIV strains and researchers are working on a multi-stage vaccine with a few separate immunisations.

The antibodies are also in clinical testing to see if they can help control HIV infection, or even kill infected cells.

A second article was published in the journal *Science* by researchers from the Scripps Institute describing in detail a vaccine strategy to prepare the immune system to repel HIV.

Part of this strategy includes encouraging the immune system to make more of certain rare B cells, the ancestors of cells capable of making broadly neutralizing HIV antibodies.

These cells mutate their genome in response to exposure to antigens. The mutated descendants in turn become more specialized, until they produce cells that can make antibodies that exactly fit vulnerable targets on the virus.

The bottleneck lies in the rarity of these special B cells. So a vaccine must induce these precursor cells to multiply, then direct their descendants down the path to making broadly neutralizing antibodies.

The article says that if they can identify certain of these antibodies that are easier for the

immune system to make, then vaccine design can select the best antigens to guide the immune system to the end of the tortuous road to making these powerful antibodies.

The paper published by the San Diego researchers can be found at <https://stm.sciencemag.org/content/11/516/eaaz2686>

The paper published by the Scripps Institute researchers can be found at <https://science.sciencemag.org/content/early/2019/10/30/science.aax4380>

First New HIV Strain in 19 Years Identified

A research group at the health care giant Abbott has discovered a new strain of human immunodeficiency virus, or HIV—the first to be identified in 19 years. Abbott continues to look for potential new HIV strains to ensure that its diagnostic tests for blood screening and detecting infectious diseases remain up to date.

The new strain, called HIV-1 group M subtype L, is extremely rare and can be detected by current screening tests.

The study serves as a reminder of the dangerous diversity of the HIV virus, it tells us that the HIV epidemic is still ongoing and still evolving. That’s why current attempts to create a vaccine have failed.

The danger from the virus persists. A radically new viral strain could evade detection in the blood supply, and avoid being controlled by drugs thus rendering future vaccines ineffective.

The paper discussing the new strain of HIV can be found at https://journals.lww.com/jaids/Abstract/publishahead/Complete_genome_sequence_of.CG_018a_01.96307.aspx

Summer Camp 2020

HFQ Community Summer Camp

a great reinvergrating time away



Announcing our 2020 Summer Camp

Fri 3rd April to Sun 5th April

Noosa North Shore Retreat.
1 Beach Rd, Noosa North Shore

\$75 per family

\$50 per couple

\$30 per individual

Camp is a space that allows everyone to be uniquely themselves and creates an atmosphere of support and inclusiveness

Online registration is now open

Noosa North Shore Retreat 3 - 5 April 2020

<https://www.hfq.org.au/get-involved/events/camp> Mob 0419 706 056

Haemophilia Foundation Queensland Inc. 

YOU are invited to attend the 2020 HFQ Community Camp at Noosa North Shore Retreat on the beautiful Sunshine Coast. Our Community Camp is a weekend with new activities, good food and the chance to meet and discuss current issues for people with bleeding disorders in a relaxed and safe environment.

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

Our community camp is highly subsidized and is for all members of the bleeding disorders

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

At camp you have your own accommodation, but we encourage you to mix with each other and share experiences with people who will soon become friendly faces. The retreat also has a General Store as well as the restaurant, 3 swimming pools and a tennis court but we have pre-booked some activities. The retreat staff are ready to take us on some new, challenging but fun activities that will help us improve our spirits and learning as well as

expand our own capabilities and expectations.

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

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

Raising Funds For HFQ Isn't Hard To Do

Facebook Birthdays

We have been really pleased at how many donations have come into us through Facebook Birthdays since the beginning of the year. Some of this money has come from supporters who would have donated to us anyway, through other means, but some of it is definitely additional revenue and makes a big difference. One of our biggest annual fundraisers is the Bunnings BBQ and the total of these Facebook donations this year have equalled what we would raise at the BBQ, with each birthday donation averaging \$225.00

It's a meaningful way for people to connect with their own community of friends and you're not forcing anyone to support our cause but putting it out there as something that's important to you. It is probably the lowest-effort philanthropy you can do because Facebook offers an easy, low-pressure way for you to do something by tapping into your existing networks.

Two weeks before their birthday, you will see a message from Facebook in your News Feed giving you the option to create a fundraiser for your birthday. You can create a fundraiser for HFQ on Facebook, write a post encouraging your friends to donate and click "create". Facebook will do the rest. Your friends will receive a notification inviting them to support us, as your charity of choice and in honour of your special day.

However, Facebook does not notify us when a fundraiser has been created so please do not think us rude if we don't thank you, it just arrives in our paypal

account as 'Facebook giving'. If you want us to know you've set up a birthday fundraiser for us so we can tell you how it went, please let us know so we can thank you.

eBay

Another easy way to help our fundraising is to let us sell your unwanted goods online through our online eBay charity store that we started in July at



www.ebay.com.au/usr/haemophiliaqld We are not big enough to have an actual charity shop but every month millions of people go to eBay to shop. If everyone on our mailing list gave us one item a year that sold for \$10 we would be raising over \$4,000 PA without the need for other fundraising endeavours.

Just as retailers offer their customers on-line stores we do too. Selling via our eBay online

store is an easy way for you to help us raise funds. All you need to do is identify the unwanted goods you want us to sell via the store and let us know what you have. Please think of items that will generate customer interest that you can donate to us.

A typical on-line charity shop's stock might include collectibles, branded merchandise and perhaps the occasional valuable or high-profile item such as antiques, books and furniture.

Modern Electronic items are another category we're keen to sell, however, any electrical item donated needs to be thoroughly tested for functionality and safety before we can list them.

You can call the office on 0419 706 056 to arrange for handing over your donations or talk to us about listing your goods that you can keep at home until sold. All you have to do is make sure your items are photographed and described to the highest standards you can manage. The buyer pays postage as well so there is no cost to you. And, if you're shopping for things, make sure you don't miss out on any bargains by visiting our eBay shop. You'll find all sorts of hidden gems at great prices, and all proceeds go to help us care for more people living with an inherited bleeding condition and their families.

The donations page on our website is <https://www.hfq.org.au/get-involved/donate-now>

Or you can use this QR code to go directly there.



Health Updates

Immune Gene Variations May Help Predict Inhibitors

A study, published in the journal PLOS One, sought to identify genetic markers that could help predict which patients were prone to develop an immune response against external factor VIII.

They analysed data from 586 patients with severe haemophilia A from Bonn in Germany. 19% developed inhibitors and the analysis revealed that patients with a familial history of inhibitors had 5.94 times higher risk of developing them.

The team sought to understand how different genetic and clinical parameters could explain the development of inhibitors in some patients. Results showed that patients with a specific HLA haplotype (called HLA-DRB1*15), and with a particular SNP in the IL-10 gene, had higher risk for developing inhibitors. Of 30 patients in this group, 23 developed an immune response against factor VIII.

The team concluded that the results “show associations between genetic factors and the occurrence of FVIII inhibitor development in severe haemophilia A patients,”

<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0218258>

Hypertension in Swedish persons with haemophilia

A report in the September issue of Thrombosis Research by Swedish researchers showed that persons with haemophilia (PWH) had higher prevalence of hypertension than matched controls using a longitudinal study design.

They identified 19.7% diagnoses of hypertension in PWH born in 1978 or earlier compared with 11.2% among controls. The findings were similar in subgroup analyses of patients with non-severe and severe haemophilia with or without HIV and/or viral hepatitis.

[https://www.thrombosisresearch.com/article/S0049-3848\(19\)30310-X/fulltext](https://www.thrombosisresearch.com/article/S0049-3848(19)30310-X/fulltext)

BioMarin planning to launch world's first haemophilia A gene therapy

Biotech company BioMarin has made a leap for an accelerated approval of their gene therapy “Valrox”. That decision was made despite a considerable backlash against the latest data, which showed worsening efficacy over time and a lower initial response in their pivotal trial — but excellent bleed rates, so far.

BioMarin says that they have good reason to believe they are on track to field the world's first gene therapy. The company is focused on getting Valrox to market as soon as possible by submitting their data based on their Phase 3 interim analysis to the FDA.

And BioMarin has outlined plans to charge in the range of \$2 million to \$3 million per treatment — with the capability of earning \$10 billion to \$15 billion a year

<https://endpts.com/billions-on-the-line-biomarin-bustles-past-enthused-rival-planning-to-launch-worlds-first-hemophilia-a-gene-therapy/>

‘Mosaic’ HIV vaccine to be tested in thousands of people across the world

A new experimental HIV vaccine that targets more strains of the virus than any other developed so far will start a late-stage clinical trial later this year. The ‘mosaic’ vaccine also seems to have the longest-lasting effects of any others tested in people.

Starting in September, scientists will test it in 3,800 participants across 8 countries to assess whether the vaccine provides any protection against HIV infection. Half of the participants will get four vaccine injections over the course of a year, and the other half will receive a placebo.

The Mosaico team hopes that their vaccine will help to protect at least 65% of the study participants. However some HIV researchers

suspect that finding an effective vaccine will take longer than the Mosaico researchers think.

https://www.nature.com/articles/d41586-019-02319-8?utm_source=PL+full+mailing+list&utm_campaign=08abd7ff3a-EMAIL_CAMPAIGN_2019_08_01_10_19&utm_medium=email&utm_term=0_e4f77dc29a-08abd7ff3a-370434349

New Data Support Long-term Effectiveness of EHL Treatment

New data from clinical studies suggests that long-term preventive treatment of severe haemophilia A or B with extended half-life blood clotting factors (EHLs), increased quality of life and reduced annual bleeding rates.

The data on Eloctate and Alprolix was presented at the 27th Congress of the International Society on Thrombosis and Haemostasis. It presented data from two Phase 3 clinical trials: ASPIRE (NCT01454739) and B-YOND (NCT01425723). These were open-label extension studies in patients of all ages.

In ASPIRE, 70 people with severe hemophilia A had switched from an on-demand treatment to prophylactic Eloctate. The median annual bleeding rate dropped from 30.0 to 1.5, and this was stable over time. Additionally, 29% of patients experienced decreased joint pain.

In B-YOND, the median annual bleeding rate among these participants decreased from 24.2 on on-demand treatment to 2.0 on prophylaxis.

In both studies, quality of life was improved, specifically “in relation to areas such as sports, leisure and physical health.

<https://hemophilianewstoday.com/2019/07/17/effectiveness-of-preventive-ehls-treatment-in-hemophilia-a-and-b/>



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MIKEY HELLER © 2019 TIMETRABBLE.COM

Happy Summer Unplugged

Fortnite. Minecraft. YouTube. Instagram. Snapchat. These days, the list of digital distractions for kids goes on and on and on. During the summer many parents are looking for fresh ideas for ways for children to stay active, engaged and unplugged. Screen-free activities for kids are a must, particularly now that it's summer. And we all understand your dilemma! I mean, it's only a few weeks into school holidays, and everyone with kids has heard it 100 times already: Can I play with the tablet/laptop for a little while?

During the summer, all parents—whether they have a child with a bleeding disorder or not—face the struggle of limiting screen time and getting kids to take part in screen-free activities because as soon as they get bored, many children's first instinct is to turn to digital entertainment. But you know, balance. And summer!

The following are some fun summer activity ideas for children—no Wi-Fi required. Some

of these require your help, but many don't — at all. So, have a read of our list and write down the ones you think will work with your kids and hang it on the fridge, or jot your favourites on a white board. It can be a quick and handy reference to have on hand every time your kids tell you they're bored, and they can add their own ideas too. It's always awesome to see how much potential for creativity and imagination our kids really do have in them.

Get your child interested in reading

Read a book. It may seem obvious. But look up lists of the best children's books of 2019, because there are bound to be some page-turning, can't-put-them-down books on this list.

Visit the library. One of the best places for a summer reading list is your local library. Swapping screen time for Storytime (with printed books) is another way to cultivate a lifelong love of books

and reading. Local libraries have free summer programs with reading activities and incentives for kids of all ages.

Bring audiobooks or podcasts in the car. If you're going on a road trip, stash the screens for a while and listen to an exciting audiobook or podcast instead.

Create your own comic book. Have fun coming up with the characters and story, and then drawing all the scenes. There are many free printable comic book pages you can download to give life to your own superhero. If your kid isn't as into comics, prompt them to conjure up a fairy tale, create a how-to manual, or write a play.

Family-friendly home activities

Have a family game night. Go old school and dust off that Monopoly or Scrabble game on a closet shelf, or get the whole family together to play one of your favourite

Continued on next page →

Summer Unplugged *Continued*

card games or board games together.

Have fun with puzzles. A big jigsaw puzzle set up on the dining room table can keep the whole family engaged. Pro tip: Work your puzzle on a piece of felt, so you can roll it up without it breaking into a million (or, 500) pieces every time you need to use your table. That way you can work on it leisurely all summer long. You can also find brain teasers and logic puzzle books at your local library.

Learn to cook a meal. Even very young kids can help with basic tasks in the kitchen. Since kids around 9 are capable of preparing a simple meal on their own, get them hooked up with a recipe for a fun summer dessert, like strawberry shortcake or blueberry pie. Be sure to give them tons of credit when dinner time rolls around. You might just spark a new passion for them!

Learn solitaire. Remember when our own parents used to say “play solitaire!” when we were bored? Time to teach your kids how to play. There are more than 150

variations of solitaire to choose from!

Easy arts and crafts at home
Get crafty! So many ideas, whether you’re getting out the glitter glue, building with clay or Play-Doh, dusting off your rainbow loom, or my pick, making creative lanyards. These are a summer holiday classic! Once your kids get the hang of it, they’ll be hooked.

Use materials from around the house. Choose an old-fashioned craft project, like milk carton bird feeders, flower crowns or tie-dye T-shirts.

Make art with recycled materials. Make a collage using pictures and words cut from old magazines.

Create a time capsule. First, choose which items to include, such as a few photographs, a recent magazine and an empty cereal box. If you don’t want to bury the time capsule, put it in storage with a label “To be opened in 10 to 15 years.”

Build something. Create a giant castle with building blocks.

Outdoor activity ideas

Take in a free outdoor concert. Listen to beautiful music while enjoying the great outdoors. Don’t forget the blanket, snacks and bug spray.

Play with water. Have a water balloon toss, or set up the sprinkler in the backyard for the kids to run through.

Take a bicycle ride or go for a nature walk. The ultimate screen free activity for kids? Just get out for a bit, and an adventure of some kind often manages to ensue.

Organize a garage sale. Clean out your wardrobes and make some cash. Task your kids with making a pile of anything in good condition they no longer need or want. More entrepreneurial teens could also try a cake stall.

You can create a colourful chalk mural or play hopscotch or tic-tac-toe.

Go camping in the backyard. Pitch a tent, play flashlight tag and roast some marshmallows over a campfire.

Happy Christmas Everyone

Xmas Jumble Words

Can you rearrange the words below to find the words associated with Christmas?

1. casualants
2. hodpurl
3. iscartooned
4. reedrine
5. wonanms
6. netpress
7. itsomelt
8. ealseknow
9. keyrut
10. hornetlop

A Christmas Carol...

Can you fill in the missing words from this well known Christmas carol?

Season's Greetings



On the twelfth day of Christmas,
My true love sent to me
Twelve _____, (7,8)
Eleven _____, (6,6)
Ten _____ (4,1-7)
Nine _____ (6,7)
Eight _____ (5,1-8)
Seven _____ (5,1-8)
Six _____ (5,1-6)
Five golden rings
Four _____ (7,5)
Three _____ (6,4)
Two _____ (6,5)
And a partridge in a pear tree!

Important Dates for HFQ Members

OBE Lunch Forum

Informal support group for men with a bleeding disorder. Usually meets first week of the month.

Australia Day Summer Event

Archie Brothers Cirque Electriq
26 January

'Red' Art Exhibition

30 March to 24th April. RBWH
Art Space

World Haemophilia Day

17 April 2020

Women's Lunch

1 March 2020 at 11:30
New venue: Tingalpa Hotel

Community Camp

3 - 5 April 2020
Noosa North Shore Retreat

Regional Meetings

Please ask for events and activities happening in your area.

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

Women's Lunch

At the last Women's Lunch we moved away from Café 63 in Stanley Street, south Brisbane to the Everton Park Hotel because it had a great children's play area and good air-conditioning.

Some people told us it was a bit too far north, so for the next lunch event we have moved south of the river to the Tingalpa Hotel (1563 Wynnum Road, Tingalpa). This is another child friendly tavern with free parking & a good children's play area.

As a caregiver, you are important. As someone living with a bleeding disorder or carrying the gene for it, you are important. As a family member of someone with a bleeding disorder, you are also important. All women deserve respect and to have a space where you can share stories and experience and gain support from each other

This is a lunch event for all girls and women affected by a bleeding disorder because bleeding disorders don't just affect individuals. They affect families, too.

Sunday 1 March 2020

11.30 am to 2.00 pm

Our aim is to provide a positive and safe place for women affected by bleeding disorders to find a strong support network and empower each other. We encourage participants to share knowledge,

experience, health tips, love and support with each other.

Come along for a lunch with good food, understanding companions and great conversation. Women with bleeding disorders, siblings, mothers, partners and carriers welcome!

For more information or to register for the next women's lunch please call the office ASAP on 0419 706 056 or email info@hfq.org.au

Haemophilia Foundation Queensland Inc.
Sunday 1st March 2020
Women's LUNCH
NOW AT Tingalpa Hotel

Tingalpa Hotel has a child's play area
and is located at 1563 Wynnum Road, Tingalpa

About The 'H' Factor

The 'H' Factor is published four times each year by HFQ by the HFQ manager and assisted by Brett Williams, our communications volunteer. We occasionally send important information and updates on local and relevant events for people affected by bleeding disorders to subscribers of our email list. If you would like to be on the HFQ Email List, please register your interest by sending through an email with the subject title 'The 'H' Factor email list' to info@hfq.org.au. You can be removed from the list at anytime.

Graham Norton

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