the H FACTOR

Issue 57

Summer 2018

Newsletter of Haemophilia Foundation Queensland

From the President

Hi Everyone,

This edition I wanted to share what life is like having haemophilia in Fiji – my wife and I love this tropical island paradise for a relaxed holiday …. only 3 hours away by plane but significantly further away from modern treatments for those suffering a bleeding condition. Just imagine for a moment what life would be like without a comprehensive care treatment centre, without government funded access to modern treatments, without a foundation that looks after your interests.

While in Fiji, I met with Kunaal, a young man who has started the first Haemophilia foundation in Fiji. Kunaal lives in a tiny house with his family where his bedroom is also the lounge room, the foundation office, as well as storage. He is 23 with severe haemophilia A. After many bleeding episodes in his life – some life threatening (inc brain bleeds), he is significantly affected with joint damage. In 2010 his rope got caught up and he was dragged along the ground by goats – he couldn't walk for three years. This and other events meant there were large gaps in his schooling.

I invited Kunaal over for a meal and his father came with him as he cannot drive. He is a smart, articulate young man with motivation to help others that suffer bleeding conditions. It has not been an easy thing to start the Haemophilia foundation in Fiji, but with some international assistance Kunaal and others now have some access to recombinant factor - but

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From the President cont...

it relies totally on donations from around the world. At the moment his stocks are very low.

Kunaal is not held back by the roadblocks of bleeds, lack of government support etc and runs educational sessions where he can for medical and other people, he also tries to educate youth in their own health responsibility and peruses health department engagement (with little to no success to date). The foundation has been running for about eight months now and it has been a real learning curve for Kunaal. He and his board are planning an awareness campaign starting with local television which is hoped to progress the Fiji bleeding disorders registry.

Kunaal is doing a great job and his quest continues. It's a credit to him and his family, and the members of his board - we wish them the best. Kunaal never asked me for anything, however, If anyone would like to assist financially – for the purchase of a generator and possibly a newer larger fridge to keep Fiji's supply of factor - here is the HFQ account to use BSB 064000 A/C 904788 (or contact Graham or myself – if you make a bank transfer, please note your name & Fiji).

Regards,

David Stephenson

President HFQ
president@hfq.org.au

Representation, Health Promotion, Education, Support
Haemophilia Foundation Queensland

HFQ's New Team Member

We want to welcome the newest member to the HFQ staff team, Samantha Williams (Sam).

Graham is reducing his work load and we are very pleased that Sam will be assisting Graham as the administration officer in the Brisbane office on a part-time basis.

So, if you call the office and Sam answers the phone, or if you see her as a new face at one of our events, please say hello and let Sam know that you are excited about her joining our team.

The intention is that Graham will still answer most enquiries and develop and run the programs and services we offer members; and Sam wis working on the office functions, like finances and membership are kept up-to-date and responsive to your needs.

Sam has spent the last 27 years in administration roles and has previously worked with a non-for-profit organisation and knows the importance of supporting the members.

Sam was born and bred in Brisbane and she has a passion for the arts and entertainment as well as camping and swimming with her family.

Some of you will get to meet Sam at the upcoming events in 2019 so please help her as she gets up to speed with our structures and needs.

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)**
- **Discounted Movie Tickets**

HFQ Management Committee

President	Mr David Stephenson
Vice President ...	Mr Robert Weatherall
Secretary	Ms Lauren Albert
Treasurer	Mr Adam Lish
Members	Dr John Rowell
	Mrs Leanne Stephenson
	Mr Mike O'Reilly
	Mr Mike Holloway

HFQ Delegates to HFA

Mr Adam Lish & Mr David Stephenson

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.

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 Bayden Sales

Haemophilia Registrar – Dr Sasha Laric

Joanna McCosker – Nurse Practioner

Amy Finlayson / Salena Griffen – Clinical Nurse

Hayley Coulsen – Physiotherapist

Moana Harlen - Senior Psychologist

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

ADULTS CLINIC

ADULT CLINIC STAFF (RBWH)

Dr Jane Mason - (On Leave till February) Haematologist	3646-8111
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 or speak to Beryl

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: Book through Joanna at QCH and Beryl at RBWH.

Art Exhibition

Some very exciting news hot off the press, for all creative people in the inherited bleeding disorder community.

Many of you have noticed the art work hanging in the ground floor walkway between the Ned Hanlon Building and Joyce Tweddell Building when you come to the Royal Brisbane and Women's Hospital (RBWH) for appointments. At the end of November, Graham and I had the pleasure of meeting with the RBWH Foundation Hospital Volunteers Manager – Simone, to discuss an opportunity to exhibit art work from the inherited bleeding disorders community during April 2019. The Art Space will be shared with the beautiful paintings from one of the RBWH Social Workers, who has generously offered for us to share this opportunity and the Art Space with her.

Given that World Haemophilia Day is held across the world in April, it is fortuitous that we have this perfect opportunity to showcase your talent and promote inherited bleeding disorder awareness in a creative way. Graham and I have already started putting ideas together for an event around the exhibition and ideas for the information about inherited bleeding disorders which will hang amongst the art work. Stay tuned for more information about the event in the next newsletter, in your email inbox or in your mailbox. So, please put your pen/pencil/ paint brush/charcoal to paper, go out and take photos, make some sculptures, etc. I can't wait to see what you can create in the next few months.

What do you need to know to exhibit in this space?

- You can choose to sell your art work during the exhibition, with 25% of the sale price of each painting going to the RBWH Foundation; or you can choose to exhibit and not sell your art work.

For those wanting to sell their art – there will be a form to complete, with bank details, etc so that you can receive your payment

- The art work will be in a public space, so please no art work that may cause offence.
- It would be good to have a short bio; outlining the inspiration for your art work
- You will need to get your art work to my office on Level 4, Joyce Tweddell Building at the RBWH by the **26th March 2019** (please let us know if this will be challenging for you).

There is no theme for the exhibition and it isn't a competition. Please be courageous, be inspired and showcase your talent.

For more information, or to register your interest to take part in this exhibition, please contact Graham at HFQ on 0419 706 056 or Loretta at QLD Haemophilia Centre on 3646 8769.

Art, Bleeding Disorders & Social Work

So, you may be asking, how does an art exhibition, having an inherited bleeding disorder and Social Work fit together?

For a number of people, the impact of having an inherited bleeding disorder will impact on their emotional well-being to the point where they are feeling stressed, develop symptoms of anxiety or depression, have a trauma reaction or are diagnosed with post traumatic stress disorder.

In addition to every day stressors; a number of events (specific to having an inherited bleeding disorder) may impact on your emotional well-being, including:

- A spontaneous bleed, (maybe when you have plans you were looking forward to)
- A cancelled or rescheduled doctor's appointment or surgery
- Difficulties performing tasks you were able to do before (maybe due to a bleed or due to damage to joints)
- Uncertainty – around work, finances, family, future accommodation and care needs for example
- Unsuccessful multiple attempts to self-infuse
- Changes of staff at the Haemophilia Treatment Centre
- An unhelpful encounter with a health professional
- Feelings of not being heard when trying to advocate for yourself
- An invasive medical procedure
- Traumatic injury
- Feeling different to others
- Not being able/"allowed' to participate in activities

One incident may be stressful enough, but there is also the impact of cumulative stress, when you have a number of stressors one after another, sometimes something small may cause considerable distress.

Research and the experience of many people has found that there are a number of ways to manage the effects of stress, anxiety, depression and trauma.

Examples include: mindfulness, meditation, exercise, being in nature, expressive writing and (you guessed it) creative pursuits like art. One fairly recent study by Kaimal, Ray and Muniz (2016), found that 75% of their study group had reductions in cortisol levels (a stress response typically shows a raised level of cortisol in the body), after participating in an art activity which was 45 minutes in length.

Their study showed that it didn't matter if you were experienced in artistic pursuits or

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Sciency stuff on Hemlibra and apology

In the last issue we mentioned Dr Jane Mason's report from the world congress and some members continue to ask how the 'new' therapies work.

First; an apology & a correction. We made a mistake when we Hemlibra was administered by intramuscular injections, they are subcutaneous injections. We also said that NovoEight was a current inhibitor treatment, it should have read NovoSeven.

Dr Mason gave the right information in her presentation, but in my writing up the event I incorrectly wrote these errors and I apologise for any confusion caused by the article as published.

To fully answer the question on how Hemlibra works is beyond the ability and understanding of the board and staff of HFQ, but we can try and give an expanded lay-person response in the hope that this is the level of detail you the reader may want.

The Sciency Bit

The current standard of care for people with haemophilia in Australia is clotting factor replacement therapy, and for those with inhibitors, therapy with bypassing agents (BPAs) like NovoSeven.

The 'new' therapies are about to change that, especially for people with inhibitors, because drugs like Hemlibra do not require factor replacement therapy or the use of BPAs to prevent bleeds. Although, these will still be required to treat breakthrough bleeds.

Hemlibra has already been used as a trial drug in Australia and in the USA it is available for treating people with haemophilia A and inhibitors.

How Does Hemlibra Work?

Hemlibra is a *bispecific monoclonal antibody* that mimics the function of factor VIII. What's a bispecific antibody? Antibodies are Y-shaped proteins that are part of the immune system's defence against foreign substances. Each antibody is unique works only on a specific molecule or protein.

The unique part of the antibody which attaches to a foreign molecule—is located near the tips of arms of the Y-shaped antibody. In nature, both arms of the antibody bind to the same antigen.

Bispecific antibodies are different. They are artificial and can simultaneously bind to two different types of protein and the term "monoclonal" means that all the bispecific antibodies are the same.

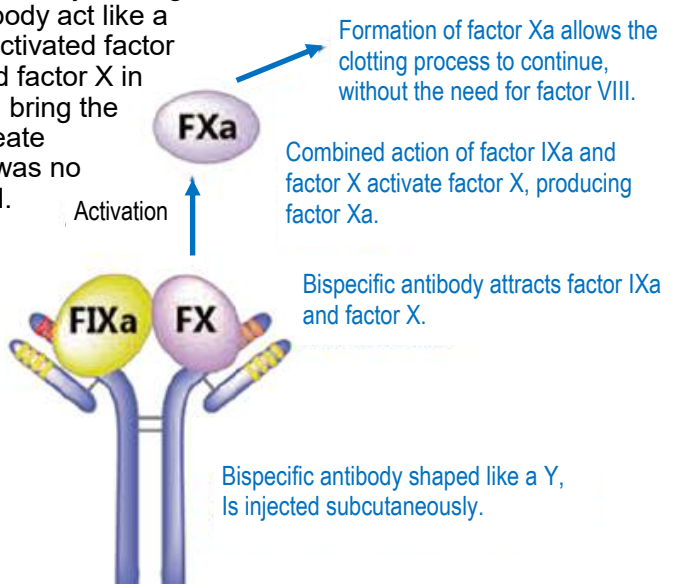
When an antibody binds to a foreign substance, it may neutralise or inactivate it. Inhibitors, for example, are antibodies that attach themselves to infused factor and inactivate it, stopping it from helping the blood to clot. All antibodies tend to persist for a long time in the blood (they have long half-lives).

Researchers investigated bispecific antibodies to see if they could bring factors IX and X together to activate factor X *without* the need for factor VIII. They designed a bispecific antibody capable of activating factor X by simultaneously binding activate factor IX and factor X. By making the bispecific antibody act like a person grabbing activated factor IX in one hand and factor X in the other and then bring the two together to create activated X there was no need for factor VIII.

A Breakthrough for People with Inhibitors?

In phase 3 clinical trials, Hemlibra demonstrated a significant reduction in bleeding episodes, and in many cases, with no reported bleeds! Helimbra is one of the top 10 most expensive drugs for rare conditions. Its cost is significantly higher than prophylaxis with factor concentrates, but Hemlibra is significantly less expensive than current inhibitor therapies and significantly more effective at preventing bleeds. It's only used for people with inhibitors at present but if it was approved for use on patients without inhibitors the price could drop significantly and become affordable in Australia.

Hemlibra is only the first of several novel therapies that will probably enter the market over the next few years. The wheels of change have been set in motion but will the manufacturers lower their prices to stay competitive? Possibly, but prices do not often drop with the introduction new treatments. Will some manufacturers go out of business? Also possible, but not likely - all the big players in the haemophilia market have been planning for the arrival of novel therapies for some time, and they're also developing their own novel therapies. This is the first rumbling of what will be a seismic shift in the haemophilia industry: within a decade, the haemophilia industry - and how we treat bleeds - will look very different!



Hemlibra, a bispecific antibody, mimics the function of factor VIII by bringing together factors IXa and X to activate factor X (making Xa). This restores the clotting process, so a blood clot can form.

Meet Robbie Weatherall

My parents lived in a renovated army barrack at Deagon, in the northern suburbs of Brisbane. They moved only three times in their married life. Between 1945 and 1962 they were blessed with five beautiful children, but with my younger brothers and myself the whole family's life would be changed forever. The three of us were born with haemophilia.

It wasn't until I was in my toddler years, when I was about nine months old, that my parents started to become concerned about the number of bruises accruing on my body for no normal reason. So mum took me to the local doctor, Dr Elizabeth Richards who did some tests that confirmed that what I had wasn't meningitis as initially thought but in fact it was sever haemophilia A. *That's when our 'fun' started.*

I spent many days in the Brisbane Children's Hospital, in 'Raff Ward'. There wasn't much the doctors could do to treat my condition. A typical bleed would be an internal bleed. It was only obvious when bleeding had continued and a joint or muscle or bump had become painful, hot and swollen. By then the damage had already begun! So much so that I would succumb to tears from the pain and unable to walk or even move whatever joint/ muscle was bleeding.

The hospital wards were situated up a steep hill, lined with a concrete staircase consisting of precisely 92 steps to climb before you would reach the Ward at the top of the hill. I felt every bump and twist. And every step of the way amplified the pain as I was carried up. I applaud my parents for having to climb that set of stairs on every visit over and over again. Eventually in the early 1960's a pathway was built, and a Rocket car was introduced to assist with transporting patients up to the ward.

Unbeknown to mum, plodding up the 92 steps would become more frequent when my brother Ian was born, for Ian had haemophilia too. Ian and I were a comfort to each other in hospital. Just knowing we were nearby each other, gave us comfort that replaced some of the loneliness. There wasn't much for me or the other kids to do while we were in hospital. There were no televisions, no radios, not a lot to pass the time away and we were not allowed to visit each other either. So rest was the main activity of the day.

Other than schoolwork there wasn't much we could do day after day, just eat and sleep (if I could), with all the pain and discomfort I was in. Lucky for us, the hospital did eventually introduce TV to the wards by the last 1960's. It broke the silence of the day and was an uplifting substitute for the company we were missing from family.

The staff and doctors did care about my parents as well as me and helped out if they could, but most times their hands were tied to the responsibilities of the patients only. There was a great doctor that my parents and I did rely on for his medical knowledge and understanding. He was doctor Grant Staples, my paediatrician at the Children's Hospital. He was quite knowledgeable about my condition. He was certainly the more proficient person to supervise the medical staff to give me the best available treatment and I was at ease with him..

Some years later, my youngest brother Wayne was born, and he was haemophilia boy number three! We three brothers were like triplets in our own way. We shared so much understanding of each other's suffering. My older brother Barry suffered too, but in his own way. He was about six years older than me and I was not really involved in his life. I could only imagine how left out he would have been most times because of the continuous attention needed towards us boys.

Barry often brought home stray animals that he would find. One day he even brought home a little baby goat! It was fun and exciting when he brought animals home and we wouldn't have been surprised if he turned up with a baby elephant one day.

My sister Julie would almost be classed as our 2nd mum. When one of us had some pain Julie would many times push us round the block in a pram to calm us down. Julie was particularly strong for me during a time of painstaking rehabilitation after a severe brain injury I had in my early teens and patiently tried to get me moving and back to health again. She is the best sister in the world!

Dad worked at Eventide Nursing Home as a cook until he retired. Even though dad worked long hours he still took time out to come up to the hospital too. My parents spent many hours and days and nights transporting us all to and from the hospital for treatment, either by car, ambulance, or bus. How exhausting it would have been for them, not to mention the anxiety of needing to leave us at the time when they felt we needed them the most. Our family was stretched on peak occasions as there was someone needed at home to look after the rest of the family.

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Women's Brunch and other supports

HFQ Social Support events are relaxed and friendly, easily accessible, and designed to encourage people to access other services while in an enjoyable setting.

We currently offer regular meetings for women affected by a bleeding disorder in themselves or their family and a men's group for men who are living longer term with a bleeding disorder.

We are also keen to offer social support to any subgroups within our community that may feel the need. For example, we provide youth events between the annual camp and we work regularly with families with young children dealing with ports and infusion issues.

Social connection is good for everyone. It provides you with:

- A supportive, long term support network for people affected by bleeding disorders within the BD community
- Improved personal coping skills through the extra support in their life
- Increased awareness of the support services available
- Improved physical and emotional health, thereby reducing the risks of isolation and stress
- Improved knowledge of services and amenities our members can access
- Greater awareness within the community of carer issues
- Improved support of our members by specialists and Allied Health Professionals

Women's Brunch

We have a regular women's brunch meeting open to all women and girls affected by bleeding disorders in some way, whether a patient, a relative or a carer. Everyone is welcome to come along and join us for a light meal and drinks.

HFQ hosts these meetings to bring the female members of our community together and allowing the women to meet with each other in a way that provides an environment for a good conversation and information sharing to support the overall 'health' and vibrancy of our members.

Socially inclusive activities, such as community lunches and social events have shown to produce positive outcomes in regards to social networking

The last gathering was in November. It was an informal meal and chat at café 63 in East Brisbane which has the benefit of air-conditioning and children's drawing equipment. Feedback from the event was that the women who attended felt it helped their well-being and life capabilities.

The next meeting is booked for Sunday 17th February 2019 so we hope to see you there!

Only my parents could come up to the hospital, because in those days' children were not permitted to go visit their siblings. Julie didn't get time to ponder on whether she missed us or not. But for sure she would have missed mum and dad and I always wanted to be home. I missed being away from the family, but I had to toughen up and 'that-was-that'.

My brothers Ian and Wayne were fighting the same difficulties I was. At the age of 8 and 10 Wayne broke his leg twice. The first time was when the neighbour's dog rammed smack-bang into his right leg. The impact was so strong that it snapped his femur in two! His second break was just simply getting his foot tangled in a garden hose, so we always kept the hoses tidy and coiled away after that.

I too, broke my arm at about the same age, except mine was diagnosed as only a bleed at first and never treated as a break so my elbow was left deformed. Identification of bleeds was sometimes a 'hit-and-miss' type of ordeal, but it just goes to show you the sort of pain we could go through with a bleed. It can be pain as massive as a broken bone or the intensity and swelling of a bad sprain. My break was put down as one of those 'Bad Bleeds".

I had a brain haemorrhage at thirteen and survived. Ian also had a brain haemorrhage, but tragically passed away a fortnight off his fifteenth birthday. It was a devastating time in our life. At that moment, having haemophilia seemed sadly hopeless.

Robbie has self-published his story "Injection of Life" and we have edited the start of his book for this article. We hope to publish more extracts during the year but 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

First World (Australia) v's 3rd World (Fiji)

Diagnosing a bleeding condition in Fiji is not easy. Kunaal, the president of the Haemophilia foundation in Fiji told the story of an 11 year old boy who was sent to NZ but got caught up in the regulations – he could not been seen after arriving in NZ as there was no medical referral…it took several trips to NZ to eventually get diagnosed. Understanding of bureaucracy & process etc is not always easy when you live in a third world country with little or no education.

Kunaal says there are no haematologists in the public hospitals in Fiji – the few in private hospitals are not affordable to the lower and middle class. So you can see how this ends - people suffering joint deformities and disabilities, some being on crutches for 10 years with significant unrelenting pain …and the bigger issue of depression (a silent epidemic) where some have tried to end their lives.

Fiji is a developing nation where patients are not yet diagnosed & understanding is confused. There is still a belief by some that factor 8 is a one off cure, and some villages chased Kunaal away as they don't believe in modern medicine. Up to 75% of the worlds estimated 400,000 people with haemophilia have little or no access to factor!

There is good news; with the help of a New Zealand doctor and 'Project Share' (a project that provides donated factor from the USA and manufacturers from around the world) - a humanitarian program operated by LA Kelley Communications) The foundation has some factor which is great, but at the moment their stocks are very low.

Storage of factor is another eye opener - the factor they can access is NOT kept at the local government hospitals. Kunaal has a fridge at home where all the factor for Fiji is kept! It is through his efforts that factor is stored and managed. There have been many issues like getting the factor to Kunaal still refrigerated – there is no street address where he lives in his tiny three room house with 5 other people.

Kunaal and his family often spend his father's income to transport factor where it is needed (health department does not ship factor around). Electricity is also unreliable and he uses newspaper to try and keep the factor cold when the power goes out. He also relies on friends in other locations to store the supply if there are longer outages …this is not just his factor - it is the total intermittent supply for Fiji!

Some money has been collected for a generator to cover the power outages, but they do not have enough yet. Space for household fridge items is a problem, but the priority is factor - which places more pressure on his mother to manage daily life – a very caring family indeed.

Family financial & emotional stress is another issue. Transport is often unaffordable for those that have to go to hospital (a 40 min taxi costs $50 each way, and income is typically $5/hr or less, for many – the minimum wage is $2.68/hr), so some avoid going for treatment unless the pain becomes too unbearable.

There are many tragic stories like the seven-year-old brother of Kunaal who, in 1993 had a nose bleed. His parents took him to hospital where the intern (no haemophilia experience) called her registrar for assistance while his brother was writhing in pain so badly they tied him down to the bed - he later died. If the doctors had understood he could have been given Cryo (Cryoprecipitate is a blood derived product available in a few Fiji hospitals), this could possibly have saved his life but they had no knowledge at the time.

Deeptesh is another young man with severe haemophilia. His life was limited – he could not play sports and when he needed treatment he was offered Cryo as the only option. However, to have the treatment he and his family had to go out and find blood donors to replenish the hospitals Cryo stock. And it's the same today - if you have no other choice than to have Cryo you need to find replacement blood donors - this is not easy as donors typically expect to be paid, driven to / from the hospital or some other reward ...life is indeed hard in Fiji.

Others like Sanjeev who also has severe haemophilia have had regular hospital stays - on occasion twice a month with elbow and knee bleeds – he missed out on 9 years of education.

Sanjeev who also has haemophilia experienced problems like others do attending hospital, where he was told to go home – they wouldn't listen or believe him.

Finally; the story of Suhal, a two year old who was hit in the head and ended up in hospital - his parents thought they would lose their only son. From that point, his life was focused around hospital - spending two weeks at a time, missing significant schooling.

This is life in Fiji in 2018. And while, things are on the improve its very much at the early stage with much work to be done.

PROBE Study Update

Some of you have helped to test the print and online survey for the PROBE (Patient Reported Outcomes Burdens and Experiences) study. This is a multi-national study on the impact of living with a bleeding disorder, treatment outcomes and quality of life. HFA has joined other haemophilia organisations around the world to participate in this study and build a collection of robust patient-reported data – crucial to help HFA understand current issues for our community, and to quantify and represent these issues to governments or treatment and service funding bodies in a credible way.

PHASE 2 RESULTS

21 countries participated in phase 2 of the PROBE study in 2016-17. This tested:

- Whether the survey questions would capture consistent responses if they were repeated twice in the same community (e.g. Australia)
- The stability of the online survey

Australia contributed a total of 103 survey participants.

An important learning from this phase was that larger numbers of survey participants will be needed at a country level to provide meaningful data. Participants were grouped as controls and into haemophilia severity, eg mild/ moderate/severe. When comparing the different groups of participants, the sample sizes were found to be too small for stable results at a country level, but could be demonstrated at a regional level – for Australia, this was the Western Pacific Region, including Japan, Vietnam, Australia & New Zealand.

The results validating the PROBE study at a regional level are available on the PROBE study website – www.probestudy.org Feedback about the online survey has been used to fix bugs and make enhancements for the phase 3 version. The international team set up a simple and user-friendly dashboard to display the country and region data for the participating national haemophilia organisations. Testing the dashboard and providing feedback was an exciting time for us as we realised the great potential of this data for HFA – both to understand the issues for our community and represent them to funding bodies and decision-makers. This questionnaire is about haemophilia, but a survey on VWD is also planned for the future.

NEXT STEPS

Phase 3 is planned to begin at the end of 2018. It is the final 'real world' stage of implementing the haemophilia survey around the world – where we invite the wider Australian bleeding disorders community to complete the questionnaire. This will be Australia's opportunity to collect current data about the experience of our community. As you can see, it will be important to gather as many survey responses as possible. Surveys will be available in print and online. Stay tuned for more information!

Our thanks to Dr Liz Bishop, Michael Kirby Centre for Public Health and Human Rights, Monash University who continues to provide oversight of the ethical process.

For more information about the PROBE study in Australia, visit the PROBE section on the HFA website - *www.haemophilia.org.au/research/probe-study.*
Or contact Suzanne O'Callaghan at HFA:
E: socallaghan@haemophilia.org.au
T: 1800 807 173

Prophylaxis From Birth to Adulthood

Whether people with haemophilia follow prescribed prophylaxis treatments is an important and complex issue faced by our community. Prophylaxis (prophy) aims to keep circulating factor levels in the mild-to-moderate range in people who would otherwise have more severe haemophilia. But individual regimens vary as we grow and change, and as factor products evolve.

Multiple studies have shown that continuing prophy beyond childhood results in decreased bleeding and pain, better joint health, and improved quality of life. Yet some teenagers resist prophylaxis and may struggle to accept responsibility for regularly scheduled infusions. It's natural for them to wonder, then, how important is adherence to a regular treatment regimen after childhood?

Prophy: Burden versus Benefit

Benefits of prophylactic infusions include decreased bleeds and pain, increased opportunity to participate in activities, increased long-term joint health, and peace of mind. On the other hand, pain and difficulty with vein access, and the requirements of time, space, and planning for infusions can be a burden.

Most parents of children with severe haemophilia come to agree that the benefits of prophy outweigh any burden. Indeed, it's now universally recognized that prophylaxis is the standard of care for children with severe haemophilia.

But when young people become responsible for their own prophylaxis, they may re-evaluate the relative benefits and burdens of infusing. A student may not leave enough time to infuse before his morning class. Or a busy young adult may want to forget about haemophilia or hide it. Some young people on prophy have never experienced a bleeding episode, so they may justify stopping prophy, thinking that Haemophilia causes no complications or symptoms. Often, young people simply forget.

Sticking to the Plan

Prophylaxis in Australia is

increasingly being prescribed beyond childhood, and as a result, more and more young adults with haemophilia are benefiting from prophy. Yet the percentage of patients who stick to their treatment could be improved.

Although parents tend to follow treatment recommendations, there is a significant drop-off in prophy adherence when paediatric patients start managing their own infusions when they move out of the family home and are without parental oversight.

One of the best ways to encourage adherence in tweens (9-13) is to start involving children in managing their prophy schedule and infusions before then. For example, children can keep their own calendar to help them remember which days are infusion days, or they can log the infusions into MyADBR. Gradually exposing children to tasks such as organizing and storing infusion supplies or placing a call to the home delivery team when it's time to order more factor helps them transition to doing it all on their own.

Limited Prior Experience with Bleeds

Parents of young children with haemophilia often strive to keep their children as bleed-free as possible. For those lucky enough to succeed at keeping painful or traumatic bleeds at bay, how can we teach children the value of prophylaxis?

Many young adults with severe haemophilia don't know what life was like before prophy became the standard of care, so it's important to recognise how naïve children may be about what life looks like without factor. In fact, having a bleed can ironically be a great educational tool as it can empower a young person to make good choices about infusions, sometimes sacrificing short-term convenience for longer-term health.

Stopping prophy will more likely cause joint damage, which is permanent and can be avoided. It is crucial for young people with haemophilia to stay aware of what's happening internally, and to remember that they have a life-threatening chronic disorder and that negative symptoms are being prevented by prophy. Hearing stories or meeting people who have experienced bleeds may be effective for some young people to appreciate the value of prophy.

Normalcy versus Acceptance

Many parents of children with haemophilia want to treat their child like any other child, with only a few restrictions. We don't want them to feel different but the quest for normalcy can sometimes

To next page ⟶

Prophy cont...

backfire if prophy slips through the cracks when a young person resents or rejects his diagnosis. Learning that while haemophilia does not define them, they do have haemophilia is important and effectively managing their disorder is something positive they can do to enhance their quality of life.

You can't force a teen to be eager to participate in haemophilia activities, prophy or otherwise: teens must arrive at that decision on their own. It's probable that getting involved with others through HFQ, with a goal of finding a balance between normalcy and the positive acceptance of the reality of Haemophilia in their own lives will help people stay adherent to prophylaxis.

Risky Behaviours in Adolescent Boys

Adolescents sometimes engage in risky behaviour during their transition to adulthood. It's unfortunate that this same period of development tends to be when most parents lose oversight of their child's adherence to prophylaxis. The fact that most people with severe haemophilia are males only compounds the problem as sometimes young men believe that they are invincible. Some young guys with haemophilia move out of the nest and begin to think, "My lifestyle has changed, I'm an adult now, I don't have to do this, I'm hanging out with people who don't have Haemophilia."

Healthcare Providers and Social Support

When people with haemophilia have good relationships with the QHC team, prophy is maintained. If a patient knows that they won't be likely to adhere to that plan, they should say so! Doctors want to formulate a plan that will meet the needs of their patients, and this requires an honest discussion.

One barrier to using prophy is that despite treatment advances, prophy still requires intravenous infusions. Needle phobia can still plague some people with haemophilia, despite years of work to overcome this anxiety. Some patients also face needle fatigue. Having a good social system in place, including encouragement and empathy from friends and family, can often help young adults keep these needle related challenges in perspective and work past the fear to get the infusion done.

Another barrier for some young people who are newly independent from their family may be whether or how to disclose their haemophilia to new flatmates, friends, or partners. Disclosure by young adults has important implications for identity and social support as well. It's important to help children with haemophilia navigate decisions about when, why, and to whom to disclose information about their haemophilia. Although some young adults may fear negative attention when sharing this information, confidently disclosing to good friends is usually well received and is more likely to result in the young person continuing with prophy.

We know that for most patients with haemophilia, adherence to a regular prophy regimen beyond childhood will provide long-lasting benefits that should outweigh any burdens. As a community of people affected by bleeding disorders we must model acceptance, confidence, and positive thinking when it comes to haemophilia management.

Whether our efforts result in an adherent young person is hard to predict. But with any luck, we may look back one day and find that not only have the new generation living with haemophilia remained adherent to prophy, but they have also grown and excelled in all sorts of wonderful ways.

Edited for size from an article published in PEN November 2017 by Christy Bergeon Burns (PEN = Parent Empowerment Newsletter published by LA Kelley Communications, Inc.) https://www.kelleycom.com/product-category/newsletters/pen/

HFQ Community Camp

What a great weekend we had for this year's community camp weekend at Noosa North Shore Retreat! We didn't expect it to take place after one of the hottest weeks in November we've had in

ages, but we are not complaining. And being able to access the swimming pool as we wanted was a huge bonus.

Our campers took full advantage of the water at Noosa NS Retreat as we did a night time beach walk on the Friday and we beat the heat on Saturday with everyone using the lake for standup paddle boarding or canoeing on the Saturday morning.

We had 22 families or couples / individuals at camp not counting Dr Simon Brown and family who stayed for the entire weekend. We use the time away at camp to let people unpack some of the clinical information they have received, and we are grateful that Dr Simon was able to attend and kindly lead a session on some of the concerns people had and campers shared a lot of their own personal journeys so thank you everyone for participating at camp and a special thanks to Simon and his family!

Across the weekend we saw our community connecting, bonding, sharing, and laughing together at meals, during activities, and in the quiet moments. It was truly a pleasure to see folks try out new things and learn many things about living with a bleeding disorder. In addition to the beach walk and the lake water activities, this year's activities included Laser tag, Kids giant games mini-golf and the giant inflatable pillow.

Community Camp is an

opportunity for families to reconnect with each other and make new connections with families in a similar situation. This builds their tool kit of resources for the ongoing experiences they face and can create lifelong friendships. They are not low-cost events as we are talking motel rooms and not open-air camping under canvas. In fact this years camp cost $14,728 (or about $200 per person) and we are pleased that there are many new activities still available to us if we return to NNSR another year.

Fundamentally, HFQ is an organsiation that is built around our community: their hopes, their abilities, their uniqueness, and their bleeding disorder. We see camp as a unique opportunity to relax and make memories without having to worry about bleeding disorders as this is an issue for all campers.

HFQ hopes that the community camp will increase each family member's resilience and ability to cope, without the pressure of financial expense. We also use it as an opportunity for parents/carers to re-connect with siblings and/or children with a bleeding disorder. This is particularly important for siblings who can be confused and disappointed when parent's attention is diverted to the child with the bleeding disorder. It gives families the opportunity to build their support network by meeting and forming friendships with other families going through similar experiences.

Art & Social Work *Continued from page 4...*

new to it. Participants found that the art was relaxing, fun and enjoyable, a distraction, took them back to their childhood, felt free from constraints and they learnt something new about themselves, for example (Kaimal, et al, 2016: 77-78). Although the number of participants in this study was small (39 participants), it has prompted more questions for research into the future.

So, now where does Social Work come in (hopefully in addition to organising this art exhibition!)? If you come and talk to me about improving your emotional well-being, I may suggest that you make some changes - increasing some activities, suggesting adding others that may work and perhaps decreasing activities or strategies that are not as helpful for you.

One of these activities to include in caring for yourself may be art or doing something creative. From personal experience, doing something creative works and I would never describe myself as a creative or 'arty' person. It is about finding a creative pursuit that you enjoy. (In the last couple of months, I have challenged myself to learn some new skills - basket weaving and macramé and then spent 5 days taking photos with my camera on manual settings!!) Having a creative pursuit/hobby not only helps to give you some time away from whatever is causing you stress, it offers opportunities to connect with the present, see an outcome, move away from thinking (and worrying) into doing something active – which may help to change your perspective or give you a different outlet.

I do understand that it is not possible to do art or something creative when you have an active bleed (this time is probably better spent resting), however at other times actively using strategies mentioned above can be helpful in mitigating the impact of those things which cause you to feel stressed/anxious/depressed for example.

In addition to the art exhibition, during 2019 there will be a series of workshops focussed on enhancing well-being – please keep an eye out for dates; where these and many other strategies will be discussed and practiced. Please remember, you don't need to manage alone. All of us at some time reach out to others for help. Asking for help shows strength and courage. If you find that you are not coping as well as you usually do, would like to talk to someone about how to improve your emotional well-being or you are worried about your mental health, there is help at the Queensland Haemophilia Centre.

Please do not hesitate to call Moana (Psychologist) at the Queensland Children's Hospital or Loretta (Social Worker) at the Royal Brisbane and Women's Hospital.

I hope I have inspired you to be creative in the next few weeks, and in so doing to look after your mental health. I look forward to hanging many art works on the walls in the RBWH Art Space and showcasing the talents within the inherited bleeding disorders community.

Loretta

References:

Kaimal, G., Ray, K and Muniz J. 2016 Reduction of Cortisol Levels and Participants' Responses following Art Making. Art Therapy: Journal of the American Art Therapy Association 33(2) pp 74-80

www.beyondblue.org.au

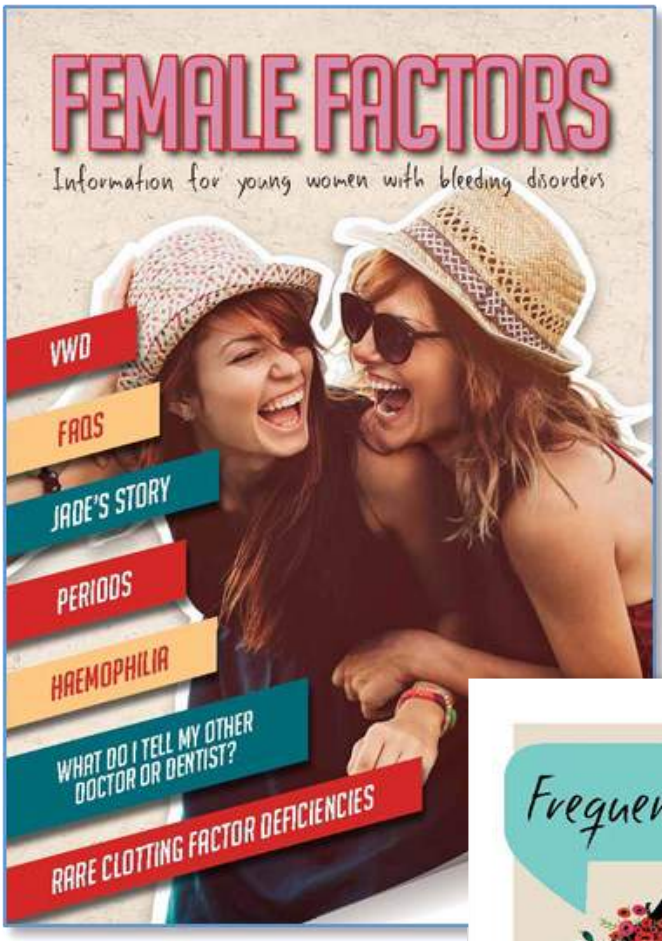
www.blackdoginstitute.org.au

www.stepsforliving.hemophilia.org/next-step/maintaining-a-healthy-body/emotional-side-of-bleeding-disorders

Female Factors – a new young women's resource

HFA has released Female Factors, an innovative new resource for young women and teenage girls.

This was developed to answer the questions of young Australian women about how bleeding disorders affect females – but in a magazine style that is fresh and engaging. There are personal stories, quotes and tips.



HFA worked with haemophilia and gynaecology experts, who put together easy-to-read information for young women.

The booklet has explanations about heavy periods and other bleeding symptoms in females, covering all bleeding disorders. It answers FAQs - such as what's 'normal' and what's not normal, or why girls with haemophilia have different bleeding patterns to their father or brothers - and gives frank but reassuring answers to some of the questions young women worry about.

How To Access It

Female Factors is available in multiple formats

- On the HFQ website *https://www.hfq.org.au/publications/women-with-bleeding-disorders*
- On Factored In *www.factoredin.org.au* under INFO > GIRLS

You can read the entire booklet online as a magazine in ISSUU, download it, or download specific sections.

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

Many people were involved in developing Female Factors. Both young women and their parents and health professional experts suggested what topics to cover, reviewed it thoroughly and wrote new content or gave personal experience to answer questions. We would like to particularly acknowledge Prof Sonia Grover, Head of Gynaecology at the Royal Children's Hospital, Melbourne and Dr Jane Mason, Director of the Queensland Haemophilia Centre, Royal Brisbane and Women's Hospital, who did a substantial initial review and wrote new content for the booklet.

And special thanks go to the young Australian women affected by bleeding disorders who contributed their personal stories and tips and focus-tested the design!

For More Information

To find out more about Female Factors or order copies, contact the HFQ office or HFA:

E: hfaust@haemophilia.org.au

T: 1800 807 173.

Career Choices

Thanks to the treatment options now available in Australia, young people with a bleeding disorder now have a greater array of career choices than ever before.

Yet having a medical condition brings risks, and it's important to think carefully about how your bleeding disorder may affect your chosen career, and vice-versa – not just now, but in the years to come.

Our parents and grandparents with haemophilia used to routinely conceal their medical condition for fear they'd lose their job.

Now that prophylaxis is the norm for those who need it, many working roles and environments that were off-limits a generation a go are wide open to today's generation of young people.

Young people today are being inspired to take on all sorts of careers, despite their bleeding disorder.

Our members successfully work in various roles, including some very physical ones. Some members with severe haemophilia A have told us they are working in construction, mining and heavy plant machinery, as well as less physical roles like office, retail and management positions.

Conversely, others have had to quit physically demanding roles that caused more bleeds – one member found that being a disability support worker was causing him problems, and has since retrained as a driving instructor.

Lateral thinking

Having a medical condition brings risks, and access to some career paths is still limited by restrictive recruitment requirements for some institutions and professions, including the armed forces. (It has to be said that such restrictions are generally there for good reason.)
Think laterally – we have a member who wanted to be a fireman but decided the risk of bleeds was too great, so they have joint the fire service – but in an office / risk management role.

Anecdotally, there seems to be a very high proportion of our members working in medical and caring roles like nurses and paramedics – perhaps because growing up with so much exposure to health services can breed a desire to 'give something back' and become part of the teams that step in to help when needed.

How does the law help?

Employer attitudes and workplace cultures are gradually becoming more flexible, supported by changes in employment law in recent decades. The future looks bright.

All employers should make 'reasonable adjustments' to enable employees to do their job. This includes many people living with a bleeding disorder – as a long-term medical condition that affects daily life at least some of the time.

Reasonable adjustments might include, for example, flexibility to allow for a treatment regime and hospital visits.

Whether or not to tell an employer about a bleeding disorder is a personal choice, though not doing so may not be in the employee's best interests. For example, if someone has trouble in their job or is treated unfavourably, it can be harder to solve the problem or make a formal complaint as the employer can claim they didn't know about your condition.

On the other hand, if an employer knows about your disability, then this should make it easier to request part-time or variable hours to fit with a treatment regime or caring responsibilities.

Employers don't have to say yes, but they must act reasonably in considering the request. They can say yes, try it for a trial period and then still say no, so it's important to be realistic about the possibilities. Employers must have a good business reason for saying no, but for smaller employers this might be that it's simply not affordable.

Employees can help by being flexible too – compromising on your ideal working pattern might enable the employer to agree to an arrangement that suits everyone. The same applies on an ongoing basis – employers don't actually have to give someone a day off to go to a medical appointment, but offering to do another shift or be on a back-up roster for someone else may help.

Opportunity knocks

If the risks are well managed by employees and employers, the majority of occupations should be open to people with bleeding disorders. With a flexible approach and some lateral thinking most people will be able to find a satisfying choice of career.

'Instead of looking at your career choice through the lens of your bleeding disorder, choose what gives you the most joy, then set about finding a way to make your bleeding disorder a non-issue. Don't let your condition run your life. As one members said; "I don't let my haemophilia determine who I am – it's only a small part. I'd urge others to think in the same way".

For a good UK resource discussing career choices go to: https://haemophilia.org.uk/wp-content/uploads/2017/02/careers_info.pdf.pdf

How far we Have come?

People in ancient times could see that some people bled differently. But they knew very little about how blood clots. It was not until just before World War II that doctors learned that haemophilia A was caused by a problem with a protein in the blood, later called factor VIII. Eleven other blood factors were recognized in the 1950s. They were given Roman numeral names to avoid confusion.

Haemophilia has been called a "royal disease". This is because the haemophilia gene was passed from Queen Victoria, to the ruling families of Russia, Spain, and Germany. Queen Victoria's gene for haemophilia was caused by spontaneous mutation. Of her children, one son, Leopold, had haemophilia, and two daughters, Alice and Beatrice, were carriers.

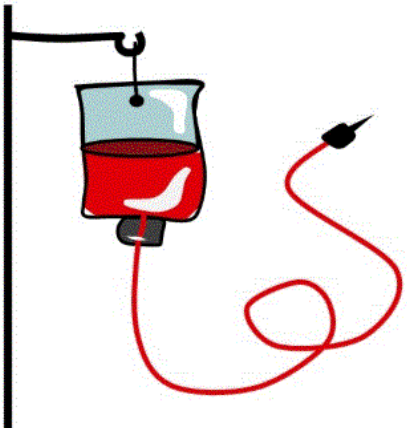
Alice, had a carrier daughter who became wife to Russia's Czar Nicholas in 1894. Their son, named Alexis, inherited haemophilia from his mother. Alexis was treated for bleeds by Rasputin a holy man with the power to heal.

Haemophilia research has come a long way as our timeline shows...

TIMELINE

- 1828 - Term "haemorrhaphilia" first used. Later shortened to "haemophilia"
- 1926 - Erik von Willebrand identifies a bleeding disorder, later called von Willebrand disease (VWD)
- 1940's - whole blood transfusions given at hospital
- 1952 - Researchers describe what is now called factor IX clotting protein
- 1955 - First infusions of factor VIII in plasma form
- 1957 - Researchers in Sweden identify von Willebrand factor as the cause of VWD
- 1964 - Dr Judith Graham Pool discovers cryoprecitate
- 1968 - First FVIII concentrate available
- 1980's - Factor VIII, FIX and von Willebrand factor genes cloned
- 1992 - FDA approves first recombinant FVIII products
- 1995 - Prophylaxis becomes standard of treatment in the USA
- 1997 - FDA approved first recombinant FIX products
- 1998 - First human gene therapy trials begin
- **1999** - Death of 18yo (suffering OTC, not haemophilia) - overreacted to the gene vector - slowed research into gene therapy - after setback, gene therapy progresses
- 2000's - FDA approves first recombinant factor products made without human or animal plasma derivatives
- 2011 - About 50 people with severe A & B enrolled in 7 different gene therapy trials - using plasmids, retroviral, adenoviral & AAV vectors, directed to fibroblasts, skeletal muscle, liver, and other target cells. Four separate trials have used AAV vectors, three of these targeting livers
- 2018 - Gene therapy trials continue (the clot thickens) - companies thinking of different strategies to deliver a curative treatment or significant improvements

Don't be a Drip! Man up & do something for yourself



Join with OBE's. A monthly meeting for men with Bleeding Disorder's, run by men with Bleeding Disorder's for social support and up-to-date discussions on living with a bleeding disorder

OBE monthly gathering 1st Tuesday of every month

From 10:30am for coffee, concludes after lunch

Phone Graham on 0419 706 056 or email info@hfqorg.au for more information.

New Improved Member-Friendly Safe & confidential

Learn Share Support Similar guys, similar experiences, similar concerns.

Health Updates

Promising data supports development of AAVhu37-based gene therapy for haemophilia A

Gene therapy using an optimized adeno-associated virus (AAV) to deliver the human factor VIII gene showed a substantial increase in hFVIII expression and no detectable antibody response for 30 weeks in some animals. Researchers compared two AAV capsids - combined with two liver-specific promoters and enhancers and concluded that AAVhu37-based gene therapy has the potential to advance to the clinic to treat haemophilia A, according to an article published in Human Gene Therapy.

Source: https://home.liebertpub.com/news/promising-results-support-continued-development-of-aav-based-human-factor-viii-gene-therapy/2410

uniQure Potential Gene Therapies for Haemophilia A & B

uniQure recently issued an update on some of it's gene therapy work. Their new gene therapy candidates represent a step forward towards delivering transformational medicine to patients suffering from genetic diseases.

uniQure has treated the first patient in its Phase IIb dose-confirmation study of AMT-061, an investigational AAV5-based gene therapy incorporating the FIX-Padua variant for the treatment of patients with severe and moderately severe haemophilia B.

AMT-061 is a a one-time administered therapy that incorporates both AAV5 and the FIX-Padua variant. It has the potential to deliver clinically relevant increases in FIX activity with low risk of cellular immune responses, which could expand eligibility for treatment with gene therapy.

uniQure also has a potential gene therapy for haemophilia A, AMT-180, AMT-180 is designed for one-time intravenous (IV) delivery and uses a type of viral vector called adeno-associated virus 5 (AAV5).

The potential therapy contains a modified factor IX gene known as Super9, which has shown an ability to bypass inhibitors to FVIII in preclinical studies, suggesting it may be beneficial for a patient population previously excluded from gene therapy approaches.

https://www.streetinsider.com/related.php?id=14541493&type=pr and https://hemophilianewstoday.com/2018/11/26/gene-therapy-for-hemophilia-a-amt-180-may-treat-regardless-of-inhibitor-status-uniqure-says/

Marzeptacog Alfa (Activated) Phase 1 Data

Catalyst Biosciences has published positive results from its clinical trials of the Factor VIIa variant marzeptacog alfa (activated) (MarzAA) in the preventative treatment of patients with hemophilia A or B with inhibitors.

MarzAA showed favourable pharmacological data in this first-in-human study and no potential safety concerns were identified. Together, these results supported further examination of MarzAA for the treatment of haemophilia A or B with inhibitors, particularly via subcutaneous administration.

Marzeptacog alfa (activated) (MarzAA) is a potent, subcutaneous Factor VIIa therapy being developed for prophylaxis in haemophilia A or B with inhibitors, acquired haemophilia and other bleeding disorders. A Phase 2/3 open-label, subcutaneous efficacy trial will evaluate the ability of MarzAA to eliminate, or minimize, spontaneous bleeding episodes.

https://onlinelibrary.wiley.com/doi/full/10.1111/jth.14247

The Contaminated Blood Scandal and The Forgotten Victims Of AIDS

1 December 2018 marked the 30th anniversary of World AIDS Day. While people still think of AIDS as being restricted to particular confines of the population or as a sexually transmitted disease, some people with haemophilia are another group of people, both dead and living afflicted by HIV.

Driven into silence through stigma, some of the affected patients in the UK have campaigned for the truth about their infections and the Governments response and a public inquiry finally opened this September. The Inquiry is currently collating evidence and is expecting to open its next round of hearings in April 2019.

https://www.huffingtonpost.co.uk/entry/world-aids-day-contaminated-blood_uk_5c016247e4b0b69ed37ac2c7?guccounter=1&guce_referrer_us=aHR0cHM6Ly93d3cuZ29vZ2xlLmNvbS8&guce_referrer_cs=1nzp0potampft8rumPTh0A

Treatment with emicizumab improves factor VIII tolerance in haemophilia A

Immune tolerance induction with standard or extended half-life recombinant factor VIII after initial treatment with emicizumab appears safe and effective in paediatric patients with haemophilia A and active inhibitors, according to findings presented at the ASH Annual Meeting and Exposition.

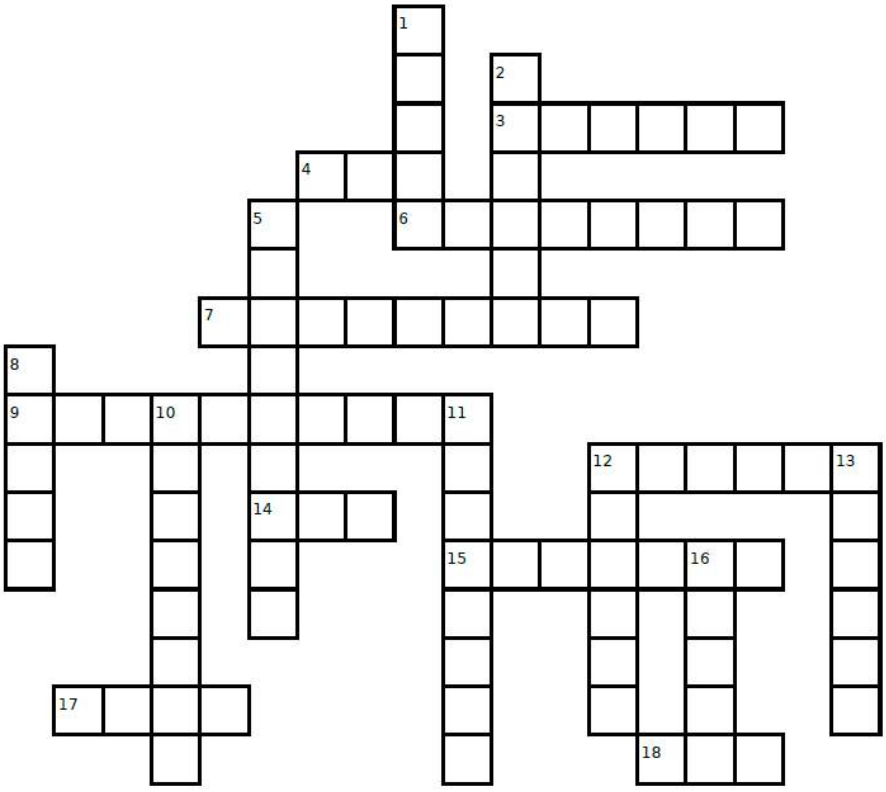
Novel non-factor therapies reduce bleeding symptoms in patients with haemophilia A and inhibitors, but the absence of [factor] VIII tolerance remains unchanged.

Researchers in the USA examined an approach, known as the Atlanta Protocol, in eight patients aged 13 months to 11 years with haemophilia A and an active inhibitor. Immune tolerance induction began after four weekly loading doses with emicizumab and standard or extended half-life recombinant or plasma-derived factor VIII.

Although early, the results suggest that immune tolerance induction can be safely administered in these patients and is able to achieve continued improvement in clinical indicators of tolerance the researchers wrote.

https://ash.confex.com/ash/2018/webprogram/Paper114249.html

Bleeding Disorder Crossword Challenge



Down:

1. Tiny particles in all cells of the body that help decide the colour of eyes, hair and everything else about the body (5)
2. A black and blue mark caused by bleeding just under the skin (6)
5. A hard substance which covers the ends of bones within joints (9)
8. The second largest organ of the body, brownish in colour, it filters and cleans blood
10. The giving of medicines or liquids through a vein using a small needle. Factor is given this way (8)
11. Moving through water; the best exercise for people with bleeding disorders (8)
12. The netting made by all blood's factors that holds the platelet plug in place (6)
12. The missing part of the blood that causes haemophilia (6)
13. A thin tube of metal, inserted into the skin, used to put medicine into the bloodstream (6)
16. A joint that connects your upper arm and lower arm to allow movement (5)

Across:

3. Alexis, a young prince with haemophilia, came from this country (6)
4. Used to cool someone down or reduce swelling (3)
6. What you get when your doctor 'sews' up your skin if you get a deep cut (8)
7. Medical care given to a patient for an illness or injury (8)
9. Name for a serious condition that can occur when a person with haemophilia has an a immune response to treatment (10)
14. Short form for a contact sport, played with an egg shaped ball, that could be dangerous to someone with haemophilia (3)
15. A band or bundle of fibrous tissues in a human body that work to move your bones (6)
17. When a blood vessel starts to leak, many molecules come together with platelets to make blood _ _ _ _.

Name the Pictures

Use the first letter of each word to fill in the five (5) spaces below.

____ . ____ . ____ . ____ . ____ .

Now re-write the letter in the boxes below. Use the letter above to help you identify five ways after infusing to recover from a bleed. A clue has been given for each word.

☐ _ _ _ _ _ _ _ _ _ — *To shield from harm*

☐ _ _ _ — *To relax and take it easy*

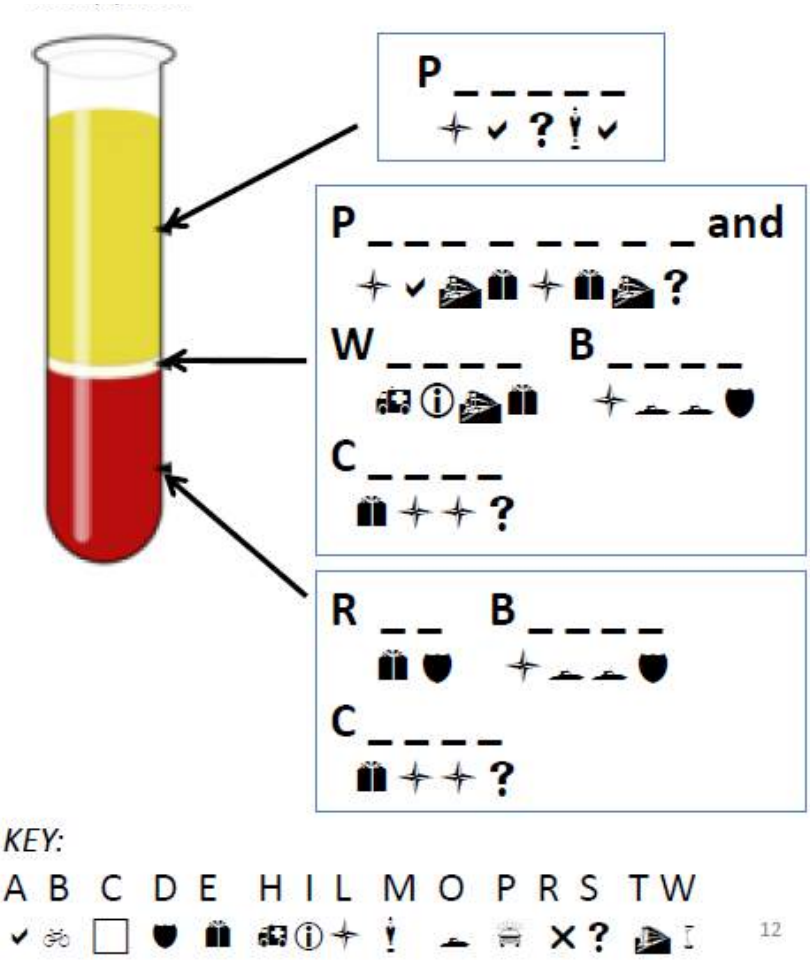
☐ _ _ — *To make cold; rhymes with nice*

☐ _ _ _ _ _ _ _ _ _ _ — *To apply pressure*

☐ _ _ _ _ _ _ — *To raise up high*

What's in your Blood?

Blood is more than red liquid. It is made up of many parts. Can you find their names?



KEY:

A B C D E H I L M O P R S T W

12

Escape Room

If you are looking to find an exciting escape room challenge in the new year , then why not join with us on **10 March 2019** as we experience one of Brisbane's Escape Rooms?

This is a fun activity that puts you in a room for 60 minutes, with up to 10 other people from the bleeding disorders community. Its designed to test your teamworking abilities, problem-solving skills, and intellect to push your brains to the limit.

The goal is to try to solve different objectives and puzzles so you and your can ultimately exit the room before the clock runs out.

Our Escape Room event is for young people although parents can come if they have their child's permission. You, your friends, and family will have plenty of choices for your escape room adventure, which we are sure will be the time of your lives finding clues and solving mysteries.

Important Dates for HFQ Members

- **OBE Lunch Forum**
  informal support group for men with a bleeding disorder. Usually meets first Tuesday of the month. Next Meeting; 5 February 2019. All welcome
- **Australia Day BBQ**
  26 January 2019
  Settlement Cove Lagoon , Redcliffe
- **Youth Escape Room Fun**
  10 March 2019
  venue TBA
- **Women's Brunch**
  17 February 2019 Café 63 Stanley St E. East Brisbane
- **Art Exhibition**
  1 - 26 April 2019
  RBWH Art Space
- **World Haemophilia Day**
  17 April 2019
- **Regional Meeting** *Please ask if one is happening in your area.* **Note:** Planning’s underway for a N Qld event in June 2019
- **Haemophilia & Rare Bleeding Disorders Conference**
  November 2019 Sydney

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

See you in 2019

Drone photo of 2018 Community Camp Participants Courtesy of Charles Eddy

About The H’ Factor

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

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