the H FACTOR

Issue 54
Autumn 2018
Newsletter of Haemophilia Foundation Queensland

From the President

Hi Hi All, hope you and your loved ones are well.

You may recall from my previous reports that the National Blood Authority (NBA) were to commence a health technology assessment for the potential supply of EHL clotting factor products and the implementation of interim and limited managed access arrangements for rFVIII and rFIX products for some (but not all) patients.

This was started last year with a proposed delivery at year end. A lot of work has been done and we are expecting an outcome soon. These initial and limited supply arrangements are not to involve additional cost to governments and will only be available for a limited period while the assessment process is being completed. The limited access programs are expected to provide some immediate benefit to some, (but not all), haemophilia patients while the evidence-based detailed assessment of EHLs is undertaken.

For those involved there is a requirement that data on usage and relevant outcomes are recorded with the MyABDR application. Without this data there will be no evidence to justify these better treatments – this is an exciting time, but reliant on patients recording in the MyABDR application.

The latest news from the NBA is published on page 16 and allows for all people on trials to continue

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Inside this issue:

Presidents Message *Continued...*

to access their 'new' treatment products with provision for some extra places for haemophilia patients with priority needs.

It is clear to me that extended ½ life products will improve prophylaxis outcomes as patient adherence will be better and, if slightly higher trough levels can be achieved better health outcomes will follow. So stay tuned – and many thanks to the NBA for committing to this.

David Stephenson
President HFQ
president@hfq.org.au

Protect Yourself From the Flu!

It's Not Too Late!

If you don't want to join the thousands of Australians who will feel under the weather this year, with a fever and muscle aches and you haven't had a flu shot yet, you should seriously consider getting one. Adults and kids with bleeding disorders can, and should, get the flu shot because the flu has already arrived, and it will stick around all winter!

If you've been wondering if the flu shot works, and what you can do to avoid getting sick, here are some answers to some common flu-related questions:

How long till the flu vaccine takes effect?

It's better to be vaccinated before the start of flu season in early autumn, but whenever you get it, it will still provide some protection. It takes about two weeks for your body to develop flu-fighting antibodies, so don't delay. Flu season typically peaks in the months of July and August but it's already started because people travel and bring it back with them from the northern hemisphere.

Should people with bleeding disorders get a flu shot?

Needles can't be avoided altogether and while many of our members avoid intramuscular injections, if you do go ahead with the flu shot, check with your QHC team to see if it should be preceded by factor therapy.

How do I know if I have the flu?

Like a cold, the flu can cause a sore throat, sneezing, stuffy nose and coughing. Flu symptoms are often more severe, however, and may include fever, aches and chills. Symptoms also tend to come on quickly.

What can I do to feel better?

Get lots of rest and drink water and other clear fluids to avoid dehydration. Because the flu is very contagious, people who think they have it should stay home until they're feeling better, or for at least 24 hours after a fever ends.

When do I need to call my GP?

Most people don't need medical care to recover. However, the flu can lead to pneumonia, bronchitis, sinus and ear infection, and can make chronic health problems, such as asthma, worse. Watch for these symptoms of complications:

- Shortness of breath or difficulty breathing
- Chest pain or pressure
- Sudden dizziness or confusion
- Severe or persistent vomiting
- Symptoms that go away and then return with a fever and cough

In children, also watch for:

- Bluish skin
- Lethargy or unusually irritable behaviour
- Fever with a rash

In infants, be on the lookout for:

- Trouble breathing
- Inability to eat
- Signs of dehydration, like not having tears when crying or having fewer wet diapers than usual

What can I do to avoid the flu?

Washing hands and trying to stay away from those who are sick can prevent the spread of germs. And get that flu shot!

Graham

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. 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	... ...	Mr Erl Roberts
		Dr John Rowell
		Mrs Leanne Stephenson
		Mr Mike OReilly

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 (LCCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown – Haematologist

Haemophilia Fellow - Dr Jonathon Holzmann

Haemophilia Registrar – Dr Terence Lim

Joanna McCosker - Clinical Nurse Consultant

Amy Finlayson / Salena Griffen – Clinical Nurse

Hayley Coulsen - Physiotherapist

Moana Harlen - Senior Psychologist Thur, Fri & alt. Weds.

Cheryl Kadinsky - Psychologist Mon, Tue & alt. Weds.

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 - Haematologist	3646-8111 *(Mobile 0452 055 025)*
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
Desdemona (Mona) Chong - Advanced Psychologist (On Leave)	3646-7937

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 LCCH and Beryl at RBWH.

Paediatric Team Update

Welcome to 2018 everyone!

The year is already flying by with lots going on and planning for the year ahead completed.

Children's Health Qld website

https://qheps.health.qld.gov.au/childrenshealth

Please have a look at this site as it has a lot of useful information about coming to Lady Cilento Children's Hospital (LCCH).

Haemophilia contact sheets and school resource online

The team has recently finished the development, review and publication of the contact sheets and school resources which we hope will benefit everyone. Over the year we will be updating and adding content and resources to our Haemophilia / Haematology service page on the CHQ website

Below is a link to our recently updated Haematology / Haemophilia service on the Children's Health Queensland internet page: *https://www.childrens.health.qld.gov.au/chq/our-services/find-service/service-detail/?Service_ID=64*

The resources include a fact sheet to provide to teachers and a medical action plan containing first aid advice and alerts for serious bleeding episodes.

The medical action plan is an electronic fillable form which must be completed online prior to printing.

- If you require the Haemophilia (this includes carriers) school resources please follow the instructions below:
- Please click onto the link and scroll down the page to find the Haemophilia heading.
- The managing haemophilia at school heading contains a fact sheet that can be printed out and given to the school teacher at the beginning of every school year or to child care settings.
- The haemophilia medical action plan (fillable form) contains information about your child's medical condition and actions to take in the event of an injury. Please fill this information in carefully before giving to your child's day care / school teacher.
- The medical action plan fillable form also contains three drop down boxes:
  - Year Level (from child care up to year 12)
  - Medical Diagnosis (includes haemophilia type, severity and if your child has a port-a-cath device)
  - Hospital Treating Team (option to select other if you live rural or have shared care)
- Once completed please print and sign in the parent signature box and ensure that you have added your contact number in the emergency contacts box prior to giving this to your child care / school teacher.
- This form can be used on an annual basis and can be altered if needed by following the same steps listed above. Please include the date that you complete the form (box provided) so that child care settings and schools have the most up to date action plan.
- The medical action plan and managing haemophilia at school fact sheet should be given together to the child care setting / school teacher. Please ensure you print both forms.

If you have von Willebrand disease, other factor deficiencies or platelet disorders then please use the Mild Bleeding Disorders heading on the same website.

Changing of the Guard - Haematology Fellow

Congratulations to Dr Olivia Starowicz who has completed her Fellow term with our Haemophilia & Haematology team. She also recently became a Consultant (just like Dr Simon) and will be working back at the Gold Coast University Hospital (GCUH) in general paediatrics, so keep an eye out for her if you attend the GCUH.

Coming into the team for 6 months is Dr Jonathon Holzmann (Fellow) who has been working in oncology and brings a wealth of experience in paediatrics. He is also a "pommie" so together with Dr Simon and Clinical Nurse Amy we are being overrun!!!! We would also like to welcome Dr Terence Lim who will be with us for 3 months as our Registrar. Both these fantastic Dr's are sitting their final exams shortly – so we wish them good luck.

Psychologist role update

Moana is now working part time so she can expand her experience and professional development in another field. But don't worry we have recruited a lovely lady, Cheryl Kadinsky who is also a psychologist and will work Monday, Tuesday and alternate Wednesdays for the next 12 months.

Upcoming Leave and other things

World Federation of Haemophilia (WFH) Congress 2018 is in Glasgow this May from the 20 – 24th.

Many of the team will be attending this educational event and gaining insight into the newest research and clinical innovations which impact the management of haemophilia.

Paediatric Team Outreach Clinics

Outreach clinic dates are set for the year as are the telehealth clinics which are held almost every fortnight on a Monday morning. If you think you haven't been seen in the last 6 months to 2 years please send us an email via LCCH-Haemophilia@health.qld.gov.au

OUTREACH CLINIC DATES 2018

Gold Coast Clinic	Wednesday 28th February, 2018
Sunshine Coast Clinic	23rd April, 2018
Toowoomba Clinic	3rd May, 2018
Townsville Clinic	7th June, 2018
Cairns	Friday 8th June, 2018
Mackay	Thursday 19th July, 2018
Rockhampton	Wednesday 18th July, 2018
Gold Coast Clinic	12th September, 2018
Toowoomba Clinic	1st November, 2018
Sunshine Coast Clinic	19th November, 2018

The Paediatric Clinic Mobile Phone

IMPORTANT PLEASE READ:

During times of sick leave or other types of leave the haemophilia mobile may need to be turned off as there is not enough staff to safely manage the phone. Please ensure you don't just send a text to the haemophilia mobile if you need clinical advice for a possible bleed or a treatment plan when you are the having a bleed; as there maybe no one on the other end of the phone. By calling you will reach the message bank and be redirected with a message on who to call.

Welcome Dr Jayne

My name is Dr Jane Mason and I am very pleased to be appointed as a Consultant Haematologist and the Acting Director of the QLD Haemophilia Centre. Many of you will already know me from my previous appointments at both the Paediatric and Adult Haemophilia Centres over the past 5 years. I am both a Paediatric and General Haematologist and am passionate about providing high quality clinical care to persons with bleeding disorders across the lifespan.

My primary research over the past 3 years has been focused around the rare genetic mechanisms leading to severe haemophilia in girls and women. I have also more recently worked with the Australian Haemophilia Centre Directors Organisation (AHCDO) on several clinically focused research projects, most notably the National prophylaxis study which we presented at the HFA conference and was recently published in the Haemophilia journal. I am currently also analysing QLD data which demonstrates that DDAVP (used in some persons who have mild haemophilia A and also for some forms of VWD) given subcutaneously (injected under the skin) works just as well compared to giving the dose as an intravenous infusion.

My appointment at the QLD Haemophilia centre is a part-time position, I am at the Royal Brisbane and Women's Hospital on 3 days per week and on the other 2 days I work as a Haematopathologist in the laboratory at QML Pathology.

I am very approachable and look forward to working together with you and with the Queensland Haemophilia Centre to continue to strive for improvements in care. The next 5-10 years look to bring a number of exciting advances in care for persons with bleeding disorders and I am committed to helping each of you navigate the journey through these changes.

I would like to thank Dr John Rowell for his ongoing support and also the whole team at the Queensland Haemophilia Centre who continue to make me feel very welcome.

Contact details
Ph. 36468111 (request to page through switchboard)
Mobile. 0452055025 (please leave a message if not answered)

Wheelchair Hire Brisbane

During the recovery phase following an injury and/or bleed your child may be required to remain non-weight bearing (No walking or running) for a recommended time frame.

This recommended timeframe will be guided by your Haemophilia Team at LCCH. During this time you may be required to hire a wheelchair:

CENTRAL (City)

Kelvin Grove: Macrae Rentals Pty Ltd
Unit 3/81 Bishop Street, Ph. 3356 3822
Adult and children's wheelchairs available
$55 per week $88 per month
(Delivery costs extra)

Auchenflower: Wesley Pharmacy
30 Chasely Street, Level 2, Stanford Jackson Building,
Ph. 3371 1754
Just one size available (larger adults)
Delivery $10

NORTH BRISBANE

Carseldine: Your Chemist
Clock Corner Shopping Centre, Beams Road, Ph. 3263 7977
$100 deposit $30 per week $100 per month *(local delivery only)*

Brendale: Walk on Wheels
Unit 1/260 Leitchs Road, Ph. 3205 5654
Multiple size wheelchairs
$40 per week $100 per month

EAST BRISBANE

Cleveland: Elan Medical Supplies
40 Middle Street, Ph. 3286 6336
$22 per week

Carina: Carina Day and Night Pharmacy
834 Old Cleveland Road, Ph. 3398 2501
Have mostly adult size wheelchairs but have one 14" paediatric wheelchair for loan
Around $25 - $35 per week

SOUTH BRISBANE

Woodridge: Mobility Rentals and Sales
170 North Road, Woodridge
Ph. 3056 0651
Adult and children's wheelchairs available at $20-$50 per week for wheelchair hire

Acacia Ridge: Aidacare
252 Bradman Street,
Ph. 1300 133 120
Multiple wheelchair sizes
$12-$20 per week

WEST BRISBANE

Goodna: Goodna Day & Night Pharmacy
219 Brisbane Road,
Ph. 3288 2231
Adult size wheelchairs only
$50 refundable deposit $40 per week $120 per month

Corinda: Corinda Day & Night Pharmacy
661 Oxley Road, Ph. 3379 2189
Just two adult size wheelchairs for loan
$50 deposit $20 per week $70 per Month

These locations do provide wheelchair hire, however there are various other locations across Brisbane and various pharmacies that hire wheelchairs as well.

Sneak peak at an upcoming workshops

This edition, I thought I would provide a sneak peak or a taster for a series of workshops I am planning for later this year around well-being. Many of us have times when we have a low mood, may worry a little more than usual, feel stressed or overwhelmed and may want some strategies or suggestions that help us live a happier life and manage those times when situations are a little challenging.

These strategies may be ones that you are already using or may be an addition to what you already do maybe every day or maybe you use them out when you notice you are struggling a bit more.

There are a lot of strategies and models which assist people with improving their well-being. For example: Dr Timothy Sharp (an Australian Psychologist) describes a ***CHOOSE*** model –

C = Clarity of life goals, direction and purpose;

H = Healthy living;

O = Optimism;

O = Others;

S = Strengths and

E = Enjoy the moment

(Sharp, 2007).

The South London and Maudsley NHS Foundation Trust in the United Kingdom have developed a Wheel of Well-being, in which strategies are focused on Body, Mind, Spirit, People, Place and Planet (*www.wheelofwellbeing.org*).

Action for Happiness has 10 keys to happiness –

- Giving
- Relation
- Exercising
- Awareness
- Trying out
- Direction,
- Resilience
- Emotions
- Acceptance and
- Meaning

(*www.actionforhappiness.org*).

All of them have been researched and importantly the thing I like about these strategies is that they allow the individual to take an active role in building on your own strengths and taking steps to improve your own well. They also have strategies which focus on relationships with others and being kind to yourself. There are strategies such as gratitude, kindness, having an awareness of your own goals/purpose and what brings meaning to your life. Many of the strategies are easy to incorporate into your daily life. However, like most things they do take commitment and practice and of course then continuing to use them on a regular basis.

Of course, I don't want to give away all the strategies in the article, as then you won't want to come to the workshops, but I will share with you a simple strategy that you can practice now.

This strategy is to explore gratitude (which fits in nicely with the three models above), The exercise is to write down each night, or perhaps share at the dinner table – 3 things that you (and your family if you are sharing it around the table) are grateful for each day.

A recent workshop I attended encouraged participants to not repeat their examples of being grateful for an entire year!! I have been doing this exercise since the start of February and I must admit I have had some struggles, wanting to write down "a cup of tea" and "chocolate" on many occasions – but so far I have resisted the urge and have found 3 new things each day that I am grateful for.

The workshops that I will be facilitating will also be in line with the World Federation of Haemophilia theme for this year ' sharing knowledge makes us stronger', where I hope that I am not the only one sharing knowledge as I know that there is a wealth of knowledge in the community around what has made you resilient and strong.

Keep an eye out in the next edition for dates and topics!

Loretta

Loretta Riley
Advanced Social Worker
Ph: 3646-8769

Increasing visibility at WHD

Awareness and advocacy have been central to HFQ's mission since the organisation was established. HFQ has reached a significant milestone this year with our patron, the Governor of Queensland, His Excellency the Honourable Paul de Jersey AC, and Mrs Kaye de Jersey hosting a function to mark World Haemophilia Day

HFQ originally got government funding because the HIV/AIDS and hepC crisis was having a devastating impact on our community. But the crises of infected blood seems to have passed, and most doctors get a cursory sentence or two on bleeding disorders during their medical training. Many members tell us that if they have to go to a hospital causality department because of a suspected bleed they first have to educate the staff what a bleeding disorder is.

HFQ's goal is to get more public attention for Haemophilia and other Bleeding Disorders and we have organised for several Brisbane landmarks, including Story Bridge, to be lit in red on the night as part of the event.

This years theme for WHD is "Sharing Knowledge Makes Us Stronger" and at HFQ we agree. We want the entire community to understand that preventing complications for people with bleeding disorders is vital and that there are many bleeding disorders, not just haemophilia A & B. Because haemophilia can have a bigger impact, we seem to have more members with these conditions than with others, but did you know that many people living with VWD are not yet diagnosed.

We also want to use this day as a platform to get a global message out. Although our community here in Australia has remained relatively healthy over the past 20 years, there are 400,000 people globally with haemophilia and untold millions with VWD. Seventy percent of them have minimal access to treatment.

At the government house function, we will also be thanking Dr John Rowell for his on-going work and care for members of our community, and we have invited the health minister and opposition spokesperson to attend. Those of you attending also will have the chance to meet with these MPs and tell them your personal stories.

As people touched by bleeding disorders you make fantastic advocates. Please use those same skills you use to advocate with their doctors, kids' school teachers or insurance companies, to talk to your local community and tell them that we are still around and we invite them to support us, especially as we wait patiently for the new treatment products that are coming on-stream; and to protect the services offered by the Queensland haemophilia centres.

We also welcome stories and photos from our readers themselves, showing or telling us what bleeding disorders mean to them. You can also post to your friendship networks via photos and videos on Facebook, Instagram or Twitter.

In the bleeding disorders community, federal advocacy remains essential and HFA does this for us, but your stories help. HFQ members are leading the way. For example, last year two of our young men, Darian and Ian participated in HFA's Youth Lead Connect program, a nationwide leadership training program for young adults. Among other activities, when they got back to Queensland they hosted local events and posted videos to speak to their local community about bleeding disorders.

Another option for story telling through art is our 'Bleeding Heart' competition (see back page and our website for details) which is now open to all young people until Haemophilia and Other Bleeding Disorders Awareness week.

One Eye Superman ...just ask me

Hi Everyone. My name is brett. This time I'm going tell to you about my other disorder. As some of you may have seen, I have a large tumour over one of my eyes, and this is why I'm writing this article; to let you all know why and to ease you mind if you want to ask me more. So here is part II; on how I live day by day with the two disorders I was born with; severe Haemophilia and Neurofibromatosis.

Neurofibromatosis is also an inherited disorder but neither of my parents have it. Neurofibromatosis (or NF) is an autosomal dominant disorder, which means only one copy of the affected gene is needed for the disorder to develop. Neurofibromatosis causes nerve tissue to grow tumours (neurofibromas) that can be benign, but they may cause serious damage by compressing nerves and other tissues.

There is no known prevention or cure for Neurofibromatosis and having severe haemophilia, it wasn't an option for me to be operated on. I am the only person in Australia that I know of to have both disorders at the same time.

Surgical removal of tumours is sometimes an option especially if they are causing problems or become cancerous, however the risks involved should be assessed first. And there's no chance of that for me

The type I have is NF1, which has seen a tumour grow that covers much of my left eye. It's called an optic pathway glioma (OPG) and because of its location cannot easily be removed via surgery, so the preferred treatment is chemotherapy. I wasn't allowed to commence that until adulthood.

In Australia there is around 1 in 2,500 people who has NF1. NF1, symptoms are often present at birth, and otherwise develop before 10 years of age. While the condition typically worsens with time, most people with NF1 have a normal life expectancy.

It is recommended that children diagnosed with NF1 at an early age have an examination each year, which allows any potential growths or changes related to the disorder to be monitored.

NF1 is quite mild in 60% of cases with people experiencing light coffee coloured spots on their skin. But growths around the eye are not uncommon, they normally grow on the iris itself but, as in my case, it can result in physical disfiguration, pain and even cognitive disabilities in about 25 to 40% of cases.

NF1 can be severely debilitating and can cause cosmetic and psychosocial issues, but it isn't usually life threatening. It's not a rare as most bleeding disorders, but because it's more visible in my case, I experienced some bullying and discrimination as a child. Unfortunately, it still continues as an adult, probably because people can be uncomfortable with my appearance and yet they don't ask or try to understand which is what this article is about.

I was around two or three years old when the NF was diagnosed. Even as a baby, my left eye was closing, and at school in Canberra I was conscious of it and the kids called me "one eye superman", which I felt was not nice and I had thought they were teasing me, but on reflection as an adult it was actually a compliment, because I was quite active at primary school.

After school I've had several jobs, from busway controller, receptionist and office jobs. I worked for the Queensland Police as a data entry operator doing typing and data entry and I worked for Serco as a busway controller when they were hired to run the Brisbane busway. But ideally, I'd like to do something that involves my crafty side and if I could get a job that included that part of my life as well, that would be just great. In an ideal world I would turn my art into a career.

Brett

For more information on NF go to www.justaskfoundation.org

Taking Charge when you need surgery

In the past few years, Mike Hargett has lost 127kg, was treated and cleared of the hepatitis C he contracted from a blood transfusion during brain surgery when he was only 2 days old. He was diagnosed with dilated cardiomyopathy in 2004 and became the first person in the US with haemophilia to receive a heart transplant.

Mike's failing heart pressured his kidneys, and he had to undergo a kidney transplant as well. It's been a 3 year emotional roller coaster and Mike was fighting all the way for a life with a brand-new heart and the ability to pee again.

Mike is only 32 and he contracted HepC as a baby. Mike lived with it for a while, but as a teenager he got sick with cirrhosis of his liver, so he was lucky in a way that, when he found out about his heart condition, the new HepC treatments were coming on stream .

His cardiologist submitted papers for early approval and funding, and in 2012 Mike started on one pill a day with the new medication. Within the first 2 weeks he was undetectable, and he's been undetectable ever since.

Mike trained is a chef and any time he cut himself he had to tell others that he had HepC. He felt the stigma that comes with HepC put a negative light on him, regardless of how he got it, and one of the unexpected benefits of treating the HepC was the psychological relief of not being in the spotlight and not having to ever disclose that again. Mike has found this to be as important as the physical benefits of having cleared it.

But magnificent as that is, it was just stage one. In 2014 when Mike found out that he needed a heart transplant, but they said they couldn't do it because of his haemophilia and because he weighed 229kg. It was a difficult time. Mike says that when clinical staff learnt he had haemophilia, he had to argue his case and ended up teaching the doctors and being his own advocate.

To get a transplant, Mike also needed a BMI of 35 or less, so he quit his job, moved in with his parents, and started working out full time. By eating less and exercising more he was able to get the weight off. It took him a year to get started and then two years to finally get the rest of it off. He also went to a lot counselling and got help for emotional eating, a result of feeling a lack of control over his personal health and family issues.

To control his eating Mike had to take more control back into his life and, because he'd moved home it also entailed establishing an adult relationship with his mum, not letting her do things for him. He also realised that anytime he went to the doctors, whatever happened good or bad, he'd celebrate with food and that had to change. He had to figure out what he could do instead. He learnt to play the piano and enjoy exercise and being outdoors …and relying on friends and close supporters.

Each success in his diet was from smaller incremental and more realistic steps that started with his mind-set. Mike set small goals and read quotes and story's from inspiring people such as Babe Ruth who said; "Its hard to be the person that never gives up". Mike found the more momentum he got by winning small goals, the better he felt and he wanted to keep doing it because he keep hitting his milestones.

Mike got people involved with his goals. Every time he didn't know what to do or turned to food, he called friends and they would talk him through it, or go for a walk or work out together. Mike does Weight Watchers because he's still learning how to eat healthy, but more than the meals is the support. Mike says that when you're with likeminded people, there no judgement.

Mikes bleeding disorder had a financial impact and, because he quit his job Mike went onto social security, but he was supported by friends and family who helped financially, made meals or took him out to juice bars or walking as a better way to congratulate his success. When he found he didn't have to use food as a celebration, that was the winner. He had figured out that he needed to take care of himself and knew he was worth it.

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St Patrick's Day Fundraising BBQ

HFQ had another Bunnings BBQ fundraiser on St Patricks Day and it was a great success! We want to thank Shannon Weatherall, our long standing organiser of this event and to all the community members who came along on the day, we hope you enjoyed your evening as much as we did!

Shannon organised the rosters and the day itself. She took time off work to stay with us and make it the success it was. As always Bunning Rothwell provided amazing support, giving us the captive audience and providing the BBQ facilities and gas.

We were constantly run off our feet on a very hot day and thanks to our willing customers who spent their money with us, we are pleased to announce that we sold nearly $1,500 worth of drinks and sausages which ended up raising $1000 after expenses, so a big thank you to those who came to help, which we appreciate.

We had people coming from everywhere, so there was never any down time and we especially thank Bob Etrahani and Michael Churchill who both took time out of their busy days to help out.

The funds we raise at events like this go back into the community for use where needed most, such as things our government grant does not cover.

Brett

BBQ Volunteers from L to R: Brett Williams, Lynn Weatherall, Robbie Weatherall, Graham Norton & Shannon Weatherall

Taking Charge continued...

Once Mike hit the right BMI he was deemed eligible to have a transplant, but the caveat was that they still didn't want to accept him as a transplant candidate because of the haemophilia. He was considered too high a risk and he went through 5 different institutions all over the country arguing his case before he found a hospital who was willing do the procedure. The cardio team at Cedars-Sinai Medical Centre in LA worked with his home state haemophilia clinic in Portland, Oregon and they came up with a plan. Mike was on a constant drip of factor 4 days pre and post the procedure. He went through almost half a million units of factor.

The two teams were totally on his side. They asked questions, did he feel right, was he on board with the care plan and did he want anything changed in it? With good due diligence and all this coordination of information between teams, there were no residual side effects and Mike bled less than 750ml of blood throughout the entire procedure. After the operation he had twice a day infusions for almost a week and a half; and then he went to daily infusions for two weeks after that, just as a precaution.

Most people think that transplant is a cure and it IS amazing. He has an extra life expectancy of at least 25 years before he needs another kidney, and the heart gives him between 15 and 20 years extra life. But many people have gone on for longer and it's not the numbers that give you life, its being compliant with the doctors, taking the meds and living the lifestyle that you need to, advocating and realising that it's about self-care and taking care.

Mike is still working on cardiac rehab and regaining his strength and independence. Now that the heart transplant (and recent kidney transplant) are over Mike is looking forward to getting into work and living his life. Mike is building a heart healthy food truck to utilise his culinary skills to prepare healthy and delicious meals. Because he's passionate about food, and providing healthy alternatives for people, the idea of a mobile food truck equipped to offer Mediterranean style heart healthy tapas seems a great niche market for him. He's also a huge advocate for organ donations and wants to get the truck up and running so that he can travel the country being an advocate for organ donation and living a heart and renal health lifestyle and just telling his story.

Edited by Graham from an amazing interview on BloodStream Podcast (Ep. 21: February 19, 2018). For more information on Michael Hargett check out his website at; www.newheart4mike.com

Treatment For All

We are truly a lucky country. While many members get factor delivered to their door or have other products dispensed as needed, the cost of products to treat bleeding disorders is prohibitively expensive for those people living in developing countries, which represents the majority of people in the world affected with a bleeding disorder.

This lack of access to care and treatment in developing countries is an urgent and important public health challenge that is being challenged by our world body, The Wold Foundation of Haemophilia (WFH). The WFH is coordinating the provision of consistent and predictable access to treatment for all people across the globe.

WFH have a Humanitarian Aid Program that was created in 1996. Since that time:

- **90 countries have been reached**
- **100,000+ people helped and**
- **462,000,000 IU's distributed**

For many developing countries, product donations are often the only source of treatment product for patients with haemophilia and other bleeding disorders. The WFH receives requests, many urgent in nature, from national member organisations (NMOs) and from recognised haemophilia treatment centres (HTCs) around the world.

The WFH also channels treatment products to support their healthcare development programs such as the twinning programs we have previously been involved with such as the close relationship the QHC has with the Philippines as part of this commitment.

The NBA says that people used an average of 110,897 IU's of factor per person in Australia in 2016. The WFH says that in the countries that qualify for donations of factor, the per capita use of clotting factor concentrate is generally less than one IU!

This is not enough to prevent bleeds and people are still dying in the developed world, so the WFH sends factor products donated by the big pharmaceutical companies to registered HTCs or to WFH NMOs in those developing countries.

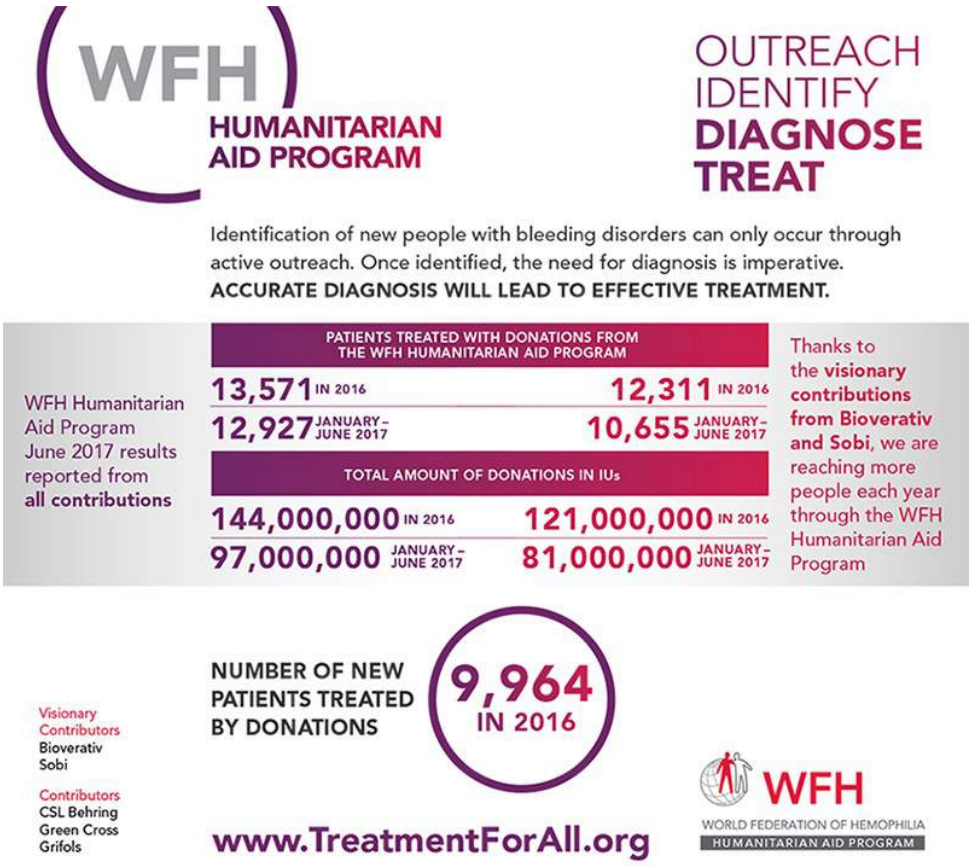
And the donations are huge! Australia pays for and uses just under 200 million IU's every year, but one of the biggest donors to the WFH Humanitarian Aid Program is Bioverativ and Sobi who have committed to give 500 million IUs over five years (2015-2020). That's two and a half years of our factor usage donated and they also give financially to support the logistics of product delivery and training of providers and patients in the humanitarian aid countries.

Amongst the other pharmaceutical companies, Grifols has committed to 200 million IUs over 8 years and CSL Behring; 22 million IUs, This allows the WFH to manage a fairly predictable and sustainable flow of humanitarian aid donations to the global community.

On the ground each local treatment centre has to obtain licensing permissions to allow the donations to be imported into the country. Once all of the relevant documentation has been prepared, the donations are packaged and shipped in a timely manor.

With increased multi-year donations and a steady flow of treatment products to the WFH network, it will be possible for people with bleeding disorders in the developing world have continued access to treatment for emergency situations, acute bleeds, corrective surgeries, and also prophylaxis for young children.

The WFH Humanitarian Aid Program has some great on-line videos that describe this important work and we encourage you to view them for yourself at: *www.treatmentforall.org*



Myths and Facts About vWD

The most common of the bleeding disorders is one most people don't know about ...Von Willebrand Disease.

While Haemophilia takes most of the public awareness and affects as many as 2,700 people in Australia with varied degrees of severity, the most prevalent bleeding disorder, von Willebrand disease (VWD), affects more than 200,000 Australians, about 1% of the population. Like haemophilia, VWD is a genetic disorder caused by a missing or defective clotting protein in the blood. In VWD, the problematic protein is von Willebrand factor, which plays a key role in the clotting process. Despite VWD being more common than haemophilia, numerous myths and misunderstandings persist about the disease.

Myth: Only women have VWD.

Fact: VWD occurs equally in men and women.

Myth: Women and men with VWD have the same symptoms.

Fact: Symptoms in both men and women vary depending on the severity of a person's VWD. Both women and men may have frequent and prolonged nosebleeds, bruise easily and have excessive bleeding after surgery or dental work. In addition, women may experience heavy menstrual bleeding (HMB) and bleeding problems during and after childbirth.

Myth: There is only one type of VWD.

Fact: There are three main types of VWD and several subtypes.

Type 1 VWD is the most common and the mildest form. In type 1, the body has low levels of von Willebrand factor. People with type 1 may also have low levels of factor VIII, another blood-clotting protein. According to the Centers for Disease Control and Prevention (CDC), 85% of people treated for VWD in the US have type 1.

In type 2 VWD, the body produces a normal amount of von Willebrand factor, but the clotting protein doesn't work as it should. There are four subtypes of type 2 VWD—2A, 2B, 2M and 2N—depending on the problem with the von Willebrand factor. Each subtype is treated differently.

Type 3 VWD is the rarest and most severe form. In type 3, the body makes little or no von Willebrand factor and has low levels of factor VIII.

Myth: VWD is easily diagnosed.

Fact: Because most men and women with VWD have type 1 and thus don't regularly have significant bleeding episodes, they may not receive a diagnosis until they experience a major trauma, either from surgery, injury or dental work. Nosebleeds, bruising and HMB may all be attributed to other causes, further complicating diagnosis. Various tests performed by a haematologist can provide an accurate diagnosis. However, some tests may need to be repeated because von Willebrand factor levels can fluctuate in the body and are influenced by stress and hormones.

Myth: There's no treatment for VWD symptoms.

Fact: Treatments are available to help control bleeding. The most common treatment is desmopressin (DDAVP), which boosts von Willebrand factor levels in the blood and can be taken by injection or nasal spray. Other treatments may include factor replacement therapy; drugs that help prevent the breakdown of blood clots; and, for women, hormone therapy such as birth control pills. Treatment depends on the type and severity of a person's VWD, so it's vital that patients work closely with their healthcare team to establish a management plan.

Myth: Because it's not life threatening, it's not a problem.

Fact: Living with VWD can have a psychosocial impact as well physical symptoms. Some people experience feelings of isolation from others who don't understand the disease. Some have exhaustion due to physical symptoms and the vigilance of watching for them. There is also the uncertainty of work and school disclosure and about if of when the next bleed will occur.

Edited from Hemaware https://hemaware.org/bleeding-disorders-z/5-myths-and-facts-about-von-willebrand-disease-vwd
For more on von Willebrand disease, visit the National Hemophilia Foundation's Steps for Living website.

Gene Therapy for Haemophilia

Gene therapy covers a diverse range of treatments for genetic disorders that seek to deliberately insert a new gene or repair the mutation the person carries within their own genetic material. The most common techniques use viral vectors and most haemophilia trials use an Adeno-associated virus (AAV) which is part of the family of cold viruses.

The AAV vector is stripped of its proteins, so it can carry the required Factor VIII or IX gene and not replicate itself. They also put in some coding for homing, so that the capsule will go to the liver, and then there are other modifications to help take it into the cell and replicate within it. if you've had the cold virus in the past and you have pre-existing anti-bodies, your body may react to the AAV vector and destroy it, making gene therapy ineffective for you.

This gene transfer method is the most developed for haemophilia but lentiviruses are also a candidate for gene therapy and have been used in other genetic diseases with a lot of success. Another method; electro chemically makes little holes in the cell and pushes the gene into it and there are several other methods too.

The gene therapy that is done in haemophilia trials involves a simple IV infusion in the elbow and participants are generally adults 18 years and older, without inhibitors, who require prophylaxis or have a certain number of bleeds per year. In the future, provided HIV and hepC are being treated, only an individual whose immune system is badly damaged would most likely be excluded from gene therapy.

Gene therapy might also be good for the people with inhibitors, because if the vector carries the gene into your liver the gene will then code for the protein to be made and secreted into the bloodstream at a continuous rate, so you will be continuously putting Factor VIII or IX into the bloodstream at a steady level and it will be like being on super immune tolerance.

Gene editing and splicing are a different technology. It's a way to repair your own gene and it can be targeted to where your Factor VIII or IX gene is. A cut is made across the DNA to lift out the mutation and splice in a pre-made cassette that contains the proper code and then by complimentary recombination the DNA would also copy the normal recording and repair your gene.

The viral vector clears from the body in about three weeks so there is no long-term effect from those viruses, but some early trials found that it also caused an inflammation of the liver and because we want the haemophilia gene to go into the liver, a lot of work is done to screen for pre-existing inflammation and to ensure trial participants don't have antibodies.

Another concern is putting the gene exactly where it's wanted. There is a risk that the gene could insert itself by a growth factor, and it's possible that the genes could then disrupt the normal regulation of growth and could cause a tumour or in a developing foetus cause a birth defect. To avoid this, the gene is inserted into the cell but not into the DNA itself.

For a full cure, Factor VIII or IX levels need to be restored to normal for an indefinite period, but some people may need a top up treatment after some time. With the trial news released late last year people have had a stable gene reconstitution for up to 4 years but we just don't know how long it will last and if you need re-treatment you will have to use a different type of vector to the one you had initially.

Right now researchers can't regulate how much gene you get. Factor IX therapies have been consistently getting levels of between 4% and 10% which is a great improvement, but not a cure. Recently a mutated Factor IX has been found to have eight times the power of a normal Factor IX molecule and it could get you eight times the current levels, or 48% and you would be near the lower limit of normal.

Factor VIII results have been more variable and some individuals have had low factor levels while others have come out with 200% Factor VIII or higher! The big discussion with Factor VIII is how much should we give to avoid both blood clots and heart attacks or strokes.

Current gene therapy does not pass the 'fix' onto your children so your children who will have to get their own gene therapy when they're old enough.

In the long run it's going to be a better treatment, it's going to give better patient quality of life, better health outcomes and ultimately be less-expensive. Once we know it's safe for us and its likely to work and offer effective return on health dollars it will make it easier to say yes, so ultimately, they will come up with a model that works in all countries and funding in first world countries like Australia shouldn't be a barrier.

Edited from an interview with Dr. Manco-Johns by Chris Bombardier. *http://www.bloodstreamexpert.com/*
For more details information see March 2018 National Haemophilia (page 5)
Always consult The QHC staff before making any decisions about treatment.

Health Updates

Many Hemophilia B Patients Have Pain, Depression and Overall Poor Health, Study Finds

A recent European study of 299 adults and 150 caregivers has found that many haemophilia B patients experience joint pain, depression and overall poor health. Other findings were that women with haemophilia B had worse health than men and that those caring for children with the disorder often experience anxiety and depression. Researchers found links between levels of patients' pain and unemployment, and levels of pain and their use of opioids and anxiolytics.

Large-scale studies covering haemophilia A and B have shown similar results but most of the patients in these studies had haemophilia A, so findings on haemophilia B have been limited so the research team designed the trial to try to address these shortcomings.

Early results showed that haemophilia B hurts patients' work life, ability to obtain an education, and ability to participate in recreational activities. Caregivers reported that it affected their children's education, relationships, and physical activity. The caregivers also said that their children's condition made it harder for them or their partners to work.

Another finding was that adults with moderate haemophilia B reported poorer overall health than those with a mild or severe disease. This indicated that patients with a moderate disease "may be more affected by pain and mental health issues than previously recognized," the researchers wrote.

European Journal of Haematology https://onlinelibrary.wiley.com/doi/full/10.1111/ejh.13055

Sports Therapy Can Benefit Rare Disease Patients

A recent study concludes that, since people with haemophilia (PwH) often suffer from impaired motoric skills due to bleedings, sports therapy is helpful to better the reduced function.

To reduce the progression of the disease, appropriate therapies adapted to the necessities of PwH are applied. Particularly, physio- and sports therapy treatments should be associated with each other, the former in the acute phase immediately after a bleed, and the latter after the bleeding has completed.

It has been proven that sports and other activities that require physical exercise, if monitored, can be considered an approved therapy for patients with bleeding disorders.

With this concept, it is possible to bring therapy to the patient, as opposed to patients having to travel to receive therapy.

http://www.raredr.com/news/can-sports-therapy-benefit-rare-disease-patients

Workers with Haemophilia More Likely to Have Stroke or Joint Disease

Workers with haemophilia are at a much higher risk of stroke, developing a joint disease, or needing a knee or hip replacement than the general population. A 14 year Taiwanese population based study reported in the journal Medicine.

The researchers compared the overall health of 411 Haemophilia patients with the general population and found that Haemophilia patients were 4.6-fold more likely to have a stroke, four times more likely to develop a joint disease — arthritis or arthropathy — and 1.29-fold more likely to need a knee or hip replaced.

https://hemophilianewstoday.com/2018/03/12/workers-with-hemophilia-at-higher-risk-of-developing-other-health-conditions/

Plan Underway To Form Fiji Haemophilia Foundation

In February at the first medical symposium focused on haemophilia held in Fiji, a plan was instigated to form the Fiji Haemophilia Foundation that will look after the interest of those diagnosed with haemophilia.

The objectives of the foundation would be to create awareness, source services and medications, and advocate for people with haemophilia in Fiji.

There is a general lack of awareness, stigma, discrimination and major gaps in medical services for people living with this genetic condition.

Over 50 participants including medical practitioners, nurses, educators, people with haemophilia and their families were at the symposium.

http://fijisun.com.fj/2018/02/19/plan-underway-to-form-fiji-haemophilia-foundation/

Hemlibra Treatment News

Hemlibra is the USA name of the subcutaneous treatment previously called emicizumab. Its approval late last year in the USA and Europe in adults and children with haemophilia A who have factor VIII inhibitors antibodies marked the first new haemophilia A treatment in almost 20 years.

Regretfully five adults with haemophilia A are reported to have died while using Hemlibra but in each of these cases, it was deemed that the cause of death was unrelated to Hemlibra.

HFQ believe that you should always have a detailed discussion with your haemotologist before starting on trials or drugs you haven't had before as only the QHC team can best understand and tune your treatment regimen with respect to your individual bleeding and clotting needs.

https://hemophilianewstoday.com/2018/04/04/hemophilia-a-patients-deaths-not-related-hemlibra-genetech-says/

Extended Half-Life Clotting Factor in Aus

HFA have advised us that all former trial patients using Extended Half Life products are confirmed as having ongoing use of their current treatment and some extras. Unfortunately there may not be much scope for many extra haemophilia A patients yet.

The NBA has published details on these arrangements to their website at: *https://www.blood.gov.au/plasma-and-recombinant-product-procurement*

They say that at the request of Australian Governments, the NBA has entered into limited interim arrangements with two companies, Bioverativ and Shire, to provide temporary access to extended half-life (EHL) clotting factor products under NBA supply arrangements for a limited number of haemophilia A and B patients with high priority needs.

These arrangements will be in place pending the outcomes of an evaluation by the Medical Services Advisory Committee to support government decisions about whether extended half-life clotting factor products should be available under publicly funded

supply arrangements managed by the NBA on an ongoing basis.

Only a limited number of patients are can be covered under these interim arrangements:

- the Bioverativ product Eloctate (recombinant Factor VIII) will be available for around 40 patients
- the Biovertiv product Alprolix (recombinant Factor IX) will be available for around 60 patients, and
- the Shire product Adynovate (recombinant Factor VIII) will be available for around 100 patients.

Further information about the limited interim arrangements is available as follows:

A general overview of the arrangements (*www.blood.gov.au/system/files/EHL-framework.pdf)*

Patient information sheet and acknowledgment form (*www.blood.gov.au/system/files/EHL-patient-info-sheet.pdf*)

Patients who wish to find out more about these limited interim arrangements should contact their specialist Haemophilia Treatment Centre clinician.

These limited interim arrangements have been put in place following consultations undertaken within 2017. More detail on these consultations can be found at *https://www.blood.gov.au/2017-closed-public-consultations.*

MyABDR: We Need You!

In 2018 there will be further development of MyABDR as part of the National Blood Authority Crimson Project. HFA is looking for a few more MyABDR users to join the HFA MyABDR Focus Group to give feedback on the current MyABDR system and proposed changes.

INTERESTED?

You would need to be:

- Currently using MyABDR
- Prepared to answer questions via email from time to time in the next 12 months
- Perhaps do some home testing of proposed enhancements.

If you would like to participate, please contact Suzanne at HFA on socallaghan@haemophilia.org.au or 1800 807 173.

Bridge to Brisbane

Bridge to Brisbane Day last year celebrated the 21st running of this much loved Queensland event, don't miss out for 2018! HFQ has several people participating and you are welcome to join with us on the run. You will enjoy a course that takes in some of Brisbane's most iconic landmarks including running over the Story Bridge and finishing at the beautiful South Bank Parklands.

Choose to take on the 5k or 10k challenge and join with the Haemophilia Foundation Queensland Team and take on the challenge to raise vital funds for people in Queensland affected by bleeding disorders. Entry has just opened offering early bird rates and if you are thinking of taking part in 2018 for HFQ then please let us know.

Make your next fun run effort mean more and fundraise amongst your friends, colleagues and acquaintances to support HFQ. As a member of our team you will be eligible for a number of rewards and incentives including HFQ merchandises.

We can also provide you with one-on-one fundraising support, including a fundraising plan and social media tools to help you achieve your fundraising goals. To join Team HFQ all you need to do to is register for the bridge to Brisbane run in your preferred category and elect to fundraise for HFQ. Once you're signed up, let us know and we will be in touch.

If you have any questions, or for more information about Team HFQ please call the office on 0419 706 056 or email info@hfq.org.au

The 7 Summits — A Hemophilia Triumph

On January 6, Chris Bombardier made history by being the first person with hemophilia to complete the Seven Summits-reaching the top of the highest peak on each continent. His accomplishment proves that with proper training, medical treatment, preparation and determination someone with a bleeding disorder can pursue ambitious physical goals.

Chris has severe hemophilia B and is fortunate to live in a country where treatment is readily available. He wasn't always a mountaineer; his first passion was baseball, which he played in college. After graduation, he returned to his home state of Colorado, where his uncle encouraged him to try mountain climbing.

In 2013, Chris climbed Aconcagua in Argentina, then 18,510-foot Mt. Elbrus in Russia. In 2014 he took on the highest peak in North America-Denali. In 2015, Chris traveled to Papua, where he summited 16,024-foot Carstensz Pyramid, the highest

peak in Australasia.

Chris summited Mt. Everest on May 22, 2017. Only hundreds of feet from the top, he lost his energy and hope. Tashi Sherpa clipped Chris into a rope and reminded him that his friends, family and community were rooting for his success and helped him to keep going.

After this success Chris was granted permission to climb Mt. Vinson in Antarctica and Chris is now one of only 450 climbers in history to complete the Seven Summits-and the only one with hemophilia!

Through his climbs Chris helped raise over $90,000 for Save One Life's programs and inspired others to sponsor more than 50 children.

To learn more about Chris and his Seven Summits Quest, visit http://adventuresofahemophiliac.com/seven-summits/
To learn more about Save One Life, visit http://www.saveonelife.net

Snack Attack

Snacks can boost your energy

School days are here again, and you need to fuel your brain with important lessons and fun information. But what will you do to satisfy your appetite when you get home?

If it's been hours since lunch but dinner isn't ready yet, it's important to grab a snack. Snacks will boost your energy and help you stay focused for crucial things like homework later.

But after school, when you're studying, playing with friends or relaxing, it's easy to go for something quick and tasty, such as potato chips or cookies. These foods may taste great, but they aren't always good for your body. Ask your parents to stock up on good-to-eat and easy-to-prepare foods for these times. That way, when you need a snack, you'll have plenty of yummy, healthy things to choose from.

Nutrition Matters

Eating healthy foods will keep your body strong, energized, and well nourished. It will also help you maintain a healthy weight. Eating lots of foods with extra fat, added sugar, and empty calories will pile on the pounds. And being overweight is an even bigger problem for people with bleeding disorders than it is for others. It puts extra stress on joints and actually increases the number of painful bleeds. And because body weight determines how much factor a person needs to treat a bleed, maintaining a healthy weight can decrease the amount of factor you need.

What Is a Healthy Diet?

Eating a variety of healthy foods will help you get the energy, protein, vitamins, minerals, and fiber you need to grow and be healthy.

Hungry Hour

Eating good food is the best way to make sure your body gets all the fuel it needs to grow and stay strong, such as calcium, fibre and protein. These good components can be found in fresh fruits and vegetables.

Here are a few tips for what to grab when your next snack attack strikes:

- Stay away from fried snacks—no potato chips, french fries, or fast food. Instead, reach for baked snacks, such as pretzels, air-popped popcorn or rice cakes.
- Drink more water and milk. Juice and sodas may taste good, but they also have a lot of sugar. Water and milk will not only satisfy your thirst, but keep you healthy!
- Stock up on fresh foods from the grocery store or a farmer's market. Slices of fruit, vegetables, low-fat cheese, and lean meat and fish are all good for you.

Quick Bites

There are many healthy snacks you can choose, and some need to be fixed ahead of time. Ask an adult to help you get parts of some of these snacks ready so you can easily make them when you're hungry:

- Slice up fruit and assemble it into a "kabob" that you can have later with yogurt dip.
- Cut up fresh vegetables like carrots or celery into sticks so you can dip them in hummus or low-fat salad dressing.
- Spread peanut butter or jelly on a rice cake.
- Mix it up with a homemade trail mix of dried fruit, cereal, nuts, pretzel minis and yogurt chips.
- Dip pretzel nuggets into honey mustard.
- Layer low-fat granola or cereal and fruit together with yogurt or frozen yogurt for a parfait.
- Make sugar-free gelatine cut-outs.

Eating these healthy snacks is another way to take care of yourself. They give you more energy to do fun things such as riding your bike or playing with friends. Save cookies, chips or pizza for special treats.

Change your snacks, too, and try different food groups—a glass of milk and whole-grain crackers, or spread peanut butter and raisins on celery to make ants on a log. By making your snacks interesting, it will be easier to pick healthy foods all the time.

Want to learn more about good-for-you snacks? Ask your teachers or parents for help in making these and other healthy food choices.

Edited for size from an article "Snacks can boost your energy" by Meredith Stanton. First published in Hemaware Junior https://

Dealing with Body Image

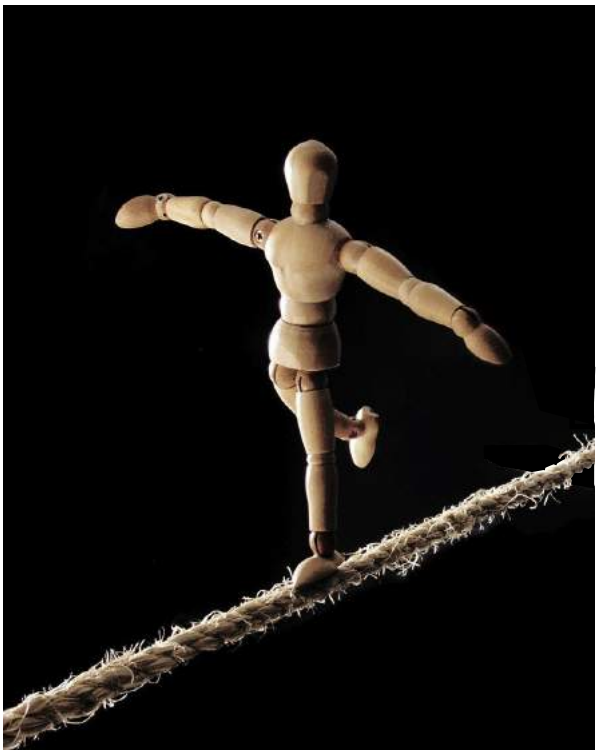
Although females stereotypically experience body image issues, boys are encouraged from an early age to think that being a man and being physically strong go hand in hand and body image issues are becoming increasingly common among males. As they grow older, the expectation to fit in, or "man up" can add to the pressure and the media's exposure to highly sexualized material also impacts on self-esteem and relationships. Due to the self-contained world of adolescence, it can be hard for parents to detect a son's body dissatisfaction.

Big muscles are typically associated with good health. However this can lead to negative self-image in the bleeding disorder population as these males are encouraged to avoid 'manly' sports and activities because of the increased risk of bleeds. With the advent of social media, online forums and blogs make it easy to seek and share information about diet and fitness and this might mean that some males are going against their physiotherapist's advice by trying to get a muscular, 'gym' physique.

Most parents know the pressures teenagers face in relation to body image issues and it's clear that negative self-image can equally affect males and females' physical and mental health. For young Australians, body image issues are the third most common source of angst after 'coping with stress' and 'school'.

Boys are less likely to talk to each other about body image issues and children with bleeding disorders may get teased at school or challenged about why they don't work out yet vanity and self-esteem issues can prevent boys engaging with the topic despite it becoming of increasing concern at a young age and through adolescence.

The body shape many of our boys are aspiring to attain is the "ripped, muscled look", and if they don't have it, it can tip them across into feeling dissatisfied with themselves. Individuals with bleeding disorders can sometimes be teased by siblings and other kids, with the refrain



that they are inadequate or a loser because they didn't do PE or are limited in the exercise and sports they do. Many kids translate that as not being good enough, feeling worthless, or not belonging.

This way of thinking can lead to unhealthy eating behaviours, bad or damaging exercise choices or over exercising, Some young men with bleeding disorders are avoiding going out with peers, being in photos and attending social functions because of their insecurities.

We, as the support network need to teach our sons and daughters that their self-worth has nothing to do with their body size and shape, and that there is no one ideal body type and to work within our limitations. While they might not be able to improve negative feelings about their own bodies, improving their body image is possible. They can;

Adopt a healthy lifestyle by eating well and staying fit, however also not letting either behaviour dominate their life.

Develop a personal identity that isn't based on size and shape

Recognise their strengths such as a sense of humour or other abilities and use them to their advantage.

Be grateful for what their body can do, as opposed to what it looks like.

Appreciate how awesome being alive is

Consult the QHC team before doing new exercise regimens or taking supplements etc.

Parents should look out for signs of negative body image in males from adolescence, and those include an increased focus on body image, avoidance of food, body shaming and making negative comments about themselves. Remind them that they are not alone: lots of boys and young men struggle with their body image.

If you or someone you know is feeling inadequate about their body or about themselves in general, it may be worth talking to someone, such as a family member, friend, teacher or the QHC psychosocial staff.

If you or someone you know is suffering from body image issues, contact the Butterfly Foundation (https://thebutterflyfoundation.org.au) or on 1800 334 673; or go to Reach Out (https://au.reachout.com/identity-and-gender/body-image) for tools and resources that can help.

Important Dates for HFQ Members

- **OBE Lunch Forum**
  informal support group for men with a bleeding disorder. Usually meets first Wed of the month.
- **Women's Brunch**
  29 April 2018 venue TBA
- **WHF World Congress**
  20 –24 May Glasgow
- **Men's Health Seminar**
  14th June 2018 venue TBA
- **HFQ Youth Event**
  Mystery Room West End. 17 June 2018 *or*
  Put-Put 8 July 2018
- **Bridge to Brisbane fun run**
  26 August 2018
- **Regional Meeting** *Please ask if one is happening in your area.*
- **Camps**

Youth Camp
12—14 October 2018 at Emu Gulley

Community Camp
9-11 Nov 2017 Noosa North Shore Retreat

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

Bleeding Heart Competition

Welcome to HFQ's "Bleeding Heart" Art Competition. The theme for this competition is 'A life affected by bleeding disorders', so this could take you anywhere from your own experiences, to how you think other people see bleeding disorders, or you could even explore feelings deep inside you!

"Bleeding Heart" is a new venture that will run in parallel with Haemophilia and other bleeding disorders awareness week in October.

It's open to all people affected by bleeding disorders. Young people up to the age of 26 are especially welcome to contribute and there are a prizes for several age groups and category types.

You may like to enter any section of the competition or all of them! Think about your life with a bleeding disorder in the family... And have fun!

Can you draw, paint, or take a photo?

There are two main categories: 2D Art and Digital Photography. As long as your artwork has some connection to bleeding disorders and what they mean to you or the impact they have on your life, you can enter the competition.

The complete rules will be posted on our website but nothing is set in stone at this stage, stay open to ideas that inspire you or messages you'd like others to know. You've got lots of time so your ideas can evolve, so go with it. There is a prize in each section and where possible all winning entries will be publicly displayed during Haemophilia and other bleeding disorders awareness week in October.

Start thinking about materials and how could you possibly create your concept. When you have an idea or a couple of ideas talk to your parents if you need materials and start to think how you might create your bloody art work.

"Bleeding Heart" will launch on World Haemophilia Day (Tuesday 17th April 2018) and is open to everyone. In addition to the open section, there special categories for young people up to 25 (the categories are: under 5, 5 -11, 12– 17 and 18-25 years who are formally diagnosed with a bleeding disorder or have a family member with a bleeding disorder. The competition aims to dispel the myth that people with bleeding disorders cannot be creative and to show that art can significantly improve their quality of life, facilitating experiential-based learning and instilling life-long skills.

For all entries, the judges will be looking for the overall look and impact, as well as the effort and execution/construction and the meaning you want it to convey. The competition will close on Friday 28th September and winners will be invited to attend the Awards Ceremony during Haemophilia and other Bleeding Disorders Awareness Week.

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
HFQ Manager & The 'H' Factor editor
Ph: (07) 3017 1778 E: info@hfq.org.au