

the

FACTOR

Issue 40
Spring
2014

Newsletter of Haemophilia Foundation Queensland

President's Message

Hello everyone,

As many of you know HFQ receives funding from Queensland Health to deliver services that provide outcomes for those affected with the significant range of issues that come with a bleeding condition. This happens in partnership with the Haemophilia Treatment Centre where we aim to be inclusive of all in the Qld bleeding community. We are currently going through a transition in funding and will be working with

Queensland Health to redefine and update our service agreement to better meet the needs across Queensland. This is a good opportunity and confirms that HFQ makes a difference and is valued by both community and Queensland Health.

HFQ activities are varied across a wide demographic, bringing people together, both new and old in different settings, running facilitated education events, youth camps with brilliant

personal outcomes for boys health, providing your magazine full of up to date information, working in partnership with the Haemophilia Treatment Centre team to target health issues, the list goes on

The last event we ran was a family support day where 12 children and 14 adults came along to share stories about their experience and in so doing learn from each other, this 'cross fertilisation' results in informal support

To next page →

Inside this issue:

| | | | | | |
|---------------------------------|---|---------------------------------|----|-------------------------------|----|
| Some people make things happen | 2 | Adolescent sexuality | 8 | Reflection on Life | 14 |
| Benefits of sports and exercise | 4 | Water Park Safety | 9 | Dental Extractions | 15 |
| Put a spring in your step | 5 | Traveling with haemophilia | 10 | Anaemia and Iron replacement | 16 |
| Spring into action | 6 | Access to the new kids hospital | 11 | Sarah's USA Adventure | 17 |
| Support the foundation | 6 | More from Congress | 12 | HepC treatment update | 18 |
| Congress & Gene Therapy | 7 | Pets are wonderful support | 13 | Treatment hope for inhibitors | 19 |

President's Message Continued...

networks and a sense of community where ' you're not alone '. Moana (Phycologist from the Children's Hospital) came along with a new family and this was simply gold, they left with a far better understanding of what a bleeding condition is and how it pans out in future, framing expectations and calming many concerns, just brilliant!

I will leave you to read the rest of the magazine but please drop an email, a phone call or even a text to the office if you have any concerns, ideas or issues.

All the best until next edition.

David Stephenson

President HFQ.....Advocacy, Health promotion, Support



Some people make things happen, some watch

“Some people make things happen, some watch things happen, while others wonder what has happened”
- Proverb

Many of us sit around waiting for something to happen. We entertain thoughts like “I will only be happy when....” Or “If only....”. Or we blame others for our situation and say “things will only get better if so-and-so changes”. By doing so, we inevitably lose control over how we want our lives to be as we “wait” for something in our external environment to change.

There is more to life than waiting and you deserve to lead a fulfilling life, whatever your circumstances are. Rather than giving control to your circumstances to someone else, how about taking control back into your life and make a decision to do something for yourself?

Spring is a great time to start something new. Spring symbolises the renewal of life and hope for the future. With clear blue skies, flowers abounding and cool weather all day long, there is little in the way of stopping you from doing something you enjoy. It doesn't need to be a complicated plan or an expensive project. It could be as simple as reigniting an old friendship, restarting an old project, exploring new hobbies or interests, joining a new social club or exercising.

Alice Morse Earle once said “Yesterday is history. Tomorrow is a mystery. Today is a gift. That's why it is called the present”. Why not start living in the present by doing something differently today? May this season be a springboard (pun intended) for you to embark on a journey of discovery, meaning and purpose as you decide to take control of your life and start to make things happen for yourself.

Dr Mona (Desdemona) Chong

Advanced Psychologist - Haemophilia

Ph (07) 3646 8769 (Available Fridays only)

Pager 57690 through Switch on (07) 3646 8111

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

ABOUT HFQ

The Haemophilia Foundation of Queensland (HFQ) provides advocacy, education and support for people in Queensland affected by inherited bleeding disorders. The Foundation employs a part time manager and is guided by a Board of Directors which meets monthly.

We can be contacted on mobile 0419 706 056; or via post at PO Box 122 Fortitude valley, Qld 4006

Members of HFQ are entitled to 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 Howard Mitchell |
| Secretary | ... | ... | Mrs Sarah Hartley |
| Treasurer | ... | ... | Mr Peter David |
| Members | ... | ... | Mr Craig Bardsley |
| | | | Mr Robert Weatherall |
| | | | Mrs Leanne Stephenson |
| | | | Dr John Rowell |
| | | | Mr Adam Lish |
| | | | Mrs Eva Turek |
| | | | Mr Erl Roberts |

HFQ Delegates to HFA

Mrs Sarah Hartley Mr David Stephenson

About The H' Factor

The 'H' Factor is published four times each year by HFQ. 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
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Queensland Haemophilia Centre Contact Details

ROYAL BRISBANE AND WOMEN'S HOSPITAL

| | |
|--|-----------|
| Dr John Rowell — Haematologist | 3646-8067 |
| Beryl Zeissink — Clinical Nurse Consultant | 3646-5727 |
| Olivia Hollingdrake – Nurse (Part time) | 3646-5727 |
| After Hours — Page Haematologist | 3646-8111 |
| Michael Hockey — Physiotherapist | 3646-8135 |
| Maureen Spilsbury — Advanced Social Worker (Mon-Thur) | 3646-8769 |
| Desdemona (Mona) Chong – Advanced Psychologist (Fridays) | 3646-8769 |

ROYAL CHILDRENS HOSPITAL

| | |
|------------------------------------|-----------|
| Dr Simon Brown — Haematologist | 3636-9030 |
| Joanna McCosker — Nurse | 3636-9030 |
| Wendy Poulsen — Physiotherapist | 3636-8506 |
| Moana Harlen — Senior Psychologist | 3646-7937 |
| After Hours—Banksia Ward | 3636-7472 |

HAEMOPHILIA CLINICS

RBWH

Appointments 3646-7752 or 3646-7751 or speak to Beryl

Haemophilia and Genetic Clinic — Dr John Rowell — Wednesdays 1.30pm

Haemophilia/Orthopaedic Clinic — Dr John Rowell and Dr Brett Halliday — 9am every four weeks

RCH

Phone Joanna about appointments

Banksia Outpatients — Dr Simon Brown — Thursdays at 2.30pm

OUTREACH CLINICS

Gold Coast Hospital, Toowoomba General Hospital, Nambour Hospital, Cairns Base & Townsville Hospitals:

Book through Joanna at RCH and Beryl at RBWH

The Children's Hospital is Moving.

The RCH team will be moving to Lady Cilento Children's Hospital in November. Please read the article on page 11 on parking at the new hospital.

Benefits of Sports and Exercise

Exercise plays an important part in maintaining good physical and mental health. Many people get incidental exercise in their daily life, perhaps walking to the train station or taking the stairs at work. But the real benefits of exercise come from dedicated exercise activities aimed at improving some aspect of your physical health, such as cardiovascular fitness or muscle strength. You may like exercising by yourself, or you may wish to join a sporting club or fitness class. This brings with it not only the physical benefits of exercise but also the mental and community benefits of social interaction.

Some of the benefits of exercise include building healthy bones, muscles and joints; building self esteem and confidence; and increasing energy levels and academic performance. Regular exercise reduces your risk of developing health complications such as high blood pressure, heart disease, stroke, type two diabetes and colon cancer. It also plays a part in decreasing the frequency of joint bleeds by improving your strength, endurance, coordination and balance.

In a study conducted by the Australian Bureau of Statistics during the 2009 census it was found that less than 1 in 5 Australian adults perform the recommended 10,000 daily steps. Rather interestingly, though not surprisingly, the percentage of people who consider that they perform adequate weekly exercise to maintain good health is 44%. If this number were true, that would be excellent. My feeling is that the true percentage of adults who meet Australian physical activity guidelines would be closer to the

19% who actually did their 10,000 steps per day. (As a side point, I realise that many of our readers are restricted in their ability to walk. I merely point out the pedometer study as an indicator of physical activity amongst the general population).

Australian Physical Activity Guidelines state that we should be achieving five, thirty minute, moderate intensity exercise sessions per week. That is, exercise to a degree which causes us to sweat. With many Australians performing sedentary jobs it is all the more important to carve out the time outside of work hours for exercise. When was the last time you sweated due to exercise? When was the last time you sweated for thirty minutes?



Many people with haemophilia have severely damaged joints and find it difficult to exercise. This is especially true for those of you who experienced frequent and significant joint bleeds, repeatedly in the same joints, before the days of modern factor concentrate replacement and prophylaxis. Interestingly we also see quite significantly affected knees and ankles in some of our younger guys who've been on prophylaxis since a young age.

There are many options for exercising – not just the typical walking, swimming or running, which most people immediately consider. I personally highly advocate for the role of resistance training to improve muscle, bone and joint health. This could be as easy as joining a gym and lifting some weights, or may require more specialist input from a physiotherapist if you have specific physical limitations. While resistance training is very safe when it is performed well, it is very dangerous if performed poorly. It is important that you seek the advice of a qualified professional prior to beginning a new resistance exercise program.

Cycling is a great option to consider for those whose knees

will allow it. I often see reduced range of motion at the ankles in people with haemophilia, due to haemophilic arthropathy. This often rules out running as a mode of exercise. Cycling on the other hand doesn't require a high available range of movement at the ankle joint. Getting on your bike has many benefits over running in that it doesn't cause high impact forces through the joints of your legs.

So whether it's for that morning walk or ride it's a beautiful time of year to

get active and get outside. If you would like to have a personalised exercise program written up for you, please don't hesitate to contact me through the Queensland Haemophilia Centre.

Michael Hockey
Physiotherapist – RBWH
Ph 07 3646-8135

Put a spring in your family's steps

There are multiple benefits of general physical activities for families and children...

So we know some of the physical benefits of physical activity for boys with haemophilia such as keeping joints healthy, however there are many psychological and social benefits as well. The more positive and rewarding experiences a child and adolescent is exposed to, the more his brain will grow in a healthy way.

Playing a sport is just one way of keeping active, general activity can also make a difference. A great way to increase your son's and the whole family's activity levels is to go and explore the great outdoors together. Spending fun time together also helps to strengthen relationships.

With the school holidays fast approaching there are many fun things for families to do.

- Take the family dog for a walk at the local park/dog friendly beach
- Go for a family bike ride

- Pack a picnic and explore a place you've never been to before.
- Local libraries run school holiday programs – great for a rainy day activity.
- Check out your local council's website to see what's on <http://www.brisbanekids.com.au/school-holiday-activities-qld/>

Contemplating more serious sporting activities? Consult with our expert physiotherapist Wendy Poulsen at the RCH who can provide a musculo-skeletal assessment if there are any issues or mention it to the HTC team at the next clinic review to receive some

expert advice to suit your individual situation.

Want to assess the bleed risk of different types of activities? Go to: http://www.brucecalc.net/about_bruce.php

Dr Moana Harlen
Senior Psychologist Haemophilia QHC RCH
Ph. 3646 7937



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Do you have a GP?

- Is your GP easy to talk to?
- Does your GP understand your haemophilia?
- Do you see your GP a lot or a little?

Whatever the answers, **WE NEED YOUR HELP!**

The nurses at the Haemophilia Centre at the RBWH are planning some research into the role of the General Practitioner in healthy living, men's health checks and ageing for men with haemophilia.

We want to find out from YOU what you think about visiting the GP.

The aim of this research is to discover how we can help you to have **proactive, productive** visits to the GP. We would like to help bridge the gap between the Haemophilia Treatment Centre and the GP.

Whether your haemophilia is mild, moderate or severe we need you to help us by participating in a survey or joining in a focus group (with food of course)!

WATCH THIS SPACE.....This project will begin once approved by RBWH ethics committee, and more information will be available then.

Spring Into Action!

I love the changing of the seasons and while we don't see the evidence of too many obvious season changes in sunny Queensland, I was lucky enough to live in Adelaide for a number of years. The tell tale signs that spring or autumn were around the corner were obvious the moment we stepped outside the door. The dramatic change in colour of the leaves and trees did little to keep the secret of a new season. Maybe you have heard the stages of our lives being described as being the like the four seasons of nature. There have been movies, songs and sociological theories written about the seasons of our life. We might easily relate to being in one or the other of the four seasons but no matter where we see ourselves, there are things that we can do and attitudes that we can cultivate which help to promote more positive outcomes in our situation, no matter what they maybe.

Mona and I are hoping to present a number of workshops over the coming year which we hope will

provide opportunity to explore and share experiences as well as enhance positive living. Keep a look out in future newsletters for information about workshops and get-togethers related to Healthy



© Josia Garber — Dreamtime Stock Photo

Communication Styles, Dealing with Pain, Carrier and Women's Issues and other topics related to enhancing quality of life in general.

Remember that you can also make your life easier by utilising health support services which are already set up in the community for your benefit. **The Patient Travel Scheme** can assist with the costs of attending the RBWH,

Public Dental Clinics can provide a overall assessment of dental needs, and your GP may be able to develop a **Chronic Disease Management Plan** or set a **Team Care Arrangement** in place for you to assist with costs of accessing allied health support in your local area. Suitability for these schemes, of course, depends on meeting certain criteria.

We still need a few more people to express interest in attending our group which will look at the book *Explain Pain* by David Bulter and Lorimer Moseley. We will design the group to suit the needs of the majority as far as time and locations.

Please give me a call on (07) 3646 8769 if you want to discuss any of these issues.

Have a great Spring!

Maureen Spilsbury
Advanced Social Worker – Qld
Haemophilia Centre RBWH

Support the Foundation

Did you know that it would take one Bunnings BBQ fundraiser every day of the year to cover the annual income HFQ currently receives? We are always looking for ideas and help to generate money to run the office and deliver the programs we offer to people affected by bleeding disorders.

You can do your bit by volunteering to help at fundraisers or running an event yourself (see back cover for Red Cake Day). We particularly want to know what businesses and

organisation's people know or work for that we could approach with request for philanthropic support. No agency you tell us about will be approached without discussing it with you first, but if you don't tell us we can't approach and we will eventually run out of money to deliver our programs and services.

You can also show your support by purchasing an HFQ polo shirt. These come in black or stone and cost \$40.00 each.

Please call Graham on (07) 3338 5645 to discuss how you can help us raise the money we need to support people affected by bleeding disorders.



Gene Therapy discussed at Congress

The session on Gene Therapy at World Congress in May was well attended and progress is continuing with different approaches with very promising data on different methods.

Gene therapy for FIX has been under investigation for more than two decades with extensive success with animal models that tried a range of different vectors and tissue types, this has now moved to using a safe vector called AAV to deliver gene therapy to the liver in humans to generate FIX. Three human trial are currently open with more to come.

The work so far appears to have ironed out problems (in men without AAV antibodies or liver disease). Ten men are showing long term expression and results of low dose go from <1% to ~2% , higher doses result in ~5%. So the question now- 'is this achievable in the wider community' given ~40% of the general population have neutralising antibody against the AAV virus, and what are the implications for those who re HCV+ There is also the question of treating children as scientists have noticed a loss of factor production in mice after they grow up. There are also some issues surrounding mass production of the product to be sorted. With significant interest and investment occurring optimism is high on all fronts.

Gene therapy for FVIII trials are planned for early 2015 using the same AAV vector process. Because FVIII is a larger molecule it won't fit inside the AAV vector envelope however scientists have discovered they can delete some of the FVIII DNA (B domain deletion) without compromise. They will start

human trials with one person at a time to check safety and efficacy so stay tuned for progress. Many other diseases and syndromes like cancer have used this process which has clearly assisted development. Current thinking surrounding people with inhibitors is also theorised to be of benefit as continuous generation of factor may act like immune tolerance.

There has been significant work to date carried out bringing decades of experimentation with animals and humans together. There is still some way to go before we see anyone benefiting from this FVIII gene therapy but it now looks to be safe enough to commence human trials.

Gene therapy for FVIII using Lentivectors.

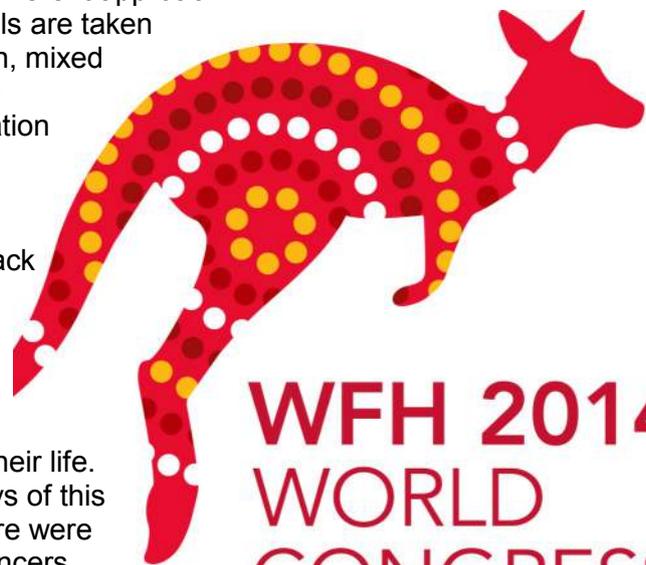
This is a very different approach where stem cells are taken from the person, mixed with a vector to achieve integration into the cells.

These are then transplanted back into the person where it permanently becomes part of the person for the rest of their life. In the early days of this technology there were problems of cancers but it's now much safer with no adverse events reported.

Interestingly they are using an engineered HIV capsule (no HIV infection issues – just using the smarts of HIV to get into cells). Yet another approach is to use engineered platelets that can produce FVIII when required at the site of a bleed but only when

it is needed. So Haemophilia A is the launch pad for this technology. Animals have been used in refining this but more effort is required as they are not there yet. Next year will see the first human to give it a go.

Current costs are extremely high and no mass production process sorted yet but that will change with time and success. So this was just three examples of gene therapies where great advances have been made since 1991 where the very first person was injected with early gene therapy, and back then the doctors really did not know what would happen. Today is very different and we wish them every success.



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Melbourne, Australia

Let's talk about ...adolescent sexuality

Let's talk openly: Adolescent sexuality matters

It is all part of normal human development as a basic human need for an individual to be socially connected to others which is reflected in changing attachments over the life span from parents to peers and then to a significant other. During adolescence a key task is to develop a positive self identity and one important aspect of this

self identity is to have a positive sexual identity. For some adolescent's haemophilia may impact on the physical, social, cultural and psychological aspects of their developing sexuality. Pertinent questions related to each of these areas may include "Are there any particular bleeds associated with sexual behaviour?", "Should I tell my girlfriend/partner about my haemophilia", "Am I making a smart decision?"

Having access to appropriate support and information can help to dispel any myths associated with such sensitive topics and empower adolescents to make smart decisions. It is important to be able to talk to someone who you can trust, who is non-judgemental, empathic and informed.

Becoming an adult means taking responsibility for your haemophilia, but you don't have to do it alone. There are different ways that information can be sought on this topic.

Discuss with a parent or someone you can trust who knows a bit about haemophilia. Call and make an appointment to have a confidential chat with any member of your HTC team whom you feel comfortable with. They also have some booklets they we can give you like this one:

Frankly Speaking about Haemophilia: Haemophilia and You – Tough Questions, Honest Answers. Bayer Healthcare AG. Post an anonymous question on www.factoredin.org.au – this website is specifically for young people - a professional can respond to your query.

Check out some other reputable websites such as these:

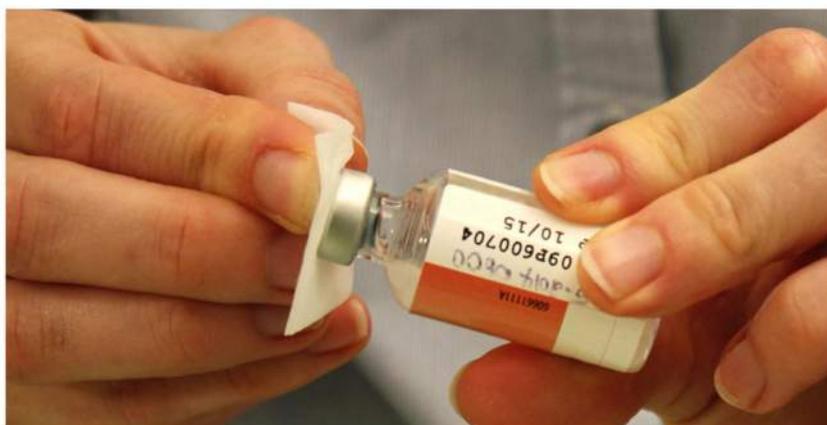
http://www.haemophilicare.co.uk/haemophilia_health/sex-and-bleeds.html or http://frankly.net/en/sex_and_relationships/hemophilia-and-sex/

Dr Moana Harlen
Senior Psychologist
Haemophilia
QHC RCH
Ph. 3646 7937



Wipe the stopper

The Therapeutic Goods Administration (TGA) advises that the exterior surfaces of injection vials are not intended to be sterile. Most protective lids do not guarantee sterility of the outer surface of a vial rubber stopper. This lid is intended to act as a shield for the rubber stopper and to keep dust and other physical contaminants away from it.



Important steps

1. Always use aseptic technique when preparing and administering injections to a patient
2. Always wipe the outer surface of the rubber stopper of injection vials with a 70% isopropyl alcohol swab
3. Allow rubber stopper to dry before inserting any device into the vial
4. For further information, please see <http://www.tga.gov.au/safety/alerts-medicine-provive-mct-lct-140707.htm>

Water Park Safety

It's getting warmer and there's nothing better on a hot summer day than cool water, slippery slides and floating around with your friends. The pool can be the place to be during the summer. The buoyancy of the water (that pressure that pushes you up, up, up to float on the surface) cushions joints and makes exercise easy.

If you do it right, you can have fun all summer long at the water park. Check first with your mum or dad and the QCH team to make sure you know what you can do and what you can't. Then, just slow down, suit up and have fun.

Slow down

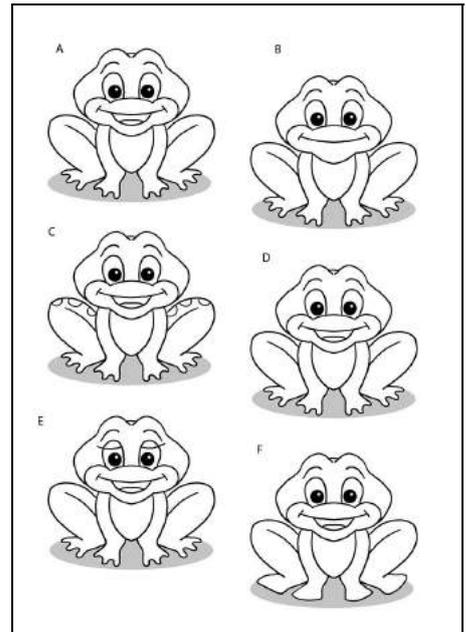
Water is awesome. Concrete is not. A stubbed toe or a wipeout on the way to the slide could do some real damage or cause a bleed if you're not careful. So slow down. Mucking about around the rides and slides is dangerous, as is running. Take your time—all the fun will still be there when you get there.

Suit up

What do you need for the pool? Your swimmers', beach towel, thongs and sunscreen, of course! But you may also need a life vest and whatever other protective gear your parents tell you to pack. A life vest can keep you safe in the water. And water shoes with rubbery bottoms protect your feet and keep you from slipping in the water.

Have Fun

To have a super-powered time at the water park, you might have to fill up on factor before you leave home. If you get a lot of bleeds, mum or dad might make factoring up part of the routine before you strap on the water shoes. They might also bring a first-aid kit to the park, just in case. Once you know the rules, water parks can be a silly, sunny way to pass a day. Just watch out for signs of a bleed, such as pain or swelling in the joints or muscles. Tell the adult you're with if you get hurt or feel a bleed coming on. That way you can come home from the pools a happy as a water bug



Match the Frog

Which two frogs are the same?
(answer at the bottom of the page)

Self infusion. You can do it.

Having to have injections is not fun, but it can if you DIY - Do It Yourself!

Yes, it can be something you do yourself. Ask your mum or dad if you can help with your infusions - mixing the factor, put the tourniquet on yourself and then talk with your Haemophilia centre staff when you feel you might be ready do the injection yourself. It is a tough thing to do so be sure you ask for help, concentrate and remember **PRACTICE MAKES PERFECT!**

Here, ten year old John Hudson talks about his experience with self infusion.

My name is John Hudson , I am 10 years old and I have severe Factor VIII haemophilia.

Two years ago, my mum learnt how to give me my factor in my veins. I had a port put in when I was 2 but because I was older and have very good veins it was time to take it out. Last year my "freddy" was taken out. I was in hospital for a week. Now we use only the veins in my arms and hands.

Sometimes it's hard and can be sore, but my Mum is getting better all the time and I'm helping her. When we find a good vein my Mum puts in the needle and I give myself the factor and take the needle out!

One day I will do it all by my self but for now I'll just be a good helper to my Mum!!

PS: Next month I start learning how to do the needles myself, with my Mum and the treatment centre's help!

John

On the Road Again: making your trip safe & fun

Planes, trains, cars and caravans - there are lots of ways to travel these days! And all the things that keep you healthy and stop bleeds fast at home can come with you on your trip.

Here are some travel tips for making your next trip safe and fun:

Pre-Trip Checkup

Depending on your trip, the friendly team at the Children's Clinic of the QHC may want to



see you before you go.

If you like to hop, skip, run and play, Wendy the physiotherapist might ask a few questions about what kind of exercises you like. She can help you come up with active things to do while you're away. And if there's a pool at your hotel, swimming is great for joints! So listen up and remember your physiotherapists tips, even when you're daydreaming about your trip.

Power Packing

To keep boredom away, traveling long distances means packing things to keep you entertained, like your favourite toys, books, games, music and movies. It also means packing supplies that keep your body strong and help you heal from bleeds.

You can help your parents round up your usual supplies, putting the important stuff in your carry-on bag and extra supplies in your suitcase. Mum and Dad might

have to order these supplies before the trip, so remind them, and know where in the carry-on bag your factor and supplies are stored.

Be Alert!

Travel can be tricky. That's why it's important to be prepared. If you have a medical alert bracelet, be sure to wear it before leaving home. And make sure Mum and Dad have your travel letter if you're going overseas. It's written by your doctor, and describes your bleeding disorder and the treatment you need to keep you healthy. You may have to present this to the airport or other security staff, so all your factor and supplies can come with you on the plane.

Have Fun

Now that you're packed, prepared and prepped, grab your camera, or book and get ready for a super trip!

Ten Pieces of Advice - not just for Children

Many adults give children advice to get them through the challenges of growing up. The truth is people of every age face challenges and good advice stays good forever. It never hurts to remember that we are all still growing up.

- If you don't try it, you'll never know if you'll like it or not.
- No one gets it right the first time.
- Practice make perfect.
- Don't worry about what other people say, you do what you know is best for you.
- If they laugh at you, just ignore them.
- You have to make up your own mind; don't wait for someone else to do it for you.
- Be your own best friend or you'll be your own worst enemy.
- Don't be afraid to ask questions.
- Everybody has to start somewhere.
- Someday, you'll look back at all this and laugh!

Visiting the Lady Cilento Children's Hospital

Car parking and access for the new Lady Cilento Children's Hospital

When the Lady Cilento Children's Hospital (LCCH) opens it will have dedicated car parking and easy public transport access for families, staff, visitors and volunteers.

To cater for an increase in traffic within the precinct, a variety of parking and access options will be available, no matter how you choose to arrive.

Traffic solutions

To keep traffic moving smoothly within the precinct, Graham Street has been realigned to create an efficient and safe intersection where Dock, Vulture, Stanley and Graham streets meet. This new intersection allows traffic to turn right from Graham Street into Stanley and Vulture streets, and traffic to turn right from Vulture Street into Graham Street.

Arriving by public transport

South Brisbane is well serviced by bus, train and ferry services all within an easy walk of the hospital.

Bus: Mater Hill Busway Station,

part of Translink's South East Busway, is located on Stanley Street, approximately 100m from the LCCH.

Train: South Bank Train Station is about 350m from the Lady Cilento Children's Hospital. There are regular services to Roma Street Station's Transit Centre, which is only two stops from South Bank. Trains also run frequently between South Bank Station and the Gold Coast.

CityCat and City Ferry: there are three ferry terminals located along Clem Jones Promenade at South Bank, approximately 500m from the hospital.

Arriving by car or bicycle

Car parking

More than 2000 car spaces will be available in the precinct for staff, patients, families and visitors.

Locations include:

650+ spaces in the hospital basement car park

1500+ spaces in Mater's Hancock Street car park

The basement car park will be mainly for use by families. The first of its four levels will have 22 designated disabled car parks with a height restriction of up to 2.3

metres to cater for wheelchair accessible vehicles. Other currently established public parking facilities in the precinct include the Mater Medical Centre, the Mater Hill and the South Bank Parklands car parks.

Set down areas

The LCCH will have two set down areas – one at the main hospital entrance on Raymond Terrace, and the other adjacent to the emergency department on Stanley Street. The set down area at the main hospital entrance on Raymond Terrace will be for general set down and taxi drop-off and pick-up. The set down area on Stanley Street will be for emergency access only. These areas will provide easy off-street access to the hospital without disrupting traffic flow within the precinct.

Bicycle

There are bicycle racks for visitors at the Stanley Street and Raymond Terrace entrances of the LCCH and the retail courtyard of the CCHR.

Lady Cilento Children's Hospital
The Lady Cilento Children's Hospital is still meant to open on 29th November.

Open days are being held in October (yet to have date confirmed) so please keep your eyes out if you would like to look it over before hand.

Contact us

For information about the Lady Cilento Children's Hospital

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childrenshospital



More World Congress Observations...

Impact on other family members

Many of our member families find it good to spend time with other families and individuals with bleeding disorders but it can also be scary for a parent or person who is new to the condition to meet people living with serious joint damage.

A bleeding disorder diagnosis can have a serious impact on the whole family. Sibling relationships and rivalries are complex but it's not all bad news and there are some positive sides to having a sibling with a bleeding disorder. It can help improve a child's ability to take responsibility as well as their communication skills. However, some none affected kids can experience anxiety and feelings of guilt. Many brothers reported that they believe that their own quality of life would be better if their sibling didn't have a bleeding disorder. Siblings also say that they need more information about bleeding disorders and that they

need more time and attention from the adults in their lives.

We were told that siblings shouldn't be seen as supplementary care givers and it's a mistake to expect inappropriate levels of responsibility from young siblings. However, it can be very helpful for siblings to feel involved and to be encouraged to ask questions and express their feelings about the impact of the bleeding disorder on the family. Parents should treat and discipline all their children the same way. Speakers said that ultimately, the best way to support children with bleeding disorders and their siblings is to support their parents and trust them to make good decisions.

Adolescence is a difficult time for parents. It is hard to step back and let a young person start taking responsibility for their health and treatment; and to make their own mistakes. Adherence to treatment can often worsen in this period as well. Transition to an adult Haemophilia Centre can also add stress; although often parents are more worried about this than their adolescent with a bleeding disorder.

Building Resilience

Life with a bleeding disorder can bring many challenges. The more resilient someone with a bleeding disorder is, the better equipped they are to deal with their bleeding disorder. However, being resilient is a process and can be encouraged, especially through positive role models. Ultimately, though, resilience comes from within. Experience of living with bleeding disorder can even make some people more resilient in other areas of their life.

Understanding and accepting your condition is an important step. It's important to accept that being normal includes having a bleeding disorder. It is part of who you are but it doesn't define you or dictate what you decide to do with your life.

Sometimes it is important to step back and look at the bigger picture; ask whether all the aspects of your life are in balance.

Tips for balancing your life

- Manage your time
- Make space for yourself and family
- Be creative
- Make plans
- Eat well
- Take exercise



Pets are Wonderful Support (PAWS)

According to medical research, owning a dog will help you lead a more active life. Whether taking it for a walk or just playing around with your dog or cat, every time you engage in those activities, it gives your cardiovascular system a healthy boost. We see improvements in cholesterol count, blood pressure and a reduction in the use of prescription drugs in people who own pets. Even overall visits to the doctor's office, especially among people older than 40, are reduced as well.

Another health benefit associated with owning a pet is an improvement in mood and mental well-being. This might be the most important benefit, since many ailments are related to our attitudes and mindsets. Pets are an excellent source of comfort, laughter and companionship.

Some of us already have plenty of structure, but others can use a helping hand to clean out the cobwebs and get organized. Pets are completely dependent on their owners for exercise, food, and health care. Having a pet can instill structure into the owner's life and will set a steady rhythm to each day.

While most pet owners are clear about the immediate joys that come with sharing their lives with companion animals it's only recently that studies have begun to scientifically explore the benefits of the human-animal bond.

The American Heart Association has linked the ownership of pets, especially dogs, with a reduced risk for heart disease and greater longevity. Studies have also found that:

- Pet owners are less likely to suffer from depression than those without pets.
- People with pets have lower blood pressure in stressful

situations than those without pets.

- Playing with a pet can elevate levels of serotonin and dopamine, which calm and relax.
- Pet owners have lower triglyceride and cholesterol levels (indicators of heart disease) than those without pets.
- Heart attack patients with pets survive longer than those without.
- Pet owners over age 65 make 30 percent fewer visits to their doctors than those without pets.

One of the reasons for these therapeutic effects is that most pets fulfil the basic human need to touch. Even hardened criminals in prison have shown long-term changes in their behaviour after interacting with pets, many of them experiencing mutual affection for the first time. Stroking, holding, cuddling, or otherwise touching a loving animal can rapidly calm and soothe us when we're stressed.

The companionship of a pet can also ease loneliness, and some pets are a great stimulus for healthy exercise, which can substantially boost mood. The key to aging well is to effectively handle life's major changes, such as retirement, the loss of loved ones, and the physical changes of aging. Pets can play an important role in healthy aging by:

- Helping you find meaning and joy in life. As you age, you'll lose things that previously occupied your time and gave your life purpose. You may retire from your career or your

children may move far away. Caring for a pet can bring pleasure and help boost your morale and optimism.

- Staying connected. Maintaining a social network isn't always easy as you grow older. Close friends and family members move away, retire, get ill or die; and making new friends can get harder. Dogs especially are a great way for seniors to spark up conversations and meet new people.
- Boosting vitality. You can overcome many of the physical challenges associated with



aging by taking good care of yourself. Pets encourage playfulness, laughter, and exercise, which can help boost your immune system and increase your energy.

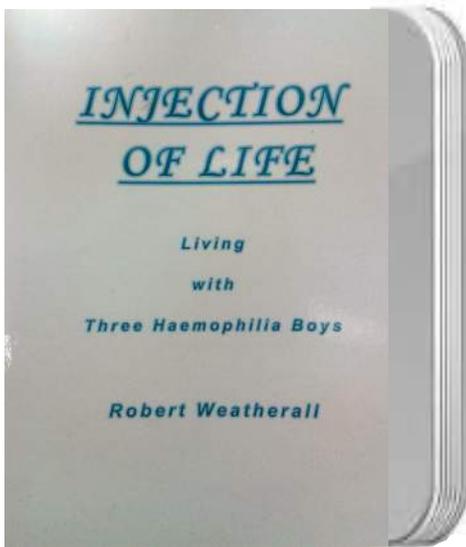
Children and adults all can benefit from playing with pets, which can be both a source of calmness and relaxation, as well as a source of stimulation for the brain and body. Playing with a pet can even be a doorway to learning for a child. It can stimulate a child's imagination and curiosity. The rewards of training a dog to perform a new trick, for example, can teach kids the importance of perseverance.

Edited for size from an article by Lawrence Robinson, Jeanne Segal, Ph.D. <http://www.helpguide.org/life/pets.htm>

Reflecting on Life

My name is Robert Weatherall, I am 62 years of aged and I have serve Haemophilia A. I am very proud and honoured to share with you my story that will not only hopefully inspire other people but also educate future generations on what it was like living with Haemophilia through my eyes.

Earlier this year I became a self-titled author and



published a book about living with Haemophilia called "Injection of life". This was something I had always wanted to do and it was motivated by people always consistently telling me that I had enough stories to write a book. I was determined to tell my story, so that's what I did.

This book on Haemophilia is a tribute to my parents for their support and love through difficult times when there wasn't much treatment available for us three Weatherall boys dealing with Haemophilia. The book openly shares the many experiences that my 2 brothers who also had Haemophilia, my whole family and everything I have gone through to get me to where I am today.

You could say I have never let what some people might

describe as, 'a lack of education' stop me from achieving something. And despite only going through to grade 4 due to health complications, I was persistent in sourcing my education in other ways. Whether it be hands on skills, observing friends and family in their occupations, joining organisations or later in life going to Tafe - I found a way of getting it.

Hard to believe these days but, I found it difficult at times to gain employment and I was told that I will stay on a disability pension for the rest of my life. But like always, I proved them wrong. I gained employment as a driving instructor through the guy who taught me. Lucky, I know. But I've always said it's not what you know, it's who you know. So future employment opportunities also occurred through similar circumstances and they seemed to accommodate considerably well for my unpredictable health.

However, as the years went on, my physical condition was not that good, restricting me to getting around in a wheelchair which led me to start volunteer work. The satisfaction from being involved in the local community has been very rewarding and I have met a lot of great friends along the way.

I am also so lucky to have a great support system around me, especially my family. My wife selflessly takes great care of me and has taken my condition on as if it was her own. I am happy to say that she too has helped a lot with making this book idea become a reality, and for that I am thankful. As well as my wife, we have four

children, 1 boy and 3 girls. They have been just as supportive in helping with anything that they can to make life that little bit easier.

Growing up with a dad living with Haemophilia has been nothing shy of normal but definitely has prepared and taught them a lot about the condition. It turns out that one of our daughters has also had a haemophilia boy, just like me. He is now 4 years old and this time round the treatment is there, the support is there and the quality of life will be there. And can I just say I am glad that he has someone in the family to relate to his unique condition and visa versa. He has definitely taught me a thing or two. But overall my immediate and extended family have always done so much for me and have been the ones to encourage and remind me of what I am capable of therefore I have never given up.

This book was no different. It took many years of writing down these stories before I was able to collate them into book form. And although this article is just a summary of a few things included in my book, I am most satisfied with taking charge and achieving this goal. Nothing would please me more than to be able to continue to share my story with the community and people alike so they can see and have an understanding of what I have gone through and not letting anything stop me as I am determined on making the most of cards that I have been dealt in life.

If you are interested in this book, it can be sourced through contacting the Haemophilia Foundation Queensland.

Robbie Weatherall



HFQ is working with HFA to run the RRC in May 2015. HFQ intends to take the event over as an annual fundraising event solely for the benefit of HFQ from 2016.

We need support from HFQ members to recommend potential sponsors and supporters for the 2015 RRC and most importantly we need you to come on the day to support the event!

We are looking for sponsors for the event - is your business or workplace interested in supporting this important local community event? How about entering a Corporate Team or getting a Team of Adults together to compete as a team?

For more information on sponsorship and corporate opportunities contact Natasha at donate@haemophilia.org.au or call 1800 807 173.

Needing Dental Extractions?

Dental extractions can be a challenge to the body's clotting function. Many people with inherited bleeding disorders require clotting factor replacement or ddAVP infusions immediately before and after dental extractions. Any procedure comes with a small risk including the development of inhibitors. There are also increased costs and time associated with hospital stay and administration of factors/ddAVP.

The Maxillofacial Surgery unit at the Royal Brisbane & Women's Hospital (RBWH) is trialling the use of a local clotting agent that is placed within the socket after extractions instead of factor replacement or ddAVP. The study has been

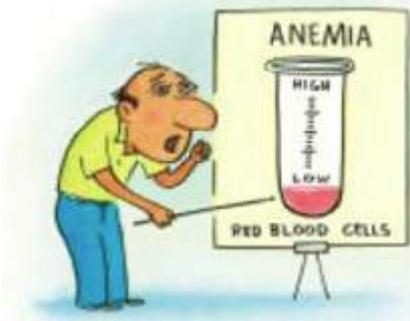
approved by the Ethics Committee at RBWH. You are eligible for the study if you are aged 18 or above, require dental extractions and have haemophilia or von Willebrand's disease. The extractions will be performed at RBWH.

If you are interested in participating in this study, see your dentist or GP to obtain a referral and fax it to 07-3646 3545. Please ensure that the referral clearly states you have a bleeding disorder.

If you would like further information, or if you have any concerns about dental procedures please contact Beryl and the staff at the Haemophilia Centre at RBWH.

Pumping Iron: Replenish iron after anaemia

“Iron-poor blood” is not an old-fashioned ailment, it’s the most common 21st-century cause of a condition called anaemia. Iron-deficiency anaemia can be caused by blood loss, whether acute or chronic. For people with bleeding disorders, anaemia is avoidable. There are ways to diagnose, treat and prevent it. The more common forms in people with bleeding disorders are iron deficiency & haemolytic anaemia.



Anaemia's Effects

Haemoglobin, the protein that colours blood cells, carries iron. When the body loses blood, it also loses iron. Iron carries oxygen to the cells and when iron loss exceeds the iron stored in the body, a person feels tired and weak.

Anaemia can cause serious symptoms. Without enough haemoglobin, the heart has to pump harder to supply the body with oxygen. If you become severely anaemic from bleeding over a long time period, you may end up having significant shortness of breath and it can cause heart problems.

Chronic anaemia may cause cognitive impairment because iron deficiency may contribute to memory and motor impairment. If patients are anaemic they may end up having cognitive dysfunction because of loss of oxygen to the brain.

For many people with bleeding disorders, if the amount of blood shed during a nosebleed is large or if it is chronically oozing over a long time period, you can also become anaemic.

Surgery is another time where for anaemia can appear. Patients with a bleeding disorder may need a pre-op blood test to determine haemoglobin and iron levels and measures can be taken to restore them prior to surgery if low.

Public Health Issue

Iron-deficiency anaemia in women of childbearing age is another common health issue. The iron demands during pregnancy and breastfeeding contribute to this. Adding a bleeding disorder to the mix compounds the risk of anaemia. If menstruation in a woman with VWD or other bleeding disorders is excessive it can also result in anaemia or lower haemoglobin.

Iron demands increase by 50% during pregnancy because you have an increase in your blood volume. So if you are a carrier or are a woman diagnosed with a bleeding disorder who is pregnant, ask your doctor if there may be an increased risk of complications. After birth women may be at risk for anaemia because labour can result in blood loss.

Anaemia of Chronic Disease

Long-term inflammatory diseases, such as cancer or infections from hepatitis C (HCV) and HIV/AIDS, can cause anaemia of chronic disease. This type of anaemia results when a long-term medical condition affects the production and lifespan of red blood cells. Careful monitoring of blood counts on individuals with HIV and/or HCV will provide a good window on what’s going on with their disease.

Treatment for Anaemia

Confirmation of anaemia comes via a simple blood test, called the full blood count (FBC). The FBC measures the haemoglobin and hematocrit (the percentage of blood cells as a proportion of the total blood volume). Treatment for anaemia depends on the cause. Doctors need to assess whether the anaemia is due to a dietary deficiency, iron loss or inability to take iron.

Patients with bleeding disorders are not immune to having dietary anaemia’s. Eating foods that are higher in iron, like leafy green vegetables and meats can help but if you are diagnosed with anaemia, you should talk to your clinical staff about the best treatment option for you.

Some people use over-the-counter iron supplements. But there can cause constipation or upset stomach so you should test brands to find one you can tolerate. How long to take iron is another matter. It can take up to a month or longer for iron stores to be rebuilt and to prevent the return of anaemia and most people stay on iron therapy until bleeding is managed or stops.

Iron injections can also be used for patients who have lost a large volume of blood, or who cannot absorb iron taken orally. Blood transfusions are reserved for cases when other measures fail or there is an immediate need.

Any person with bleeding issues should be mindful of anaemia and take head of the mantra, “If you feel something is wrong, it may well be!”, and raise your concerns with your clinic team.

By Sarah Aldridge

Edited for size from an article originally published in Hemaware July 2010 <http://www.hemaware.org/story/pumping-iron>

Adventure in the USA

Our family of four recently returned from a trip to Hawaii and Los Angeles. My husband and I travelled with our two sons, aged 9 years and 18 months. Our eldest son has severe haemophilia so we had to 'factor' in a few extra things like securing travel insurance for an existing medical condition, flying internationally carrying needles and clotting medication, refrigerating medication while staying in various hotels and infusing on the run.

We visited Waikiki Beach in Hawaii which was balmy and very festive, we swam at a waveless beach - we thought we'd leave the 60 foot waves to those fearless surfers! In Los Angeles we did some star spotting at the Hollywood Walk of Fame, played some air guitar at the Hollywood Hard Rock Cafe and strolled along Rodeo Drive in glamorous Beverly Hills. We cheered along at a baseball game at Dodgers Stadium. My husband and son scored a few touchdowns playing Grid Iron football together at Newport Beach. Disneyland really was the 'Happiest Place on Earth' for us and we all had a great time exploring the different 'lands' and experiencing some very high-tech and exciting rides.

Travel Insurance

I travelled to the USA with my son four years ago and ran into the problem of securing travel insurance for an existing medical condition like haemophilia. At that time we had success with Covermore who provided our son with medical cover for haemophilia-related issues for an additional fee. However, our application for cover with them this time was unsuccessful. We tried other companies such as Cuna Mutual and Medibank Private and got the same result.

We had success with Southern Cross Insurance who provided our son with unlimited medical cover for any haemophilia-related issues for an additional fee of approximately \$200. We thought this was a good deal for us considering the potential cost of admission to hospital in the USA. Fortunately our son had no bleeds overseas and did not need any hospital treatment.



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Flying with factor

The Haemophilia Centre at the Children's Hospital provided us with a letter we could present to authorities if we had any trouble getting through airport security with our needles and clotting medication. The airlines like people to keep any medication nearby in case of a medical issue in flight, so we had to take the factor on board in hand luggage. The airline had no space to refrigerate medication in flight. We had the factor packed in with ice packs however by the end of the flight (9 to 10 hours later) the ice packs had melted so the medication was still cool, but not cold anymore.

Refrigeration of factor

Fortunately all the hotels we stayed at had small in-room refrigerators so the medication was kept cold. With the exception of the hotel in Los Angeles, where first the fridge had a meltdown and ceased to work, then I had a meltdown when I

realised all the medication was no longer cold or even cool. My husband raced down to the reception desk and requested a replacement fridge and was told yes, he also asked if there was a fridge we could use in the meantime and he was told no. A construction worker who was renovating the bar area overheard our plight and said that while the bar was only half built, there was a perfectly working fridge there that we could use, so he saved our day in a big way.

Infusing on the run

My husband currently infuses my son with factor so on the trip they set up on the desk in the hotel room. We bought disinfectant to clean the desk surface and had our usual local anaesthetic cream, tourniquet, spare alcohol wipes, needles, cotton wool balls and band aids on hand.

We did a lot of walking on the trip, some days 2 or 3 hours and other days up to 6 hours, not to mention being thrown around a bit on roller coasters and white water rapids rides! So it was great to know that our son had factor on board when we went off on our daily adventures.

We travelled to a developed country, so it may be different for travellers to a developing country. But in our experience, our son's haemophilia didn't impact on us visiting any of the places we wanted to visit or doing any of the activities we wanted to do. For those of you thinking of travelling overseas with a child with haemophilia, I encourage you to go for it. It might mean a bit of extra planning and thinking on your feet while you're there, but hey that's something we in the bleeding disorders community are all used to!

Sarah Hartley

HepC Update from HFA

HFA welcomes the recommendation of the PBAC to add simeprevir (Olysio™) to the Pharmaceutical Benefits Scheme (PBS) for the treatment of genotype 1 chronic hepatitis C.

However, we were disappointed to see that the PBAC rejected sofosbuvir (Sovaldi™) for the treatment of genotypes 1 to 6 chronic hepatitis C on the basis of its high cost and limited information about cost-effectiveness.

Listing these new hepatitis C drugs on the PBS would mean the cost is subsidised by the Australian Government. The PBAC is the government Advisory Committee for the PBS.

Both drugs have already been approved by the Therapeutic Goods Administration for use in Australia. But without subsidies they are out of reach for most people with bleeding disorders and hepatitis C.

You may recall that HFA surveyed community members on these new treatments and made a submission to PBAC with their answers about the potential impact of these drugs on people with bleeding disorders and hepatitis C.

About sofosbuvir & simeprevir

Sofosbuvir and simeprevir are part of the new wave of direct acting anti-viral (DAA) hepatitis C

drugs. In clinical trials they had very high success rates, few side-effects, and shorter treatment courses (eg, 12 or 24 weeks). They need to be taken in combination with other medications (eg, interferon, ribavirin, ledipasvir) to be effective. Professor Ed Gane from New Zealand explained more about these new DAAs at a recent conference in Brisbane – tinyurl.com/new-hep-c-treatments.

How safe and effective are these new treatments for people with bleeding disorders? Sofosbuvir has had encouraging results - in a small study in of people with bleeding disorders in New Zealand, it has been shown to be both safe and highly effective when it was combined with ribavirin and ledipasvir, including for people who have previously had unsuccessful treatment¹.

Next steps

Advancing liver disease and limited treatment options is a real problem for some of our community members with hepatitis C. Treatment that can cure their hepatitis C is a high priority.

HFA will be following up with

more representation to government on these new treatments. The first step is to arm ourselves with some more detailed information about the potential



benefits of these treatments for our community members in particular, and we will speak to hepatitis specialists about this. We have also asked the Australian Haemophilia Centre Directors' Organisation (AHCDO) for their advice and help with understanding the situation for people with bleeding disorders and hepatitis C nationally. This involves clarifying the data and producing a report that does not identify individuals but gives solid evidence of the reality for our community members.

By **Suzanne O'Callaghan**

Policy Research & Education Manager

References

1 Kulkarni, R, Mauser-Bunschoten, EP, Stedman, C, Street, A. Medical co-morbidities and practice. Haemophilia 2014;20(Suppl. 4):130-136.

Keeping track of your app (myABDR)

Queensland has been the best state for registering and using myABDR and it works well with people's normal treatment and recording routines. People like the quick, simple steps to record treatments and the ability to add bleed details and bleed location to treatment notes

Other features are being added, so don't ignore version updates and **regularly update your app** at the Apple apps store or Google Play so it continues to function well.

If you haven't used it yet staff at QHC and HFQ can help you trial the app to see if it works for you or you can register online at www.blood.gov.au/myabdr

Plant-based research improves hemophilia treatment for inhibitors

About one-quarter of people receiving treatment for haemophilia develop inhibitors that can make treating future bleeding episodes challenging.

Prof Henry Daniell, director of translational research at the University of Pennsylvania has published a new study suggesting a patient's immune system can be "taught" to tolerate the clotting factor infusions.

Prof Daniell & his colleagues have created a plant based drug delivery platform which uses genetically engineered plants to produce bio-therapeutic proteins.

To promote tolerance to factor VIII they fused genes that

encode parts of FVIII into another gene that they then introduced into tobacco plants. They grew the plants, then ground them up to make a solution which was fed to mice with haemophilia A .

After giving the mice infusions of FVIII, rodents fed on normal plant solution formed high levels of inhibitors, while the group that was fed the modified plant material formed much lower levels of inhibitors.

Not only could the researchers prevent inhibitor formation, they could reverse it, as well. After feeding the modified plant material to mice that had already developed inhibitors, the mice's inhibitor formation slowed and

then reversed, decreasing three- to seven-fold over a few months compared to mice fed normal plant material.

Though other therapies exist to teach the immune system to tolerate clotting factors, this new finding offers a promising alternative.

"The only current treatments for inhibitor formation are expensive & risky for patients," Prof Daniell says. "Our technique, which uses plant-based capsules, has the potential to be a cost-effective and safe.

By Katherine Unger Baillie
Science News Officer. University of Pennsylvania. Published with permission

The Do's and Don'ts of Iron Supplements

Some foods, vitamins and medications can affect iron absorption. Consult with your doctor before you take iron supplements. These guidelines can help you get the most out of your supplement and avoid problems.

DO

- ◆ Increase your intake of iron-laden foods, such as green leafy vegetables, dried beans and peas, lean meats, citrus fruits and iron-fortified cereals.
- ◆ Plan ahead. Taking your iron supplement one hour before meals increases the absorption rate.
- ◆ Take your supplement with a vitamin C supplement or orange juice, which increases absorption. Mega-doses, however, can cause excess absorption.
- ◆ Wait at least two hours after taking antacids or certain antibiotics, such as penicillin derivatives, before taking your supplement.
- ◆ Tell your doctor that you are on an iron supplement. It can produce false positives in tests identifying blood in the stool.

DON'T

- ◆ Drink caffeinated beverages within an hour of taking your supplement. Coffee and tea can decrease absorption by 50% to 60%.
- ◆ Take your supplement with milk or calcium supplements, which decrease absorption.
- ◆ Leave your supplements within reach of children. Accidental overdose of iron-containing products is a leading cause of fatal poisoning in children younger than 6 years old.

Important Dates for HFQ Members

OBE's (Old Boy's Essentially) Meets in SE Queensland on the first Wednesday of each month.

HFQ AGM The AGM and Board elections are on 15 October. At 30 Helen Street, Teneriffe

End of Year Event At Thunderbird Park on 23 November for a Pizza Buffet (with laser Skirmish for the more active).

Community camp 2015 We've rebooked Noosa North Shore Retreat for 20 – 22 February 2015

Red Run Classic 17 May 2015

17th Australia & New Zealand Haemophilia Conference 2015 Gold Coast. 1-3 October

Please call Graham at the office on **07 3338 5645** for more info on any of these events and activities.

Red Cake Day 12 – 18 October 2014

Red Cakes can change lives; it's true! We are calling on our friends and supporters to help us celebrate Haemophilia Awareness Week by taking part in Red Cake Day.

Haemophilia Awareness Week is an opportunity for HFQ, as well as individuals and families to raise awareness about haemophilia, von Willebrand disorder and related inherited bleeding disorders during the week of 12-18 October 2014.

The money raised will support some of our programs and services such as Family and Youth Camps.

Like RCD on Facebook www.facebook.com/RedCakeDay

For more information on Haemophilia Awareness Week and Red Cake Day call HFQ on 3338 5645 or email Graham at info@hfq.org.au

