the H FACTOR

Issue 44

Spring 2015

Newsletter of Haemophilia Foundation Queensland

From the President

HFQ works in partnership with the Queensland haemophilia centres (both children & adult centres). This partnership generates an effective collaboration to address community and Queensland Health priorities.

Activities like the HFQ community camp make a clear difference to efficiently maintain and improve the health of those in the bleeding community. Measuring community issues and engaging these together with medical staff in a safe and relaxed setting results in a 'two way' understanding that then feeds back into health treatment plans and community engagement / outcomes.

This year the HFQ community camp attracted both regional and local people with coagulation disorders (65 attendees). Significant planning time with medical staff and an experienced voluntary facilitator (thank you Dave) was done and particular focus was placed on targeting people with greater needs. I requested we put more focus on the 'Q&A' sessions this year which allows people to share their experiences and stories in group settings (all together as well as separate gender sessions - with children entertained elsewhere allowing more focused sessions). Feedback on this was impressive – both from medical staff and community members.

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Inside this issue:

Presidents Message *Continued...*

Other formats work but the 'Q&A' model is a clear winner for all. There was laughter, serious times, tears, fun, education, sharing of tips and tricks as well as clearing up misconceptions. It is also important to balance the 3 day event with activities and we did this with - rock climbing, kayaking, high ropes as well as specific activities for the younger children. A key player in the success of the camp is our manager Graham – many thanks Graham for a brilliant HFQ community camp, well done!

David Stephenson

President HFQ …..Advocacy, Education, Health

Red Cake Day

Haemophilia Awareness Week is an opportunity for individuals and families as well as HFQ and other organisations to take part in a campaign to raise funds and awareness for haemophilia, Von Willebrand disorder and other bleeding disorders during the week of 11-17 October 2015.

There are many ways you can get involved with Red Cake Day and Haemophilia Awareness Week:

- Organise a Red Cake Day at your school, hospital, workplace or local town
- Set up an information stand in your workplace, school, hospital or library
- Hand out promotional items in your local area
- Organise a casual clothes day at your workplace or school
- Organise a luncheon, sausage sizzle or morning/afternoon tea
- Sell our HFQ raffle tickets to friends and family (see page 17)
- Set up a fundraising page – this way people who cannot attend your event can donate as well. You could also run a virtual Red Cake Day and ask your family and friends for support https://nfp.everydayhero.com/au/haemophilia-foundation-australia
- Set a fundraising goal and tell everyone you know what you are doing.
- Send out invitations to your family and friends.

If you'd like promotional items visit the HFA website or call Graham at the HFQ office (Please note that stocks are limited).

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 email (info@hfq.org.au) or 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 Adam Lish
Secretary	... ...	Mrs Leanne Stephenson
Treasurer	... ...	Mr Peter David
Members	... ...	Mr Craig Bardsley
		Mr Robert Weatherall
		Mrs Sarah Hartley
		Dr John Rowell
		Mr Erl Roberts

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 CENTRES

CHILDREN'S CLINIC

PAEDIATRIC CLINIC STAFF (LCCH)

Switch: 07-3068 1111 Haemophilia Mobile 0438 792 063

Dr Simon Brown — Haematologist

Haemophilia Registrar Dr Melanie Jackson

Joanna McCosker – Clinical Nurse Consultant

Wendy Poulsen — Physiotherapist

Moana Harlen — Senior Psychologist

Contacting the Clinic ***Please call the mobile for urgent enquiries (during office hours only).*** *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 — Contact the Administration Officer for Haematology or 2e outpatients for queries regarding clinic appointments

Haemophilia Outpatient Clinic — Dr Simon Brown — held in 2e outpatients Level 2, Thursday afternoons 1.30 – 3.30pm

Contact the Administration Officer for Haematology Department

ADULTS CLINIC

ADULT CLINIC STAFF (RBWH)

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
Rebecca Dalzell — Physiotherapist	3646-8135
Michael Hockey — Physiotherapist	3646-8135
Maureen Spilsbury — Advanced Social Worker (Mon-Thur)	3646-8769
Desdemona (Mona) Chong – Advanced Psychologist (Fridays)	

Contacting the Clinic ***Please telephone in the first instance.***

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

OUTREACH CLINICS

Gold Coast Hospital *(9 Oct –Adults)*, **Toowoomba General Hospital** (12 Nov), **Nambour Hospital** *(18 Dec)*, **Cairns Base Hospital** *(9 August 2016)* **& Townsville Hospitals** *(8 August 2016)*: Book through Joanna at LCCH and Beryl at RBWH.

SBM* — A Pilot Pilates Program

SBM is a newly designed program that we have been running since the beginning of August. It was developed by Rebecca Dalzell, the physiotherapist at the Qld Haemophilia Centre, and Monique Kurki, a Musculoskeletal Physiotherapist and Pilates instructor.

It combines evidence based Physiotherapy and Pilates principles to specifically address the unique needs of the men attending who are all living with a bleeding disorder and have either; joint problems, osteoporosis, or poor mobility and increased falls risk.

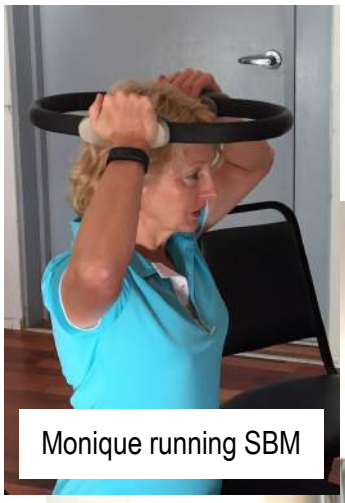
Research has shown that weight bearing exercises such as these improve bone density, falls risk, strength, core stability, function and general well-being. These in turn impact on people's ability to participate in community activities.

This program is a 10 week trial we are running because there were no specific exercise class available for this group of men and they found it difficult to access general community programs due to their complex musculoskeletal needs.

They signed up because they wanted to enhance their bone and muscle strength, prevent further bone loss, reduce their falls risk and enhance their overall function, condition, mobility and quality of life.

So far it's been a great experience and the men attending SBM tell me they have enjoyed the instructions from Monique, doing the exercises with other men and that they have also enjoyed the social connections made. They are enjoying the opportunity to meet with other men with bleeding disorders to share stories, learn from each other and encourage one another, motivating each other to pursue greater health benefits. But it's the change in thinking about posture and balance that they will take away with them after the program ends that's just as important.

Monique has applied similar principles in osteoporosis patients previously, and saw significant improvements in the same areas as our men have identified. At the start of SBM Bec and Monique asked the men to do a Balance/ Falls Risk and Quality of Life measure so they evaluate the success of the program when it ends.



Monique running SBM

Monique and Bec hope to present the preliminary findings at the Haemophilia Conference on the Gold Coast at the end of this month (October).

The outcomes achieved through SBM so far have been an improvement in the participants' confidence, greater wellbeing and enhanced strength, endurance, and general function. This means that we can expect to see our participants getting outdoors a bit more and perhaps pursuing more activities then previously.

If you'd like to be part of the next group, pleas let Bec or Graham know and we'll let you know when we it runs again.

* SBM = 'Strong Bloody Men'.

New Quality of Life Study

Calling all adult individuals with haemophilia

The Queensland Haemophilia Centre (RBWH) is inviting all individuals with Haemophilia to participate in a psychosocial survey in the upcoming months.

In this study, we seek to gather your perspective on various issues as we would like to identify current needs in the community and develop relevant programmes to help meet your psychosocial concerns.

An information pack will be sent out to all adult clients who meet the inclusion criteria in the coming months to invite your participation in this study. If you agree to participate in the project, we ask for your contribution in two phases. Phase 1 involves getting a baseline measure of your current functioning relating to haemophilia issues. In this phase, you will be required to complete a questionnaire pack which will take approximately 30 minutes. Phase 2 involves getting follow-up measures for us to understand how things relating to haemophilia have changed for you over time. We will be approaching you again at the one year anniversary of the completion of the baseline measure.

Please note that your participation is completely voluntary and does not impact on the medical treatment that you are receiving from the hospital. You can also withdraw from the study at any time. This study has been reviewed and approved by the Royal Brisbane & Women's Hospital Human Research Ethics Committee.

In recognition of your time, you are invited to enter a draw to win a Bunnings gift voucher. There are a total of three gift vouchers available for each phase, valued at $100 each. To participate in this draw, you would need to fill in your details in the "Prize Draw" form and send it back to us using a separate reply paid envelope enclosed in your questionnaire pack. The prize will be drawn at the Queensland Haemophilia Centre at the end of each Phase (18 Dec 2015 for this Phase) and the winners notified accordingly.

If you are interested in participating in this study, please contact Maureen or Mona at (07) 3646 8769 directly.

If you can set aside 30 mins of your time to complete a questionnaire – we want you!

Please call Maureen or Mona (07-3646 8769) for more details to help you can decide if you want to participate.

All respondents can win one of three $100 Bunnings vouchers!

Taking Part in Market Research

With new clotting factor products now coming on the market, you may have noticed that market research companies are actively looking for patients and parents/carers to interview or survey about their bleeding disorder or their treatment. But is it a good idea to take part?

WHAT ARE THE PROS AND CONS?

Taking part in market research studies can be valuable for you and for others. In Australia research has a big influence on decisions about health services, treatment and care. If you participate in research, you can have your say on treatments and how they are packaged or presented.

But before you take part in a market research study, it is important to know more about its benefits and risks for you and whether it will have any impact on your health or privacy. Also, bear in mind that the laws and standards for relationships between pharmaceutical companies and community members is quite strict in Australia and different to other countries.

HFA regularly reviews market research studies before we promote them on the HFA web site. We check they are meeting Australian standards and ask to look at their interview or survey questions.

Examples of what we ask or check:

- We ask whether they pass the research participant's personal information on to the pharmaceutical company (not OK in Australia!) or another mailing list (only OK if the participant has given permission – for example, if you agree to take part in further surveys).

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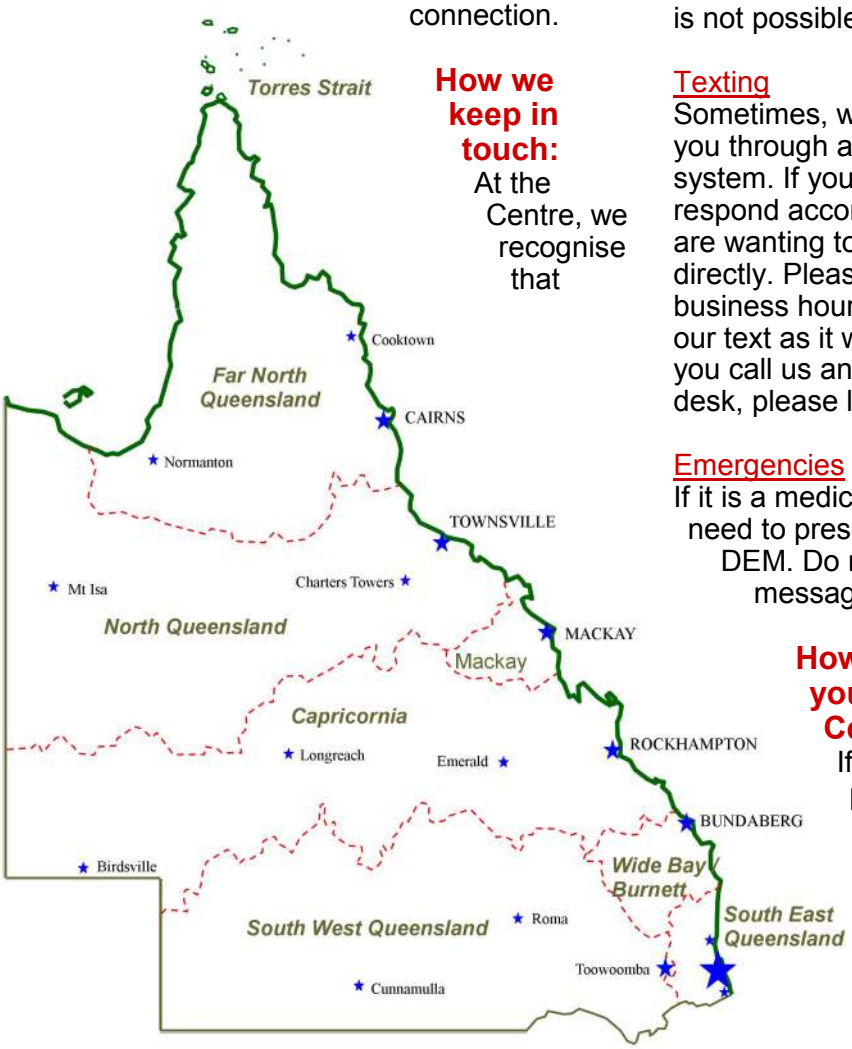
Keeping in Touch

About 7 million people - or 32% of the total Australian population - live outside of major cities. They choose to live in these areas for reasons such as a sense of employment, community, peace, reduced traffic, contact with nature and other lifestyle benefits. The flip side of this that Australians living in rural and remote areas have lower health status than their counterparts in urban areas due to a lack of convenient, affordable and timely access to general practitioners, specialists and after-hours care (National Rural Health Alliance).

The Queensland Haemophilia Treatment Centre has patients spread throughout the state of Queensland and Northern New South Wales. It tries to increase accessibility to its services by running several face-to-face outreach clinics per year to different areas of Queensland. Patients can also reach staff members by phone or email for non-urgent cases. Regional hospitals also consult with the Centre for medical management of individual patients.

Despite these efforts to address medical needs of individuals with haemophilia, they may not be sufficient to address the psychological sense of isolation of living with an inherited bleeding disorder in a regional and rural area. Accessibility of psychosocial programmes and activities become a practical constraint and can impede social connection.



How we keep in touch:

At the Centre, we recognise that comprehensive haemophilia care includes meeting people's psychosocial needs and concerns. Sometimes, individuals would call the psychosocial workers to discuss their needs or situation. At other times, we cold call our regional and rural members to see how they are going.

Phone calls

Phone calls are our primary and most reliable form of contacting you. Unfortunately, our call would be reflected as a private number on your phone. For people who screen their calls, this means they would not pick up the phone and for people who miss our calls, they do not know who called. We leave a message when we can but sometimes this is not possible.

Texting

Sometimes, we are able to page you through an online paging system. If you get our page, do respond accordingly. Often, we are wanting to speak to you directly. Please contact us during business hours. Do not reply to our text as it will not get to us. If you call us and we are not at our desk, please leave a message.

Emergencies

If it is a medical emergency, you need to present to your local DEM. Do not leave a phone message.

How you can help yourself and the Centre:

If you have a psychosocial need (e.g. wanting to connect with members of the haemophilia community) and do not know where to start, I would like to encourage you to contact either the Foundation or Maureen/ Mona to have a confidential chat about your needs. Depending on what you need, we can direct you to the appropriate source or connect you to the right person. We won't know what you need, unless you speak to us.

A Tortuous Route to a Capable Fatherhood

Having a child with a bleeding disorder makes considerable demands on the child's parents and affects the whole family. A recent Swedish study looked at the lived experience of being a father to a child with severe haemophilia to help them develop family supportive strategies.

Life in a broken world

The dad's in the study described feelings of fear and distress when they were told that their child had haemophilia. Their worlds collapsed and everything they had taken for granted disappeared. It was a chaotic and sad point in time, and some fathers imagined that their child would die or become disabled.

The fathers grieved for a fatherhood they had dreamed of and the loss of this imagined fatherhood caused some of them emotional pain. Some dads thought of their child as fragile and because sports and physical activity is one of the key avenues for some fathers to get involved with their sons, they feared that they would miss out on this opportunity to be with their sons and teach them self-esteem, responsibility and good values.

Capable fatherhood

Before diagnoses some fathers felt that GP's and others saw them as child abusers. In some cases, health care professionals even accused fathers of being too harsh with their child and this lead to some doubting themselves and their capability as a father.

All the participants described the time after diagnosis as very difficult and sad. Some dads experienced a sense of helpless and powerless because they could not protect their child from the illness and a feeling of despair and of losing control of the situation arose.

Many dads said that their child was constantly on their minds during the first few years after diagnosis. They felt they had to be nearby in case something happened. Some guys also worried about what would happen when their child reached adolescence – that they would once again lose control.

Burdens on the relationship & family

Most fathers felt that the relationship with the child's mother was negatively affected by the illness. The grief, worry and many hospital visits put a strain on the couple's relationship. The dads made efforts to 'be strong' for the rest of the family and some dads felt relegated to the bread-winning role (or escaped to it) while their partner took on many of the responsibilities for their son's daily treatment and care, this in turn, lead to guilt about having abandoned their partners during this difficult time.

In families with more than one child, fathers can feel guilty about not being a good enough dad to the other siblings. As the haemophilic child takes a lot of attention dads can feel like they have neglected the other children or that they treat them differently. In some families, pressures like this can lead to separation and the dad's role drastically changes again as they have to separately take responsibility for the child's illness.

Feeling capable as a father

At the time of study most participants felt they were caring and capable fathers, who were managing the illness and their own fatherhood with increasing competence. They said that being able to look after and treat the child at home contributed to feeling capable as a father. When using a port, the families were able to give treatment at home and the dads who were part of this process felt they regained control of the situation and often saw it as a starting point back to independence.

Feeling grateful and hopeful

Many dad's were aware of the high cost and felt grateful for living at a time and in a society where factor concentrates were available. Feelings of gratitude and hope helped get through the grieving process for the fathers and allowed them to become better dads.

There was also a strong desire and hope for a cure and many thought that this might be possible in the future, through gene therapy. The thought that their sons could have healthy children also gave hope and reduced the father's worries about the future.

Study Results

The dads surveyed gradually grew into fatherhood through a process that the researchers called a tortuous road to capable fatherhood. The first stage was facing a new, difficult and demanding life situation. The fathers experienced life in a world suddenly filled with powerlessness, concern and loss. The loss of their envisaged fatherhood was a point of great sorrow in being a father to a child with haemophilia.

As they began to make conscious decisions based on their own resources, knowledge and life-

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Man Up — becoming an adult

From about 11 years on, children start to transition from dependence to independence. You should start to become familiar of you own medical needs and the steps you need to take to maintain maximum health. As you start to take charge of the prophylactic measures you need to control your bleeds over the next 6 years or so, you also start to become an adult.

As a person with a bleeding disorder growing into adulthood you are not a "victim" but a "survivor", there is nothing holding you back to be whatever you want to become within reason. You can start to take personal responsibility for your own life and let go of your parents doing everything for you. We hope that as you move through your teenage years you can become a mentor and tell the others who are coming up behind you about how you applied yourself at school and in the community and what it takes to be the fully functional independent adult you are becoming!

So when do you become an adult? What does that mean for managing your bleeding disorder? Teenage life can be seen as the transition years when you move from being a child dependant on your parents to an independent adult. Arriving at mature adulthood is determined by what you do and how you act, not how old you are. Ask yourself;

- Are you in charge of all of the medical procedures you need to maintain good health or is someone else in charge?
- Are you self-injecting or is someone else still in charge of injections?
- Do you talk your health and concerns when you meet with the HTC team or does someone else?
- Do you have a social network that you can rely upon to support you when need support?

If the answer to any of these is no, then you're not there yet, you are still transitioning and that's OK. Many teenagers experience difficulties as they make this transition. It's tough having to make decisions for yourself and be responsible for the consequences of those decisions. It's not just a time of social change and increasing responsibility there are also physical changes happening so it can be difficult succeeding in high school or uni, holding onto a job, or trying to live on your own. Try to find someone you trust that you can use as a sounding board and talk through the difficult choices you are now being asked to make.

As an emerging adult you will still have medical emergencies, you may also experience financial setbacks, or get into trouble with authority figures. You parents should be willing to help you through these as long as you haven't burnt your bridges with them or told them where to go. Sometimes it's your parents who are trying to hold on to their control over you because they think of you as a child, keeping your room in case you move back home or continuing to provide unasked financial support, it may be time for you to be the adult and tell them politely that you are now managing your own affairs.

Of course you may move between these experiences. We do not go from child to adult in a day but as an emerging adult you should drop your childlike needs and become less dependent on your parents for your ongoing medical care, physical care, financial support, housing, food, clothing, etc. until you know you are coping and you no longer need them in this role.

A good place to start this process or to check how far along the transition you are is by talking to the social work team at the QHTC's. Have a talk with them on how you can take charge without hurting your parents or being hurt yourself. With good supports around you, you will successfully grow into independence. You will be able to manage your personal health and you are going to become all that you are capable of becoming!

Adapted by Graham from a presentation by Jim Messina to the Hemophilia Foundation of Greater Florida on how children make the transition from being dependent children into independent adults.

Talking about von Willebrand Disease (VWD)

Although they outnumber people with haemophilia, people with von Willebrand disease (VWD) feel invisible at times. Some feel stigmatised, or that their symptoms are dismissed, and many deal with untreated problems and pain.

At HFQ we truly welcome all People With Bleeding Disorders to our events and activities. As part of our commitment to raising awareness of VWD and improve patients' access to care, here are some highlights from a background paper published last November by the National Hemophilia Foundation (NHF) in the US on the needs of the people with VWD:

Prevalence of VWD

In the report women accounted for 60.5% of enrolees; men accounted for 39.5%. The report found the prevalence of VWD differs between those presenting to HTC's (0.01%) and US population surveys which estimated it at 1.3%.

The discrepancies in estimates of people within VWD call attention to the need for more information on the relationship between VWF levels and clinical symptoms of bleeding episodes.

Patient variation

The report found 83% were type 1; 11% were type 2 and 6% were type 3. This compares with VWB estimates for those presenting for treatment which showed 85%, 13% and 2%, respectively. The report also found that 15% have multiple mutations. In addition, a patient's phenotype—symptoms and bleeding patterns—varies widely in VWD. Levels of von Willebrand factor (VWF) and bleeding don't necessarily correspond. The report makes the point that this complicates diagnosis.

Diagnosis and reporting

Diagnosis of VWD is not straightforward, especially for those with type 1, or people with low levels of VWF and mild bleeding. VWF levels also fluctuate in response to age, exercise, pregnancy or stress, which can skew the test results.

Patients themselves often under report their symptoms. Women don't disclose heavy menstrual bleeding (menorrhagia), and there also seems to be no consensus among physicians on whether VWD testing should be a standard screening tool to determine the underlying cause of menorrhagia.

Diagnosing VWD in men is also tricky. The report said that VWD is typically unobserved in males except in cases of life-threatening bleeding events. Compounding the problem, most GPs and other providers do not see patients with bleeding disorders and their unfamiliarity with testing protocols for bleeding disorders leads to even more missed diagnoses.

The report recommended that the treatment approach for VWD should be personalised for each patient, depending on the type and severity of VWD as well as the nature and site of bleeding.

Assessment of care

The report says that from 1996–2010, there was a 150% increase in the number of patients with VWD using HTC services in the US. The increase in VWD patients, particularly among females, was the largest source of growth of HTCs during this time, in fact, of the females seen at HTCs in 2010, 80% had VWD.

People with VWD reproted that they felt their care was insufficient and that providers treated them as lower in priority than patients with haemophilia.

Psychosocial concerns

People with VWD reported diminished health-related quality of life, specifically in terms of emotion, cognition and pain. Menorrhagia disrupted the lives of woman under 25, impacting on physical activities and sports, social events, school and work.

The mistaken notion that VWD is a women's disease stigmatises men and leads to under-diagnosis, said the report. It also found that people with VWD had difficulties expressing their VWD related issues with their GP's, suggesting that doctor education is critical to ensuring that people with VWD receive the range of care needed to achieve and maintain their health and quality of life.

Research

The report found there was limited information about the pathophysiology, epidemiology, treatment, and effects of VWD. It said there was a growing need for more studies on VWD alone, not in combination with haemophilia, and that systematic evidence reviews are needed to achieve the best management guidelines possible.

Future focus

The paper concluded with several recommendations to renew the focus of Health Care Services and suggested that patient advocacy organisations like HFQ should re-examine and strengthen our patient and community advocacy for VWD to help improve care for people with VWD by ;

- Advocating for improved screening and diagnostic protocols for and classification of VWD
- Advocating for improved education and training of GP's and gynaecologists in VWD to improve their awareness, diagnosis and management of VWD.
- Improving HTC protocols for recognition of and focus on VWD, including comprehensive care of VWD distinct from other bleeding disorders

For a copy of the report please go to: https://www.hemophilia.org/sites/default/files/article/documents/HemophiliaSummitFinalReportOct2012.pdf or contact the HFQ office for a copy.

MedicAlert Bracelets are so Lame

But they could save your life

So it's Saturday night and it's a time to dress up and go out with your mates. It's really important to fit in and that medic alert bracelet just doesn't work for you. Besides everyone you are going to hang out with knows you're a bleeder so what's the need to carry a lame bracelet that tells the world there is something wrong with you?

It's great to fit in and it feels good to look good but you should always focus more on being alive than being fashionable. Nobody wants to feel like an outcast but no one wants you dead either! If it's important for you to wear something that someone else might want, that actually makes you feel proud; then you probably don't want that old stainless steel bracelet. While the metal plate with one of the medical symbols is a mainstay of all good MedicAlert designs they are offering a lot of choice these days. As well as the metal bracelets and necklace pendants, you can get sports bands and dog tags.

There are plenty of alternative companies and alerts out there now (although some cost a bit of money) but it's better to stick to the official alert than getting something made up on normal jewellery or advertised on-line. If you end up not being able to speak for yourself at the time of an accident it's no good if the ambulance or first aid person ignores your fancy bracelet as just a fashion accessory.
If you're going to buy from a different source, show the design to your HTC team who may even ask the opinion of the emergency department personnel.

Saving lives during medical emergencies is exactly why Haemophilia Foundation Queensland encourages everyone who has a bleeding disorder to wear some form of medical ID. We also offer rebate to HFQ members who buy them because in a car accident or other medical emergency, medical personnel need to know if an unconscious injured person has a bleeding disorder.

It changes the response to treatment in a lot of ways. It should help you get the medical response you need including the emergency department knowing to give you factor to stop the bleeding before doing a CT scan. This is especially important in the case of head injuries and surgery. In the United States some people have even died after being shot and taken in for surgery without factor.

The MedicAlert Symbol of Medicine:
A snake wrapped around a staff

Guidelines for Wearing Medical IDs

Whatever Medical Emergency Device you choose it's no good if it doesn't display an easily visible and familiar medical symbol, such as the caduceus, (see image above). It should list your personal diagnosis, factor deficiency and emergency contact. If you're not sure what it should say talk to the staff at the HTC who will the authorise it as being authentic.

When you were a baby you probably didn't have an ID bracelet because your parents could speak for you and you might have chocked if they put a medical IDs with beads, charms or other detachable parts on you that you might have swallowed. This is also the problem with some of the more fashionable medical IDs currently available. Not only can they be overlooked as a fashion statement, but they can also break or come off during regular activity.

As a baby boomer I was never given much choice but kids today (Millennial's) demand styles with more flair than the plain metal bracelet and information tag of my youth but it's still a fine balance to strike between style and functionality and you don't want vanity to prevail, so stick to the official Medic Alert catalogue if at all possible.

MedicAlert's bracelet and necklace styles feature a stainless steel, gold or silver chain and information plate with lettering in myriad colours. Other styles include colourful beaded bracelets, sports bands and watches. They have come a long way, but what has remained consistent is the emblem and the quality of the authenticated information engraved on the ID and stored with the issuing company.

This is the hidden part of the proper MedicAlert items. When you purchase a MedicAlert ID you have register as a member and the HTC clinical staff will review your medical information before it's engraved on the metal plate. In an emergency, the first person there can call for more specific information on you and your family contacts can also be notified of the incident.

So if you have thrown away your old MedicAlert bracelet please check out the new ones available and get one you are willing to wear. It just might save your life!

Playing Safe

Elbows. Knees. Ankles. All those bendy, bony parts of your body are shaped especially to let you run, jump and skip. And sometimes it's so much fun, you don't ever want to stop — not even for that achy feeling of a bleed.

But stop right there! Those same joints that let you scramble and hop around are also prime targets for those sneaky bleeds that can take you out of the game. If you want to keep playing or get pack into the game as soon as possible, you need to learn how to protect your joints from the inside out.

Listen Up

Your mum or dad has probably said you can't play some games even when you want to and even though you might not like it it's important to listen up and follow their directions. That way, when you go outside to play, if you've taken prophylaxis or anything else your HTC recommends, you can be sure you're protected. It's not fun to have to stop playing to treat a bleed, but if your parents tell you to, or if you notice it yuorseld, you should always do it. That way, you can be playing again sooner!

How you carry yourself

Your joints have their own built-in armour, it's your muscles. Having strong, flexible muscles will help keep your joints protected and stop them bending too far, or bleeding as much.

When you're moving around check out what's on your feet and what's under them. Playing around is always safer for your joints if you're on grass or a cushioned surface. And while you may love to run around barefoot or in thongs, if your parents have said you need to wear the right shoes, try to keep to it because they protect you too and always tie the laces tight even if it's not cool.

Sometimes school backpacks can be too heavy. If you can feel it causing a tingly bleed, talk about it to your parents. It's better to carry a few less books than lug them round and risk a bleed.

Get Out There

Sometimes it may feel like there's a lot you're not allowed to do, but if you think about how you can play it safe, there may be ways you can play without putting pressure on those joints that bleed most often.

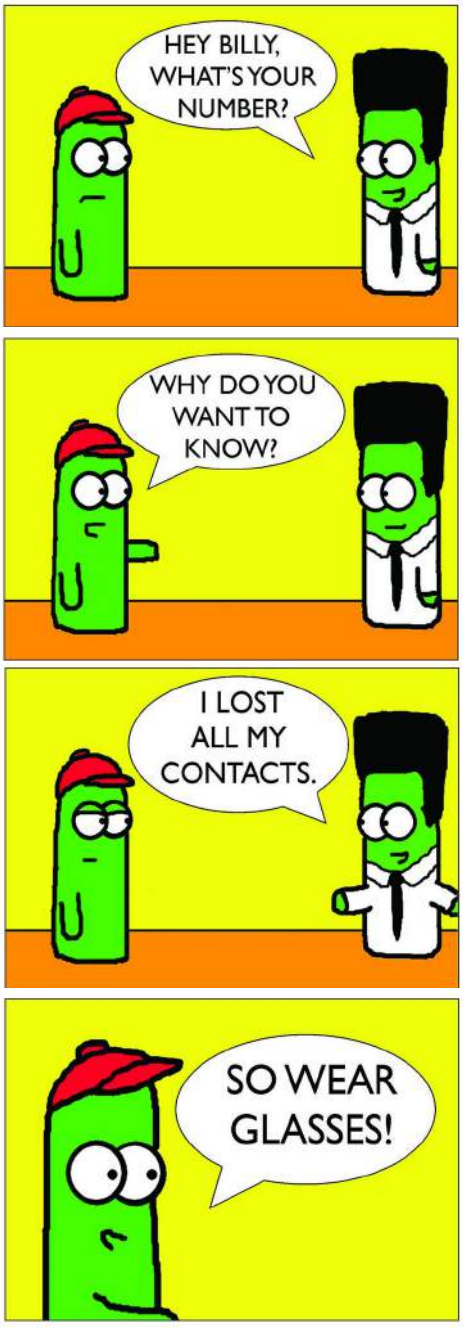
Before any exercise, it's always important to spend a few minutes stretching. If you get elbow bleeds, try exercising something that works your legs more than your arms. If you get a lot of ankle bleeds, try bicycling instead. But make sure to wear a helmet.

Edited for size from an article that appears at: http://www.hemaware.org/story/game-0

The Slobs

by Conor Birkett

First published by the Irish Haemophilia Society.
http://www.haemophilia.ie/content.php?id=7&article_id=698



Who Knew (Fun Facts)?

- The first video games were introduced in the 1970's with titles such as 'Computer Space' and 'Pong' - ask your parents what games they played
- Website addresses such as http://www.hfq.org.au are known by the term Uniform Resource Locater (URL).
- Dogs have 42 teeth. Cats have 30 teeth. Adults have 32 teeth.
- Natural gas doesn't have an odour, strong smells are added to it by humans so it can be detected when there are leaks.
- Your food takes 24 hours to go through the 9 metre long digestive tract where it gets mixed with acids and then squeezed and squelched until all the body absorbs all the nutrients it needs. Then, the smelly leftovers are ready to exit the body. Plop!
- Your heart beats around 100,000 times a day, 36,500000 times a year and over a billion times if you live beyond 30.

What's in a Name?

OBE's has been the name we use for events targeting those men who have survived with their bleeding condition for enough time that they are now mature and independent adults.

Some people have asked what OBE's stands for and others have 'point blank' refused to attend an OBE event because of what they assume it says about themselves. For some time now we have been looking for a new group name to describe this group of wonderfully resilient members of HFQ.

It is with great pleasure that we offer you a new name for OBE's ...the Wonkys.

Created as an affectionate term, this could describe the character of these men but more rightly it describes how life has affected them. They meet monthly at a support lunch and often that involves a speaker talking on a topic that these men are dealing with in their lives. As discussed elsewhere (page 4) a current program for these men is 'SBM', a pilot palates class that is showing great results. We have also run workshops form them on dealing with ageing and mobility issues.

With factor being available to everyone in Queensland who needs it, this group continues to grow in membership and because living with a health condition carries it's own needs and issues we will continue to try to support these men, so please look out for other Wonky events in the near future and consider joining us.

Parenting Tip: The 4-1 Rule

There is a wide array of "voices" speaking on the topic of parenting these days. At one end of the spectrum, is the absolute parenting "expert", who makes no consideration of your child's needs. Then there is the "dare-not-disappoint-the-child-for-fear-of-destroying-their-self-esteem!" parenting "expert. Most of us land some place in the middle of these two extremes

Parenting children well is an incredibly challenging pursuit, and with the demands and pace of life we confront in today's culture, we are rarely able to gain clarity and composure as it relates to our parenting skills. A quick review your parenting skills is to ask; Do I like that what I claim about my current parenting practice or do I want to tweak it (enhance, or adjust?) and how can you do that in a small but consistent way?

The Parents Empowering Parents (PEP) is a program designed to promote effective parenting skills to parents of children with haemophilia, and one tip they offer is the "4-1 Rule" as a key concept in the Parenting. In short, it means try and give four positive comments for every 1 negative comment.

Four positive comments should be made for every one time that a parent issues a negative comment. Negative comments most often relate to something that you have requested of a child and to which he has failed to comply. By changing the statement, you can develop a Positive Directive (see chart below), which then falls closer to the category of Positive Comments. Remember that your tone of voice also affects how your child will react to the directive.

Negative Comments	Positive Comments	Positive Directives
"You never do as I ask."	"Way to go!"	"I asked you to put your shoes in the closet; please do it now."
"It's your fault because you don't ever listen."	"I like the way you listened just then."	"When I am talking to you, I appreciate your paying attention."
"You did that all wrong."	"You have a good sense of humour."	"You're doing pretty well. Here, let me help you with the hard part."
"You are always breaking things! Don't you even care about your brother?"	"Thank you for picking up."	Please pick up. When you are finished, I'll help you check to see that it's all gone."

These examples of positive comments, negative comments, and alternative ways to take the sting out of negative comments are taken from page 62, PEP Parent Manual

Blended or step-families & Bleeding Disorders

The blended family is here to stay. According to the 2006 Australian Census data, one third of registered marriages involve at least one previously divorced partner and 14% of all kids under the age of 18, lived in a blended or step-family.

Finding a new partner is a wonderful thing and creating a new family can be amazing but not everyone adjusts at the same speed and creating a blended or step family can be complex and stressful. It doesn't matter what your family is called as long as you've made a commitment to making it "your" family.

Effective blended families and step-parenting takes planning and preparation. So before you move your partner and children under one roof, discuss your expectations and develop a plan so it's clear to everyone involved what you are agreeing on and committing too.

Your parenting plan should meet the needs of all the children in your new family including the child with the bleeding disorder so they all feel they belong. It should cover medical, financial, educational and even religious activities, along with family rules and tasks that you and your new partner agree to. As the new parents in this family you should discuss topics such as family meetings; who will pay the bills and which parent will take children to appointments and activities.

One key aspect new families have to agree on is discipline. Couples should discuss parenting styles early on and how you will stand together so you have a united front when issues occur. Once you agree on a plan for your family, share it with your children and also review the plan from time to time and adjust as you see fit.

Although the children should not make final decisions on parenting methods or who the parents are, you have to listen to children's feelings and give them credence. Your kids should be informed and encouraged to make suggestions at the time the family comes together and when you review your plan. Remember that time and patience are key when bringing a blended family together.

Learning about Bleeding Disorders

Part of the preparatory process for a blended family involves learning about the child with bleeding disorders and their needs. Both adults should meet with paediatric haemophilia treatment centre (HTC) staff to discuss what you or your partner need to learn about the child with the bleeding disorder and how to care for them within your new family.

It's best if the new parent can also learn from the HTC nurse how to give infusions because you can never guarantee that the natural parent will be nearby when needed. However even if you're an expert at giving infusions, try to give the child a choice. If he is not comfortable with the stepparent doing so, that's OK.

Step-children may be conflicted over loyalty to their natural parent versus their new parent.

- For tips on helping your child's siblings cope with his bleeding disorder check out: *hemaware.org/story/how-help-children-cope-their-siblings%E2%80%99-bleeding-disorder*.

Adjustment tips for the child with a bleeding disorder

As your child adjusts to life in a blended family, some changes in their attitude are to be expected. Affection and love develop slowly. It takes time for any child to build a relationship with a new step-parent and stepsiblings, so don't try and force an immediate bond.

Adults should show unconditional love and acceptance, realising they may not be reciprocated until much later. Because situations vary, your HTC social work team or a relationship counsellor can help you navigate the adjustment period. Also seek professional help if your children display extreme guilt or anger, become withdrawn, act very uncomfortable with new family members or exhibit troubling behaviours such as fighting or refusing to go to school. While you can't give children permission to veto the new relationship, if a child says, 'I don't like that person, you need to listen and figure out why.

Adapted and reduced for size from an article by Leslie Quander Wooldridge. Originally Published in Hemaware April 2015 http://www.hemaware.org/story/blended-families-and-bleeding-disorders?tr=y&auid=15613394

Managing Money Makes the World Go Round

Living with a health issue (like living with children) can cost money. We can find ourselves with unexpected debts that can cause pressure and detract from the joy of living.

Avoiding or overcoming debt is all about making the most of what you've got and knowing where it is going when it leaves your bank account. Here are some ideas on how to control those expenses.

Cut and Control Spending

Understanding your current spending habits can help you prioritise and cut back if needed. Are there any lifestyle changes you can make? How about sharing child care duty or trading services with neighbours or friends? Can you cut back on something? Is Netflix really necessary? Would switching your phone or IT company save you money? Can you do without that morning espresso?

Look for ways to save money every day, from unplugging appliances, to using LED bulbs or buying at second-hand shops and garage sales you can save money. Comparison shop on-line to get the best deal on new purchases and always take care of what you have, routine maintenance helps your car run better, last longer, and get better fuel economy. Every bit of money saved improves your finances.

How can you stay on budget? Be creative! Save money on food by pre-planning meals. Check the unit price when grocery shopping and in most cases economy size is cheaper.

If you have a baby breastfeed, (instead of formula) when you can; use websites to find items people are giving away or selling cheap (Gumtree etc); make more food than necessary and freeze the extra; or take turns babysitting with friends.

Other Options

If you need to figure out additional ways to save money consider switching your bank account to one with no monthly fees. You can try to refinance or consolidate your loans.

Have you looked into any CentreLink help that may available? Some charities may also have services available to you. Talk to the social work team at the haemophilia centres

before you consider selling off

household goods or getting a second job.

Not All Debt Is Created Equal

Avoid getting into debt on items that depreciate instantly, such as clothing. Who wants to be paying three years from now on an outdated TV? Pay cash for these as much as possible or consider lay-by. Try to avoid pay -day lenders and credit cards .

Digging Out

If you have fallen into debt, there are fixes available, but seek help from a financial advisor first. You can try to fix your debt yourself by slowing or stopping your credit card spending and making a plan to pay it off.

Smart Investments

Roll any superannuation accounts you have into one program. Building an emergency fund worth can help cushion you from unexpected expenses.

Invest in your child's education. This isn't just money, parents who are involved in their children's education and provide them with learning opportunities are more likely to have kids who do well in school and succeed regardless of it being private or public schooling. Parents can help children learn by: having books available; reading to children; limiting children's television viewing and Internet time; taking them to museums, etc; help them with homework; talk to them about their day.

Avoid Other Mistakes

Companies can increase your interest rates for no other reason than a late or missed payment to an unrelated company. If you fail to pay a bill you may be asked for a pre-payment in future. Educate yourself on your options and choices that could negatively impact your finances.

Coming in from the Cold

When you start to control your spending and know where your money is going, you start to see that financial goals are possible. You can accomplish your goals one step at a time. Once you conquer one debt, you can move on to the next one.

Also remind yourself that your life should be a joy, not a burden, and you don't have to spend money to show love.

Edited for size from an article by Celina Tinsley at: http://www.feministsforlife.org/rkoas/rkoas-money-management/

4 Actions To Improve Boys' Literacy

In 2012 a survey in the UK found that in boys aged between ten & eleven years old;

- One in five boys (20%) don't make the grade in English
- One in four boys (23%) don't make the grade for reading

One in three boys (32%) don't make the grade for writing

As a result a National Boy's Reading Commission was set up and made a series of recommendations for improving boys' literacy. Among the recommendations are several you can take on as a family. They included:

1. Reading should be promoted for enjoyment and parents (especially fathers) should be involved in their boys reading strategies

2. Every teacher (and parent) should have an up-to-date knowledge of reading materials that will appeal to disengaged boys

3. Every boy should have weekly support from a male reading role model

4. Parenting initiatives must specifically support literacy and fathers

See http://www.helpingmen.co.uk/2013/03/best-practie-17-10-actions-to-improve.html

Market Research *Continued from page 5...*

- We check whether an "online support group" is actually market research capturing people's comments and experiences for a pharmaceutical company.
- We also check to see whether the questions are too delving or intrusive and might be distressing or trying to encourage a person to seek a specific product.

SOME POINTERS

If you are interested in taking part in a market research study:

- Check the HFA web site under Bleeding disorders > Participating in research to see whether the study is listed (NB - we only list studies researchers have sent to us)
- HFA doesn't permit researchers to recruit participants by posting directly on the HFA Facebook page so beware of answering any research requests posted there by researchers who are not from HFA!
- Ask the researchers more about the study and how they will protect your privacy – there are a list of useful questions on the HFA web site

You might also find it useful to discuss the market research with someone independent of the study, eg a member of your Haemophilia Centre team or your Haemophilia Foundation or your GP.

If you have any queries about a research study, contact Suzanne O'Callaghan at HFA E: socallaghan@haemophilia.org.au or T: 1800 807 173

Capable fatherhood *Continued from page 7...*

ideals they described themselves as becoming capable. Feeling capable as a father improved as they became involved in home treatment of their son and while haemophilia fundamentally changed many dads' life views and experience, this reduced their sense of loss and powerlessness.

The study showed that many dads faced an existential question: What father shall I now become? Society encourages dad's involvement in sports activities and children's success can be a proxy measure of good parenting so we should all recognise the complex cultural context that creates the dreams of fatherhood.

The study found that most dads want and need to be involved in the parental responsibilities that haemophilia diagnosis requires. So it is really important that home treatment is working well for both parents before dads can feel capable as fathers. If the fathers can be more actively involved in the daily care of their child's disease mums will also feel less guilty that they may have abandoned their partner during the first years when they focused their son's daily treatment and care

Ultimately, a sense of being a capable father was related to a sense of independence and control of one's life situation. Support for both parents of a child with severe haemophilia is essential. Awareness of the fathers' struggle to feel capable is also vital while supporting the family in the early years after diagnosis.

Adapted for size from an article published in Haemophilia Journal 2015 (pp1-7) by L Myrin Westesson, C Sparud-Lundin, et all.

HFQ subscribes to this journal and f you'd like a copy of the paper or other articles that appear in this journal please contact the HFQ

Gene-Sequence Swap to Cure Haemophilia

A new study shows that chromosomal defects responsible for haemophilia can be corrected in patient-specific stem cells.

People living with a bleeding disorder can live in a state of stress and anxiety: their joints wear down prematurely and they have bleeding episodes that feel like they will never end. Their bodies lack the ability to make the clotting factor responsible for the coagulation of blood so any cut or bruise can turn into an emergency without immediate treatment.

In about half of all severe Haemophilia A cases the cause is identified as "chromosomal inversions", the order of the base pairs on the chromosome are reversed so the gene doesn't express properly and the person lacks the blood coagulation factor VIII (F8) gene, which causes blood to clot in healthy people.

The Centre for Genome Engineering at Yonsei University in Korea has experimented with stem cells and found a way to correct this inversion and reverse the clotting factor deficiency that causes haemophilia A in mice.

This was the first time a stem cell was used in a procedure like this. Cells were collected from patients with the chromosomal inversions causing haemophilia and turned into stem cells. The team then applied a protein nucleases to them which reverted the F8 genes in the mice and enabled them to function correctly.

Corrected stem cells were induced to express the F8 gene and these new endothelial cells were able to reverse the F8 deficiency. To verify that the process worked, the endothelial cells with the inversion-corrected genes were transplanted into mice with haemophilia A and the mice started producing the F8 clotting factor on their own, which essentially cured them of haemophilia A.

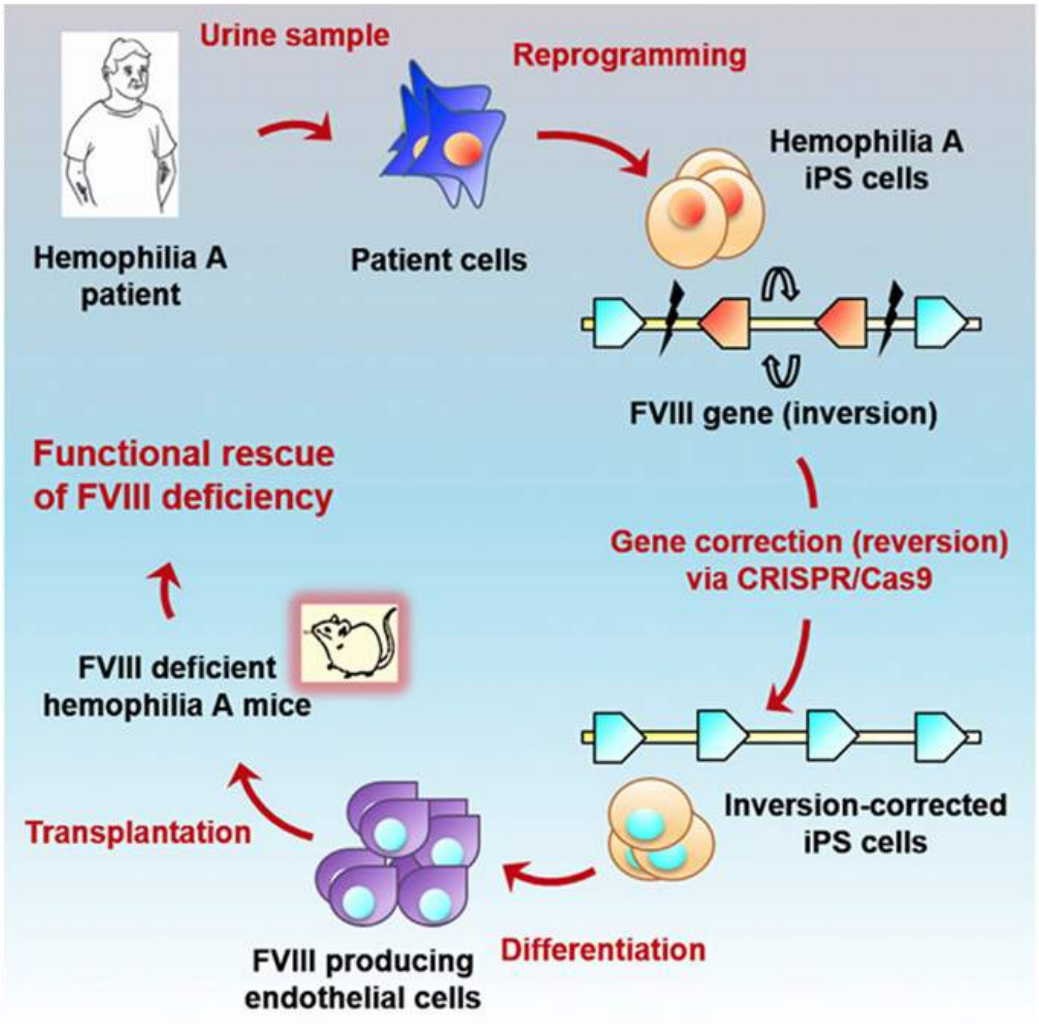
According to the tem leader Director Jin-Soo Kim, they used RNA-guided engineered nucleases to repair two recurrent, large chromosomal inversions responsible for almost half of all severe haemophilia A cases. He says this is the first demonstration that chromosomal inversions or other large rearrangements can be corrected using protein nuclease in patient stem cells.

Equally as important (to the ability to reverse the chromosomal inversion) is the fact that there was no evidence of off-target mutations resulting from the correction. This was a precision procedure: only the parts of genome that the team wanted to change were affected.

These findings open the door for further testing and if the results are anything like the mice trials, the future of this treatment looks promising.

Article adapted for size from a press release issued by the Institute for Basic Science (IBS).

The original publication can be viewed at: http://www.cell.com/cell-stem-cell/abstract/S1934-5909%2815%2900300-8



HFQ Fundraising Raffle

Please help us with our fundraising raffle. We are selling tickets at $5.00 each and we need your help…

Ensuring there is a supportive environment that will enrich the experience of patients at the haemophilia clinics and providing vital programs and services not funded by the state government is important to us. Yet there are not many opportunities for us to successfully fundraise, and when a wonderful family run compony such as "Reddog Bikes and Hobbies" offers the UTV we are raffling off, it's important that all members get behind the raffle and help us sell as many tickets as possible.

It feels great to know the funds raised will help children and their families living with bleeding disorders. But that's not the only reason to support us by supporting our raffle.

HFQ is a non-profit, patient support and advocacy group; one in three of the people we support have no prior exposure to bleeding disorders and nearly 50% are financially distressed because of time off school & work dealing with their bleeding disorder. These kids and their carers depend on us, and we always put their needs first.

Where do we spend the funds raised?

We provide programs and services that will never be reimbursed by the state government and we do it because no families deserve to be left behind. Our programs allows all people affected by a bleeding disorder to participate & contribute to their local communities.

Supporting our raffle will ensure that HFQ raises the much needed funds we will use to help our members far into the future.

HFQ really does need your support. We use our fundraised money to help subsidise accommodation & support for regional families accessing hospital services in Brisbane and we help the amazing state wide Haemophilia Centres with items they can't easily get within the hospital system.

Please call the office mobile on 0419-706-056 if you'd like a book of 20 tickets to sell, or let Graham know if you'd like to purchase tickets yourself

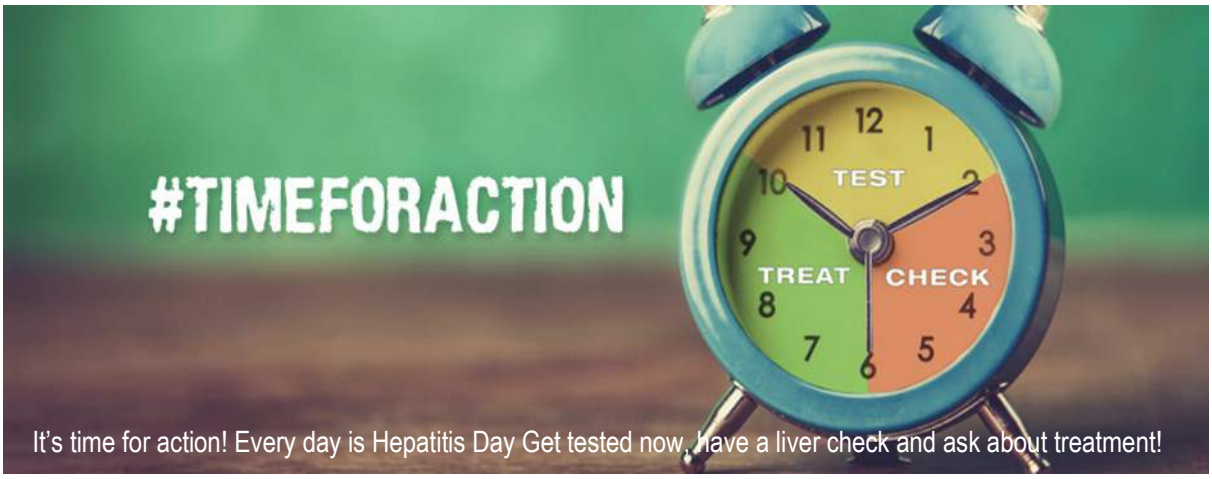
We are amazed and grateful that the prize has been offered for free and we also thank Crossfire for their generous support. Now **we need you help** to raise as much money as possible between now and 19 December when the prize will be drawn.

Hepatitis week is every week

Nearly 250,000 Australians with Hepatitis C hope new drugs will soon be approved by the Pharmaceutical Benefits Scheme (PBS).

The currently available drugs can require 6-12 months of treatment and for many patients they cause debilitating side effects like nausea, hair loss and depression.

While they have an 80 per cent cure rate, the emotional and physical cost has been very high for some of our members who got Hep-C through infected blood products. The stigma associated with Hepatitis C means that some of our members are reluctant to tell their family or work colleagues they are infected.



It's time for action! Every day is Hepatitis Day Get tested now, have a liver check and ask about treatment!

But new drugs from Europe and the US are providing hope. The medications we're seeing approved overseas now are around 12 weeks on treatment and have very little side effects.

28 July was World Hepatitis Day and it came and went without any announcement about government funding for the new treatments and for those of you with hepatitis it is not enough to just wait in hope, nor is it OK to think about your liver just once a year.

For some of our members they are at that stage where they're looking at potentially moving onto more advanced liver disease and they're sitting there weighing it up and saying how much is my life worth. Don't wait for the new drugs to be approved. Start thinking about what you or someone you love with hepatitis needs right now.

Many people with bleeding disorders are affected with Hep-C but we don't know how many. Only you can know and if you're over 25 or may have had untreated blood products at some stage in your life, you should get tested if you don't know your Hep-C status. It's that important.

If you were born before 1990 and have used factor you could be at risk.

The World Hepatitis theme was true on 28 July and it's just as true now ...and every day IT IS TIME FOR ACTION!

Get tested now if you haven't already done so. If you know you have hep-C ask for a new liver check ...and ask about treatment!

If you haven't had a liver check in the past 2 years get your liver checked again and have it checked regularly from now on because if they don't know the status of your liver they can't put you onto any medication (the current ones, or the new ones coming soon). If you want Hep-C treatment you need to have a current liver health assessment to start with, so why not get a liver health assessment now?

It's also vital that you let your Haemophilia Centre know about your liver test results and treatment because they can act as a short cut into liver treatment programs for you, but that doesn't mean you can ignore the Hepatitis clinic if you've already have a liver test. You need to stay in touch with them too for the latest news and updates.

Even if you don't have Hep-C, you can help someone you know who does. Because it is difficult to think about liver failure and dying, you could start that important conversation about caring for themselves. Why not talk to your brother, husband or son about [looking after] their liver!

The Pharmaceutical Benefits Advisory Committee (PBAC) continues to recommend other new hepatitis C treatments for listing on the PBS but the decision to fund these new treatments lies in the hands of the Federal Government.

There is a great webcast – Hepatitis C Treatment: What you need to know – that you can watch online at: www.webcasts.com.au/hepatitisaustralia/

Health Updates

Phase II/III trial starts for Hemophilia A or B patients with Inhibitors

A global phase II/III study of CSL Behring's recombinant fusion protein linking coagulation factor VIIa with albumin (rVIIa-FP) also known as CSL689 has started.

The study is in patients with haemophilia A or B who have developed an inhibitor. It will evaluate the pharmacokinetics (PK), efficacy, and safety of the (rVIIa-FP) for on-demand treatment in patients who have developed an inhibitor to factor VIII or factor IX replacement therapy.

The study is part of the PROLONG-7FP clinical development program. Earlier studies have confirmed that rVIIa-FP has favourable pharmacokinetic properties compared with the existing recombinant FVIIa product and that it has good tolerance, and a 3- to 4-fold increase in half-life compared with the current rFVIIa-products.

Originally Published http://www.prnewswire.com/news-releases/csl-behring-enrolls-first-patient-in-global-phase-iiiii-study-of-rviia-fp-for-on-demand-treatment-of-patients-with-hemophilia-a-or-b-with-inhibitors-300132820.html

Subcutaneous treatment for Haemophilia A

The U.S. Food and Drug Administration (FDA) has granted breakthrough therapy designation to ACE910 (RG6013, RO5534262) for the prophylactic treatment of people over 11 years old with haemophilia A and factor VIII inhibitors.

Early trials showed that once-weekly subcutaneous injections worked well irrespective of the presence of inhibitors and the new designation is designed to accelerate the continued development and review of ACE910. Although it's not registered in Australia If all goes well this could be a significant treatment option in future.

Originally published: http://www.gene.com/media/press-releases/14603/2015-09-03/us-fda-grants-breakthrough-therapy-desig

Antidepressants and Common Painkillers Together can Cause Bleeding

A new Korean study says that combining the use of antidepressants and painkillers can lead to increased risk of bleeding soon after starting treatment

Compared with use of antidepressants alone, the team found that combined use of antidepressants and NSAIDs was associated with a substantially increased bleeding risk. They found no statistically meaningful differences in risk of bleeding between different types of antidepressant drugs, or with age.

Being male was the most common factor for a higher risk of bleeding with combined use of antidepressants and NSAIDs. The addition of NSAIDs to antidepressant treatment increased the risk of intracranial haemorrhage within 30 days of the combination starting, especially in men, the authors concluded.

Originally Published: http://www.medindia.net/news/using-antidepressants-and-common-painkillers-together-can-cause-bleeding-in-patients-151087-1.htm#ixzz3lbmuY74D

Scientists Develop a Gel That Stops Bleeding

Bioengineers from the US, have developed a highly elastic bio-material that can mimic the elastic tissue of skin and blood vessels when exposed to light and stop bleeding at one go. It heals wounds by acting as a sealant - sticks to the tissue at the site of injury and creates a barrier over a wound. It can also be incorporated with cells in a dish and then injected to stimulate tissue growth.

The material, known as a photo-cross-linkable-elastin-like polypeptide-based (ELP) hydrogel, offers several benefits. It is possible to combine the gel with silica nanoparticles - microscopic particles to immediately stop bleeding with one treatment

Originally published: http://www.medindia.net/news/scientists-develop-a-gel-that-stops-bleeding-with-one-treatment-150696-1.htm#ixzz3lbmxwPNP

Risk for Osteoporosis.

In Australia 2.2 million people are affected by osteoporosis. About 11% of men and 27% of women aged 60 years or more are osteoporotic, and 42% of men and 51% of women are osteopenic (some bone density loss leading up to osteoporosis).

Having a coagulation disorder with a level of joint damage has a proven link to changes in bone density. As you grow, bone is laid down and in older age bone density reduces naturally, however with joint damage this process is changed. It might be minor and more significant depending on when and severity of joint damage. The good news is that it can be measured and treated if required. Next review or medical appointment ask the question ***– please see the flyer on Osteoporosis included with this magazine for more information***

For more information see also: http://www.ncbi.nlm.nih.gov/pubmed/12049064

Important Dates for HFQ Members

Wonky's (Previously OBEs) Meets in SE Queensland on the first Wednesday of each month.

Regional Meetings The Haemophilia Clinics travel to centres with clusters of people with bleeding disorders. Where possible HFQ try to host a local meeting to coincide with these visits so please ask if one is happening at the time of your next centre visits. More details will be in later issues.

Haemophilia Awareness Week & Red Cake Day 11 – 17 October 2015

Youth camp 2015 30 October – 1 November 2015 at Emu Gully. Open to siblings and affected youth.

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

Youth Camp @ Helidon

Haemophilia Youth camps provide an important role in giving children and young adults a sense of community and are often the first time that they have been around other children with a bleeding disorder. The camaraderie provides participants with a sense of relief that they are not the only ones with a bleeding disorder. As a result our young people emerge from camp as stronger and more self-reliant individuals.

This years youth camp is on again from 31 October to 2 November. It allows teens to connect with others who are facing similar challenges. The weekend retreat also addresses physical activity including canoeing, high ropes and even rock wall climbing. Physical activity will help strengthen muscles around joints and prevent joint damage.

Some teens also undergo leadership training to become mentors for younger children who are learning skills to be able to self-infuse and survive all that life throws at them.

Youth camp can introduce young people to the benefits of self-infusing, a life changing experience as they see other boys doing it. Learning with their peers is a powerful motivator and incentive!

This years youth camp is also open to siblings impacted by their brothers bleeding disorder. It's open to all young people over 10 although preference will be given to the boys with the severest forms first. We have enough facilitators so parents can leave them alone and know they will be safe, but if your child is on the younger side please talk to us about staying with them or perhaps visiting for the Saturday only.

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.

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