From the President

Hi everyone,

'Quietly confident' is my take home message to the Qld bleeding community after the recent world congress on bleeding disorders (over 5,000 attendees - a mixture of medical, patients and industry). When I look back just a few short years we had some progress in aspects like gene therapy and longer acting product etc., but it is nothing like todays international investment into research, new products, innovative bypass products. It is so much more.

The conference covered every aspect of bleeding conditions as well as opportunities to ask researchers & specialists questions. Large and small companies are striving to tweak their products which will hopefully deliver great outcomes for patients - some with very exciting late breaking data from their trials, some innovative methods to address inhibitor treatment and more.

So with all this activity I am quietly confident you and I will have better treatment options in the near-ish future – some believe 15 years, my take is much less than that if current trials prove effective. However one of the big questions is how much drug companies will want to charge for these new treatments and how the National Blood Authority will respond. Australia's tender

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Inside this issue:

President's Message *Continued...*

process was mentioned a few times – how we have achieved very low treatment costs (some products in the USA for example are 5 times more expensive). Cost aside, the big community advantage I see is better treatment compliance as needling frequency will reduce – I know some currently don't stick to their current treatment plan due to this issue.

On a different matter - I would ask you to encourage those who have HepC but have not looked seriously at the new treatments to consider for a moment what a 90%+ cure will mean (with typically no side effects). I know some people have not been tested, some have fears based on old treatments and others think they are OK as they 'feel OK'. Make no mistake you're better off without HepC – I know from personal experience. There is a real possibility now to eradicate HepC from the bleeding community! Australia is leading the world in this …. support & empower the people you care about.

David Stephenson

President HFQ …..HFQ – keeping you informed
Advocacy, Education, Health promotion, Support

World Federation of Hemophilia Congress

In this issue of H Factor we offer a series of reports on the World Federation of Haemophilia (WFH) World Congress held in Orlando from 24 – 28 July 2016. Dave Stephenson (President) and Graham Norton (Manager) represented the Queensland Haemophilia Foundation at the congress.

We both left Orlando feeling that things really are changing. From next-generation clotting factor concentrates, to alternative coagulation therapies, to gene therapy, and fantastic new diagnostic tools; every session seemed to offer advances that will help our members.

The reports in this magazine are indicated with the congress logo and we have tried to record key points from the various sessions that we attended, or were ones that we felt may be relevant to our community of people with a bleeding disorder in Queensland.

They are mostly a summary of Dave and my notes so they will not be a detailed explanation of some sessions which, while exciting, were very technical and will be better explained in future issues by our haematologists and other QHC clinical staff who are across these matters.

In case people are interested, we've also included an article giving a brief summary from the opening session on activities of the WFH itself.

In the interests of time and practicality, details of individual workshop presentations are re-written from the notes we made so they will be a brief overview, but hopefully coherent enough to read. If you'd like to clarify anything mentioned here, you can approach Dave or myself, or check out the webcasts and slide sets from selected sessions on the 2016 congress page of the WFH website (*http://www.wfh.org/congress/en/*).

Dave and I are very grateful to HFQ for the opportunity to attend congress and encourage anyone from our community to consider future congresses which will be in 2018 (Glasgow, UK) and 2020 (Kuala Lumpur, Malaysia). Find out more at wfh.org.

Graham

Graham Norton (Manager)

ABOUT HFQ

The Haemophilia Foundation of Queensland (HFQ) provides representation, health promotion, 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 on the 3rd Tuesday of each month.

We can be contacted at the office on (07)3017 1778 or 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 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
Alex Connolly – Clinical Nurse (Part time)	3646-5727
After Hours — Page Haematologist	3646-8111
Physiotherapist (to be confirmed)	3646-8135
Michael Hockey — Physiotherapist	3646-8135
Loretta Riley — Advanced Social Worker	3646-8769
Desdemona (Mona) Chong – Advanced Psychologist (Alt Tuesdays and every Friday)	3646-7937

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

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

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

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

OUTREACH CLINICS

Gold Coast Hospital, Toowoomba General Hospital, Nambour Hospital, Cairns Base Hospital & Townsville Hospitals: Book through Joanna at LCCH and Beryl at RBWH.

Recognising a Joint Bleed

Todays young people with severe bleeding disorders are clearly benefiting from prophylaxis. However, because joint bleeds are so infrequent, some kids don't recognise them, or don't treat them properly when they do occur.

Prophylaxis decreases the likelihood of spontaneous joint bleeds that can lead to permanent damage. So it's important to know the signs and what to do next. If somebody has never had a joint bleed, they may not be as vigilant in looking for and treating them.

Know the Signs

The most common sites for joint bleeds are the knees, elbows or ankles. When a bleed happens the joint and surrounding area become swollen, which can result in irritation or pain. Many people describe it as a sensation of heat and bubbling and they won't want to move the joint.

Bleeds into the joint cavity can cause synovitis making the joint incapable of normal function. The synovial lining is fragile & at high risk of repeated bleeding.

Target joints are those that have had repeated bleeds. By the time a joint bleed causes pain, decreased range of motion and obvious swelling, it's likely the damage has already occurred. That's why it's important to notice subtler signs.

Infants don't get many joint bleeds because they aren't mobile yet, but your baby may limp or refuse to bear weight, or won't want to get up if they have a bleed. Sometimes they'll hold their joint where it hurts.

Any change in the way a child walks, or unwillingness to use or bend a limb should be taken seriously and addressed. Noticing that your child is acting out of character is another sign, but it can vary, even among siblings.

Don't Wait to Treat

If you think something's wrong with how your child's acting you can call the QHC, but if in doubt, dose with factor! If they aren't treated quickly it can eventually lead to joints that can't fully flex or extend.

Time matters so try and carry at least one dose of factor with you at all times (following storage guidelines when traveling) so you can dose if you need to.

When a joint bleed happens, infusing with factor isn't enough. To prevent joint bleeds from recurring, stick with P-RICE; Prophylaxis, Rest, Ice,

Compression, Elevation. RICE is crucial in the 24 to 48 hours after infusion.

Active children and teenagers tend to re-bleed if they don't rest up enough. If you don't stay off the joint and move too soon after you treat, the bleed may not stop completely or you could bleed again and it could become a vicious cycle, with healing taking longer. And needing more factor.

Ice means using a cold compress every couple of hours, to reduce swelling.

Compression involves wrapping the joint in an elastic 'Ace' wrap. The compression helps reduce the bleed when you use the proper wrapping technique.

Elevation can be as simple as using pillows to prop up the joint above the rest of the body to keep the blood away from the joint and reduce swelling and discomfort.

Exercise Makes a Difference

Once the joint has healed, children can return to their activities. On page 9 are some sports that the World Fed says are OK for children with haemophilia. Sports like swimming because it's easy on the joints and builds strength & endurance. Being strong and active, having good nutrition, and avoiding obesity are extremely helpful for all people with bleeding disorders.

Research has shown that active children with haemophilia tend to have stronger muscles and connective tissue than their counterparts who don't exercise regularly. However it's important that you talk with the QHC team if you are considering allowing your child to play a high-contact sport.

After a bleed, parents may want to protect their children from everything in sight but you don't want a couch potatoe for a child, so talk to your children about sports that are safe and encourage them to participate in ones that appeal to them.

And as kids grow into teenagers try to get them to be diligent, because if they don't, as they age, a problem joint may start to show. When a child is 13, they don't always pay attention to the signs that they are having a bleed. so parents can try subtly spot-checking for signs of swelling of changes in your child's motion. Just because they think they're OK, doesn't mean they are! Someone has to think of the future.

Edited for size from an article by Laura Putre. Originally published in Hemaware Spring 2011 *http://www.hemaware.org/story/unfamiliar-bleed*

Value Mental Health....

October 9-15 is mental health week and this year's theme is "Value Mental Health". So, I am putting out the challenge for everyone to make a pledge to do something regularly to enhance their own mental health.

In the interests of full disclosure and to start the challenge – I must admit that I do not always nurture my mental health 100% of the time. It's not always easy to do these things regularly, but I encourage you to try to regularly undertake activities that bring you joy and happiness. Here is an example of one of my self care activities to start the ideas:

Gardening: I am a keen amateur gardener – so love spending time in my garden encouraging my plants to grow and of course discouraging weeds. This is often when I find myself using mindfulness to be in the present moment and not focus on the negative thoughts of more weeds coming up!

I was intrigued to hear Sophie Tomson from Gardening Australia present a talk on the health benefits from gardening at the Nambour Garden Expo in June. During her talk she cited beyondblue's report "Beyond Blue to Green: The benefits of contact with nature for mental health and well-being".

This report states that there is growing evidence to support that access to nature improves health and well-being. So, you don't need to have green fingers and be a gardener, merely being in the garden, spending time in a park, rainforest, the beach or similar can impact positively on your stress levels and mental wellbeing. Sophie mentioned during her talk that even being able to see nature through your window (or a picture if your room doesn't have windows) helps reduce your stress.

The Queensland Government "Healthier. Happier." website supports the health benefits of gardening – with named benefits including that it encourages;

- regular physical activity,
- stress relief through spending time in green spaces,
- it gives you a sense of purpose and direction, and
- you can see the outcome of the work you have done. (*www.healthier.qld.gov.au/articles/health-benefits-of-gardening/*)

So, enough of my self care adventures - here are some more ideas to get you started on caring for your own mental health:

- Have a self care plan and use it regularly, not just when things are getting tough. Please contact me if you would like a template to get you started.
- Practice gratitude – an example could be starting a gratitude journal and writing down 3 things you are grateful for at the end of each day or creating a ritual where you share the things you were grateful for during the day amongst your family at the dinner table
- Undertake an act of random kindness – random acts of kindness do not need to cost anything – holding a door open for someone, letting someone with a small amount of shopping go ahead of you in the queue, do the dishes, take the rubbish out, clean up your room, etc without being asked - the list is endless.
- Smile more often
- Engage in some exercise
- Have enough sleep
- Practice yoga, mindfulness, tai chi, laughter yoga
- Hug someone (with their permission of course)
- Eat healthy meals
- Stop for lunch
- Volunteer
- Enjoy your hobbies
- Spend quality time with friends and family; Send a friend a text, phone them, organise a visit to let them know you are thinking of them
- Read a book or do some art
- Let someone know you are thankful for what they have done for you
- Spend some time in nature
- Potter about in the shed
- Explore new places

The QLD Mental Health Week website outlines "100 ways in 100 days" – exploring numerous ideas on valuing your mental health at *https://www.qldmentalhealthweek.org.au/* if you need more inspiration.

I look forward to hearing of your journeys in valuing your mental health and learning what sustains and nurtures you.

Loretta Riley
Advanced Social Worker RBWH

(Adapted from: www.reachout.com; www,beyondblue.org.au; www.blackdoginstitute.org.au, www.health.qld.gov.au)

Raising Awareness

Red cakes can change lives! They can. That's why HFA and HFQ are calling on our friends and supporters to help us celebrate Haemophilia Awareness Week (11 - 17 October) by taking part in Red Cake Day.

Australia has hundreds of "health awareness days" and this is ours. Awareness is about sending a message, getting attention, and getting people to talk about our issue, at the very least on social media. It's a way for people to be part of something like eating cake!

Remember the Ice Bucket Challenge? Do you know what cause it was raising awareness for (Motor Neurone Disease) and do you know if people sent money to the cause?

So it's not enough to host an event; you need recall, and you've got to follow it up with something else; Red Cake Day is great but what happens the day after?

People might become knowledgeable about bleeding disorders but without doing something to help address it. You could just have yummy cakes, but it will be better if you use Haemophilia Awareness Week to give people a window into what a real person who's living with a bleeding disorder is going through.

The public's level of understanding about the importance and implications of inherited bleeding disorders to people affected by them in Queensland is important. Raising public awareness is not the same as fundraising (but that can be done at the same time) – it is explaining issues and disseminating knowledge to people so that they can be informed and make their own decisions.

High public awareness occurs when a significant proportion of Queenslanders agree that the wellness of people with inherited bleeding disorders and their ability to contribute to society is an issue that needs support, understanding and help.

Why do we need your help in raising public awareness?

People affected by inherited bleeding disorders can only be effectively supported when the entire community understands what is happening to you and what you need to live successfully in Queensland today. In order to support people with inherited bleeding disorders, the public needs to have a common understanding of what haemophilia and other bleeding disorders are, and how they can help people living with the condition remain healthy and well.

There are many ways you can get involved with Red Cake Day as an awareness activity during Haemophilia Awareness Week:

- Organise a Red Cake Day at your school, hospital, workplace or local town.
- Set up an information stall in your workplace, school, hospital or library.
- Hand out promotional or educational items.
- Organise a red clothing day at your workplace or school.

- Take a plate of red cakes and give them out for a donation (Or organise a luncheon, BBQ, morning tea, etc)
- Set up a fundraising page – this way people who cannot attend your event can donate as well.

Make your goal one where your friends and colleagues see the face of someone with a bleeding disorder on red cake day.

People want to do something, which is good, So in addition to awareness-raising, try to get them to do something like getting the people you talk to at red cake day to write or call their local MP asking them to raise it in parliament and support the work of HFQ.

We still have promotional items available and different ideas on how you can help raise money & inform your local community at the same time. Please call us for more information or go to: *https://www.haemophilia.org.au/get-involved/events/red-cake-day*

Your Org, Your Activities, Your Participation

In late August we met with our funding manager at Queensland Health. It was a good opportunity to determine for ourselves if the programs we offer continue to be important to the wellbeing of our members.

Bleeding Disorders in Qld

There were 1,153 patients in Queensland on the ABDR in 2013-14 and 171 have severe haemophilia A or B. The cost of clotting factors in Queensland is $31.6 million.

People with bleeding disorders are part of a group known as “rare disorders” and the cost to stay healthy is quite high on a per person basis.

I know many members are grateful that they can get treatment products (in many cases at home) and that we have a fantastic amount of clinical support through the QHC’s here in Brisbane; so what need is there for a Haemophilia Foundation?

60 years ago treatments were not available. HFQ was a patient support and advocacy group, seeking solutions to common issues faced by each other. Over time people with bleeding disorders has been excited by new treatments and battered by mistakes that happened along the way.

Replacement therapy and its newer long acting variants has meant that people can live near normal lives. But in the early days it was made from human blood and anyone now in their mid 20’s or older, may have been exposed to blood borne viruses like HIV and HepC.

Programs & Activities

People living with less severe bleeds, family members and carers are also impacted and while these people may not be dealing with daily treatment issues the impact is still very real.

These are all the people HFQ works and we work closely with the QHC to respond to needs identified at clinic, but member input is the best way to find out what needs are not being addressed.

This is why we run community and youth camps. It’s why we provide financial support to those in need and it’s why we run catch-up’s and support groups. They work to help people feel well connected and able to contribute to their local communities. It’s also why we receive government funding to make these programs and activities work.

HFQ Meetings

With government funding comes the need for good governance. Our board meetings are usually on the third Tuesday of each month and all members are welcome to attend.

Board members are voted in at each Annual General Meeting and we need a cross-section of people and experiences. Mums or dads with newly diagnosed babies, people with VWB who cope with most activities, Young adults with fresh ideas, partners and people living with the condition. All are welcome to make an active contribution to our organisation.

If you have a specialised skill-set or a passion an a particular area, one of our working groups may be a better place to get involved. For every activity we run, member involvement is crucial. From designing the program, to setting up the venue, to hosting the event; your help is welcome.

Participation

Many members benefit from participating in our programs and we have many members who are thriving and doing well. Giving back at the times you are doing well, so that you can be the inspiration and motivation for those who are not in such a good place right now really helps. So please consider if you can be there to support another family or member to help them reach a similar place to where you are.

We are especially looking for people to host events and be the local contact. This is something only a person impacted by a bleeding disorder can do. While board members attend each event to help, they are also there to get input from you on what we could do differently or better. Members running events and board directors are the people to talk to and who can help address the needs we would otherwise never hear about.

Graham

Can I Cope?

So many people have posited to me "Can I Cope with the Bleeding Disorder in my family?" recently, that I ask myself; what does 'Coping, with a Bleeding Disorder' look like?

We seem to live in difficult times, amid fears, threats and even violent attacks, but terror and fear comes in many forms. Many of us are also unfortunately victims of terror, veteran victims to our fears and experiences of living with bleeding disorders.

Bleeding disorders can cover generations in a family, but the impact is on the individual; it's how it affects you. It can also be cumulative as we have grown up with a parent or sibling that may seem to take all the families energy, resources, or focus.

Being a genetic condition you or your child might also be the first in the family with a bleeding disorder, but the impact is still real and still individual.

However you become affected by bleeding disorders the, impact can be very different depending on what you believe, how you approach it and what others tell you or respond to the condition. Regardless of impact we end up having to cope with it.

You don't have to do it on your own. We are really lucky in Queensland that the state government funds a holistic health service that includes psychosocial workers and other dedicated allied health supports like physiotherapy to help in coping.

It also funds HFQ to provide support and programs that build resilience and help members improve their own wellbeing. wheather you having a bleeding disorder or are affected by one in your family. We are here for you.

Our programs and services are available, but until you use them and participate in the activities run for members, it can be hard to really understand what has happened and without that, it's hard help ourselves and others.

Over time HFQ members have learnt a lot about being victim to a health issue like bleeding disorders.

Many members say there is no closure. There is no graduation certificate for coping with a bleeding disorder. One member told me their in-laws asked them (*about their teenage boy*) "Isn't he over it yet?" No, there is no closure, but you can achieve a state of 'disclosure', you can find better ways of coping, new friends, other interests and a new mission in life.

Families affected by bleeding disorders don't move on, they move with. Sometimes with dashed hopes and memories. Sometimes with the pain; with the love; and with the will to survive, thrive and bear witness.

Post Traumatic Stress disorder isn't restricted to soldiers and it's not just "in your mind". As a person affected by a bleeding disorder you may something similar to PTST. You have to work with your mind and body to deal with any pain (physical, psychological or social) you may experience.

You can't overcome a bleeding disorder, but you can become. Someone else. The person you were before a diagnoses of a bleeding disorder hasn't changed, but that person never had to deal with the experience of living with a bleeding disorder in the family or within yourself.

In any trauma, there can be an emotional or physical shattering, but there is also an opportunity for rebirth, to overcome and survive despite the bleeding disorder.

You don't need to be distracted from the condition or any pain or suffering it may cause. It's not going away and if you don't engage with the effect it has on you, you may never move beyond trauma. What helps many people is support.

It is not good to be alone. It can be hard to tell friends and neighbours, but as a bleeding disorder community you can help and support each other.

There is a difference between fate and destiny. Living a life affected by a bleeding disorder can have a sense of meaning and purpose and you should try and transform fear and fate into destiny and future, to get the most out of life.

Those who have lost a loved one to a bleeding disorder or have had to make compromises in life because of it are not victims, they are survivors. The way you survive a loss or reduction in life quality will determine its impact on yourself and those still around you. Holocaust research has shown, trauma can be passed down generations if it is not processed and when individuals are impacted it also affects their communities and society at large.

The pain and grief of a bleeding disorder, the trauma and stress it can create, causes ripples that affect everyone. Whether they know us personally or bump into us at the supermarket. If you let bleeding disorders affect you in a bad way, it will hurt more than just you.

Thoughts from Graham after recent discussions with members and on reading the book; "The road to resilience" by Sherri Mandell

Playing Sports this Season

Yes you can play sports!

Exercise is very good for you and your family, and it is very beneficial. Most sporting activities are safe, but there are some sports such as boxing and rugby which are not recommended for people with haemophilia.

Just because you have haemophilia does not mean you cannot play sports! If you keep yourself fit and play sports you are less likely to get a bleed.

Everyone can enjoy sports no matter where you live or what age you are. Swimming is great fun and fantastic exercise for children with haemophilia. Cycling, golf, tennis, athletics and fishing are also recommended.

The more you look after yourself and keep fit, the more this will help your muscles, and you will feel much healthier.

Why don't you get your whole family involved in a sport? Now I know some of you would just love to play rugby or AFL or even MMA, but just think about it, it would not be very nice to get a head injury would it? So you have to think about it very hard before you pick a sport.

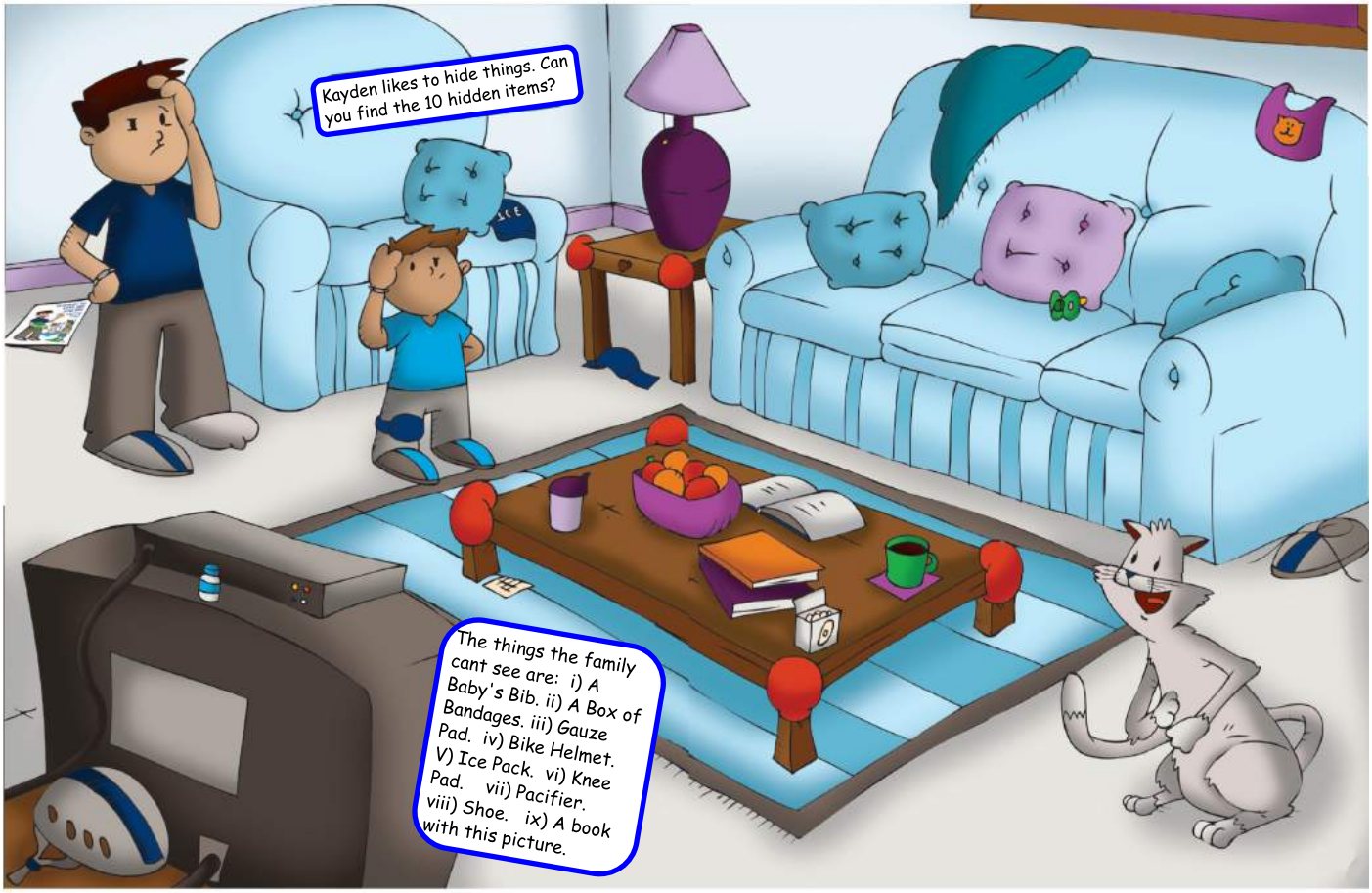
Recommended for children with haemophilia;

- Cycling
- Tennis
- Athletics
- Fishing
- Frisbee
- Hiking
- Swimming
- Tai Chi
- Walking

Not recommended for children with haemophilia;

- AFL
- Baseball
- Basketball
- Diving
- Karate
- Mixed Martial Arts
- Mountain Biking
- River Rafting
- Rock Climbing
- Roller Blading
- Roller Skating
- Rowing
- Rugby
- Skateboarding
- Skiing
- Snowboarding
- Softball
- Soccer
- Wrestling

This article was edited for size rom the WFH publication 'Go for it'.



Puzzle used with apologies to the artist as no reference could be found for correct attribution

Summer Camp

Yes folks it's on again. With a NEW Venue; NEW Date; and NEW Activities. **So Save the Date!**

We have received a Gambling Community Benefit Fund grant to run this years camp. So we've found a great (new to us) venue on the Sunshine Coast

This is a highly used facility by groups and schools, but it's not your traditional school camp. There are rooms for couples and singles as well as separate family rooms ...and it's just a walking track away from the beach! We can use all the facilities available to make this a great weekend away, with other people living with a bleeding disorder in the family.

Come along and say hi to old friends and meet new friends at this wonderful new (to us) facility which seems to be a safe family friendly venue.

We haven't confirmed any activities yet but there will be activities for everyone like the pool and beach, as well as up-dates and discussions on health and wellbeing. Please let me know if you have ideas on what would work well across the weekend.

The weekend will be fully catered (breakfast, lunch and dinner); and the accommodation (Some wheelchair accessible units) has ensuite bathrooms; fan or air-conditioning; mini fridges; microwave; kettle; and linen.

We've tried to keep the costs low for everyone at: $75 per family; $50 per couple; or $30 per individual. Subsidies are available so if costs or other barriers are stopping you from attending. Please talk to Graham at the office or your QHC psycho-social worker to arrange the help you need help.

To book your place, or for more information please contact HFQ
T: 07 3017 1778
M; 04189 507 123
E: info@hfq.org.au

Red Cake Day Colouring Competition

We are calling on our friends and supporters to take part in Red Cake Day during Haemophilia Awareness Week.

Red Cake Day is an opportunity for individuals and families as well as Haemophilia Foundations and other organisations to take part in a challenge to raise funds and awareness about haemophilia, von Willebrand disorder and other bleeding disorders during the week of 9 - 15 October 2016.

You can be involved bye entering the Red Cake Day colouring competition. There are three categories i) Children under 4 years; ii) Children aged 5 to 8 years and iii) Children aged 9 - 11 years. Photocopy the next page or carefully cut it out from this magazine, colour it in and sending it back to: Haemophilia Foundation Australia 7 Dene Ave, Malvern East VIC 3145 by Friday 28 October 2016

Don't forget to clearly write your name; your age; your school, kinder or childcare centre and your contact details.

Red cakes
can change lives!

It's true.

9-15 October
2016

Youth Camp

Camp has a way of changing people and HFQ has been providing a summer youth camp for children and teens with bleeding disorders for some time now.

The mission of HFQ's camp program is to safely challenge young people to explore and master new skills in a supportive camp environment and to educate affected young people about their bleeding disorder and its management.

HFQ's philosophy is that by fulfilling this mission, our camp program empowers and motivates young people with bleeding disorders to seek a life of freedom and independence that is not limited by their chronic condition.

In the last few years camp has been at Emu Gully which uses the ANZAC theme as a way of building resilience and comradery along the lines of our camp mission. It gives young people the opportunity to interact and forge friendships with other people experiencing similar challenges and concerns of living with a bleeding disorder.

Previous Emu Gully camps have provided an educational and fun weekend camp for boys with bleeding disorders between about 10-18 years. From last year we have opened it to siblings and also welcome any young people up to 26yo.

Craig, James, Ian, Adam and Trace are all living with a bleeding disorder and act as team leaders supporting the younger children and providing all important mentoring.

Boys who attend last years camp told us they felt better connected and had an increased sense of self-confidence after camp. And a couple of boys found the confidence to start doing their own self-infusion.

This year we are again looking at how we infuse for ourselves and James and Ian are collecting stories and experiences to include in a short YouTube clip they are developing.

Camp will also offer the opportunity to make new friends and participate in a number of fun activities that entertain, amuse and challenge.

Although your camper might come home tired, they will also come home with new physical skills and have learnt how to share, cooperate in a group and differentiate between right and wrong.

What Does WFH Do?

The WFH works with its 127 member organisations to support and improve global treatment and care while promoting diagnosis and safe treatment in developing countries.

Alan Weill, President of the WFH, Jorge de la Riva, WFH president and Val Bias, CEO of NHF, welcomed the conference delegates and applauded the efforts of everyone in the bleeding disorders community who were striving to provide "Treatment For All". They then contributed to a panel discussion about the exciting developments being made in the world of bleeding disorders. The overall theme was clear; progress is being made, and lives are being impacted in a positive way.

The session showcased the commitments the WFH have made to positively impact the world bleeding disorder community now and in the near future.

There is the WFH Humanitarian Aid Program - Lasting change for those most in need.

- The success of this program rests on ensuring a sustainable and predictable supply of treatment products.
- In numerous developing countries, the lack of access to treatment is an urgent need and an important public health challenge.
- Since 1996, 322 million IUs have been donated to 90 countries, directly helping over 100,000 people who are in urgent need.
- The expansion will now include over 500 million donated IUs in a five year period

In addition to the WFH Congress and Meetings Programs there are four other major programs that were touched on during the evening. They were the Patient and Healthcare Development Program

- This program works in partnership with member organisations like HFA, to help foster patient and healthcare development. For example the Haemophilia Foundation of Nigeria (HFN) only exists on donations, but as diagnosis rates within Nigeria have increased, so has the need for access to treatment products.
    - in 2015, only 178 patients were diagnosed. One year later that number increased to 271 as word has spread that predictable treatment is now available.

The Treatment Product Safety and Supply Program

- This program helps to make sure patients are getting the products they need and learning how to use them safely.

Educational Resources

- WFH educational resources provide critical support to the global bleeding disorders community. We saw these in the exhibit area at congress and they are also available on-line.

Research and Data Collection Programs

- This program seeks to create better evidence for the management of inherited bleeding disorders.

The session concluded with the final inspiring thought, "Together, we can make the impossible possible."

Alternative Coagulation Therapies

Data from a 16 patient Phase I/II clinical trial of emicizumab was presented at congress (we've previously reported on this under a different name - ACE910 when it was granted breakthrough therapy designation by the FDA) . The trial was in patients with severe haemophilia A and it shows encouraging safety and prophylactic efficacy.

Emicizumab was created by a Japanese company (Chugai Pharmaceutical Co.) and is being co-developed by Roche. It is a bispecific antibody engineered to bind to both factors IXa and X. It replaces the function of the missing FVIII, thus improving clotting function and preventing spontaneous bleeding. The trial showed it works in haemophilia A patients regardless of inhibitors.

The data showed that patients who received the once weekly subcutaneous injections experienced a sustained decrease of 95% in annualized bleeding rate (ABR), irrespective of their inhibitor status and prior treatment regimen. There were three arms using different doses (0.3, 1.0 or 3.0 mg/kg/week) and they were followed up for an average of two years. The ABRs for the three cohorts were 1.4, 0.2 and 0.0, respectively. No thromboembolic adverse events or clinically significant laboratory abnormalities occurred.

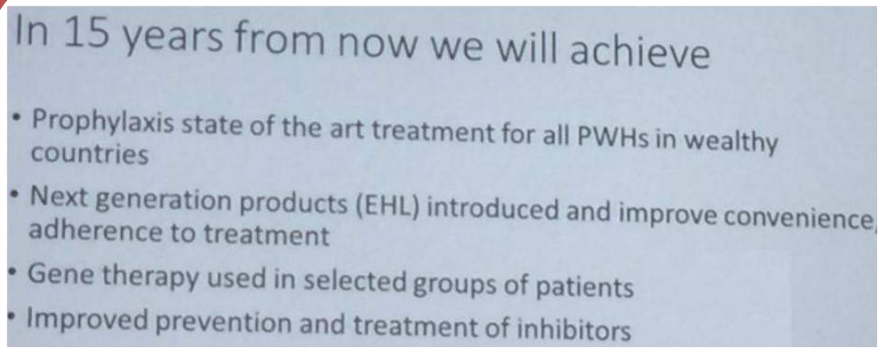
We have posted a video link to helps explain the trail results to our FaceBook page *Facebook.com/HFQLD*

World Congress—Hope for the Future

After attending several presentations Dave was left with the impression that change will be a lot earlier than 15 years. For both of us, this year's world congress displayed a clear up-shift in global activity, there are many more players – large and small companies as well as research institutions looking at all aspects of bleeding conditions for treatment – after safety and efficacy is proven the challenge for all will be cost.

In Australia the National Blood authority currently spends about $477m annually on plasma derived and recombinant blood products and this is with an efficient tendering process that works to deliver cheaper product.

What will the new products cost? – only time will tell.



There was a range of different views on what the future will look like for treatment of bleeding conditions – one presenter picked 15 years

Point-of-care ultrasound

A presentation from Karen Strike, physiotherapist from Ontario Canada and Annette von Drygaslski from San Diego in the USA showed great promise at seeing joint bleeds at home for proper treatment.

Most Haemophilia Treatment Centres use ultrasound technology at the clinic to answer two crucial questions.

1. Is a bleed actually a bleed or is it another type of injury or pain requiring different treatments?
2. After a bleed, has the bleed fully resolved—that is, has the blood completely disappeared from the joint or muscle—and can normal activities begin again?

Annette has been trialling this in regional patients homes using a small smart phone driven ultrasound device. She said people were easily trained to use it and it meant they didn't have to travel to get a confirmatory diagnoses of a bleed.

If they couldn't diagnose or confirm the bleed, the image was relayed to the physio for further clarification. This technology will continue to evolve so that in the future we hope patients can use the diagnostic device at home and transmit images via the Internet to the QHC for analysis.

Von Willebrand (VWF) – recombinant treatment

Recombinant products have been the norm for some time now but are now expanding beyond Haemophilia A&B. Dave met a lady at conference that told a story of a woman with VWD that required treatment for a serious medical issue, she received the traditional blood derived product but this comes in a significant volume.

This was a problem as her body couldn't physically take any more volume. Phone calls were made and on compassionate grounds recombinant VWF was given to her and she was then on the road to recovery, this is just another one of the many amazing life stories at conference.

Von Willebrand disease (VWD) is the most common inherited bleeding disorder, in which a person has a deficiency or impairment in the protein, von Willebrand factor an important component of the blood-clotting process. Patients with VWD can develop severe bleeding from the nose, gums and intestines, as well as into muscles and joints. It is estimated that approximately 1% of the US population has VWD, with men and women equally affected. There is a recombinant product but not yet currently available in Australia.

Treatment Plans

There was discussion about treatment plans which contrasted the old style standard 'off the shelf' treatment of say, prophylaxis twice a week, with a more modern approach of individualised considered treatment that matched the different requirements of patients to achieve a cost effective treatment plan and that also delivers positive patient outcomes.

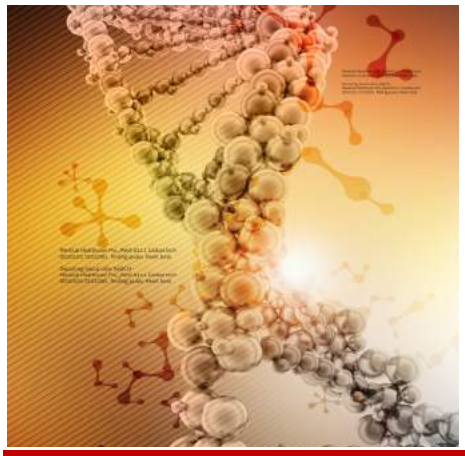
One approach to minimise damage is by using biomarkers to adjust a treatment plan.

The message presented at conference was that the way forward is better collaboration between patient and treating practitioner to deliver improved compliance, more tailored treatment plans, and better self-awareness. This is a great topic to discuss with your clinician.

World Congress—Gene Therapy

There have been 11 haemophilia gene therapy trials of which 6 are currently open. Each of the trials (Phase I / II) is testing factor VIII & IX. There is also a stem cell approach using lentiviral vector for factor VIII under development.

The results so far have had good news mixed with new challenges. Eg., some types of gene therapy may be linked to liver cancer and antibodies can occur to some the vectors currently being trailed. Much of the presentations were complex and difficult to follow, but the trials with good results seem very exciting and transformational advances are on the horizon, although not yet for today.



Pfizer and Spark Therapeutics announced the results from their Phase I / II trial of SPK-9001 for treating haemophilia B. Four patients received a single infusion of a novel adeno-associated virus (AAV5) capsid expressing a high-activity human factor IX variant (Padua gene).

12 to 31 weeks after the single treatment was administered they had factor IX levels of between 21 and 42 percent. There was no sustained rise in liver enzymes and no patients needed a course of immunosuppressive steroids to counteract any immune reaction.

Another company Biomarin presented interim data on its Phase I / II trial of BMN 270 for haemophilia A with an AAV5 vector. Haemophilia A has (till now) been less impressive and produced only low increases of factor VIII levels (below 5 %).

Biomarin said that of the seven patients treated with a high dose and 12 to 28 weeks after it was administered, six patients had factor VIII levels above 50%. The other one had only 10% FVIII, but this is still higher than many previous trials were able to achieve.
At the time of the congress presentation, four patients had been followed for 20 weeks and their mean factor VIII levels were 146% of normal, which is great and two patients had factor VIII levels above 200%. All of them had no unexpected events or need for medical intervention.

The list goes on – Gene therapy shows great promise but there is good and bad in it as a future treatment / cure for bleeding disorders.

The possibility of less frequent injections or even a single treatment is thrilling, however this is could be an expensive proposition and with talk of $1m for an injection that is 'curative', or a once a week injection or some other regime – the question of cost / benefit is obvious.

There is good YouTube clip that helps explain gene therapy and its potential at: *https://m.youtube.com/watch?v=bfqLD7iTR0U*

Extended Half-Life Clotting Factors

Australian company CSL Behring presented results from the phase III clinical studies of their recombinant extended half-life factor IX product called Idelvion. This is a recombinant factor IX fused to albumin. Albumin is a naturally-occurring plasma protein that has a long half-life in circulation. Linking it to factor IX also gives the factor IX a much longer lifetime in the bloodstream.

CSL data from its PROLONG-9FP studies evaluated the efficacy & long-term safety of the product when used for routine prophylaxis at dosing intervals of 7, 10 and 14 days. They also presented efficacy and safety results in patients undergoing surgical procedures. They obtained excellent results with a median annualized bleed rate of zero and there were no serious adverse reactions and no inhibitor development.

Octapharma reported on its fourth-generation factor VIII concentrate called Nuwiq. Nuwiq is manufactured using a human cell-line (as opposed to a hamster cell-lines), and shows stronger binding to von Willebrand factor, potentially prolonging its half-life by a couple of hours. Interim data from the GENA-05 trial in previously untreated patients (PUPs) showed inhibitor development in 20.8% PUPs who had reached 20 exposure days to Nuwiq, the point at which most inhibitors have already developed.

High-titer inhibitors had developed in 12.8% of patients. These percentages are lower than have been observed with previous recombinant FVIII products and are very promising; however, data with more patients over a longer term is needed to confirm these results.

Who Decides?

If you have a partner or loved one, if you have children or assets you should consider what you want for them if you cannot indicate your preferred decisions. While having conversations about your wishes is crucial, the most common legal way to ensure your decisions are carried out is with a will, or a power of attorney.

One of the biggest assets we have is our health and no matter how good or bad it is, we all have preferred ways of managing it. Some people want a doctor who keeps ahead of research and will try everything to keep you healthy and well. Others want a doctor who is conservative and only treats you with proven treatments and minimal side effects; but have you thought about the decisions you might have to make about your health, but

can't, if you were in a coma?

Hospital admissions routinely aks if you have an Advance Health Care Directive (AHCD) because only AHCD's can ensure your personal wishes on your health care are understood and carried out. Having conversations about your wishes is crucial but having a substitute decision-maker and an AHCD will avoid situations where a person you may have spoken with does not quite remember what you said. They may also be under stress themselves and unable to make decisions needed, or they may not relay your views fully, if they were not really in agreement with them when you talked to them in the first place.

AHCD's and Enduring Power of Attorney for personal/health matters are legal documents in Queensland, so they are the best way to ensure your health care decisions are carried out if you are unable to make the decision yourself (there is some provision for doctors not to follow them if they believe them to be unclear, or no longer appropriate because changes in medicine).

An AHCD should include information that you would like health professionals to know about you and any specific desires you might have about whether or not you would consent to certain medical treatments. But it doesn't have to be on that form, as long as it, like the AHCD has been signed by you, discussed with a doctor and signed and dated by them to ensure you understand what decisions you are making (and signed by an eligible witness) it is legitimate!

You can also use the AHCD to appoint someone to act in accordance with your instructions and to make health decisions on your behalf.

The type of information that an AHCD should contain is any special health conditions, your allergies to medications; any religious beliefs that would affect your care and your views about the quality of life that would be acceptable to you. Quality of Life decisions could include things like directions about using antibiotics, or whether you want to be kept alive (assisted ventilation, or receiving food by tubes, etc.) if brain dead or having cardiopulmonary resuscitation (CPR), to keep your heart beating.

If you don't want to make an AHCD you can make a general written statement of your values, wishes and preferences. It can also include directions about whether you would, or would not, consent to specific treatments in particular circumstances. This is called a 'common law directive' and can be used to guide any persons who have to make decisions on your behalf.

Whatever type of document you make, take it with you if you are having a hospital procedure and it is vital to give copies to people who may have to make decisions for you in the future and to make sure they understand how you want them to use these documents, and to review them regularly.

There is a great government website called My Care, My Choices which gives good information at: https:// metrosouth.health.qld.gov.au/acp

There are forms available for download from the Department of Justice and Attorney-General. Go to http:// www.qld.gov.au/law/ then select legal-mediation-and-justice-of-the-peace for the main page.

Tool Time!

At the world Congress in Orlando and back at home in Brisbane, we are getting reports about some tools that could help members. One that we hope to have at both youth camp and the community camp is a brace that limits mobility and mimics the loss of movement you experience when a joint bleed occurs. It should let people better understand how this impacts on daily life (and encourage people to keep up their factor treatments!). Another couple of new tools are listed here for your information.

Cool Sense ~ kool solution

COOLSENSE has come out of the cosmetic sector (read Botox) and is a hand held topical anaesthetic device that numbs the skin prior to injection. We could see it has a metal rod that when the unit is kept in the freezer, is ready for use (once it's cooled down) by anesthetising the injection site and the unit is temperature-controlled so you don't freeze yourself, or use it when it's too warm. It's also got an antiseptic dispenser to clean the unit with each use and help prevent a skin cold-burn.

CoolSense provides pain relief and prevents the skin from being harmed and burned during the injection. It acts upon application and within 3-5 seconds it numbs the site of injection. Jo and the team at LCCH have begun using them as there is no down time waiting for creams to work.

CoolSense can be used repeatedly until the battery runs out and as long as it is cooled down in a freezer. So maybe not at your summer picnic, but never-the-less it could improve quality of life for members providing you have a freezer handy and can afford the $170.00 price tag.

Because it is suitable for babies, children, adults and the elderly we'd like to know what you think of it? Is this a device that might work for you? Should we have a loan scheme for members to trial or use? Please let us know.

More Information at: http://www.balancemedical.com.au/coolsense/

Wicked Wheels

Some members who use wheelchairs have mentioned SmartDrive Power Assist to us. It's being sold through Wicked Wheelchairs and is a powered assistance device that seems amazingly powerful. Their advertising says it will push you up the steepest hills and ramps, through the thickest carpets, and over the most plush grass.

They say you will go further, do more, and live more freely than you ever imagined! Perhaps more importantly the SmartDrive unit has an anti-rollback feature that allows you to stop on a hill and then get going again.

The system weighs under 6kg, and the motor attaches to a hitch on back of the chair, so it's very light and should be easy to install and fit on almost any wheelchair, including folding chairs.

Because SmartDrive is detachable you don't have to leave it on a wheelchair. You can use it when you want it and take it off if you don't. The other feature we liked is that it's got a swing arm making it flexible. As the SmartDrive unit freely rotates about its axle, it means you can do wheelies or drop off curbs making rough terrain no big deal. The advertising says it moves with you and will follow you wherever you want to go.

Wicked Wheelchairs say that some people may be eligible to have the SmartDrive Power Assist fully funded through the Queensland Government's CAEATI scheme.

Check it out for yourself at Wicked Wheelchairs on the Gold Coast.
Phone 07 5500 0882
www.wickedwheelchairs.com.au

Hep C at Congress

Current treatment for bleeding conditions has progressed significantly over the last decade, people are living longer, but many suffer comorbidities. New Hepatitis C treatment is the best news in decades – a good news story where a short course of oral treatment gives a near uniform cure with next to no side effects – unlike past treatment options.

Talking to patients at congress as well as medical professionals makes it clear – get treated and get cured. One patient questioned his doctor, asking him to check that he was on the correct medication as he had no side effects – he was cured in very short time! So what are you waiting for?

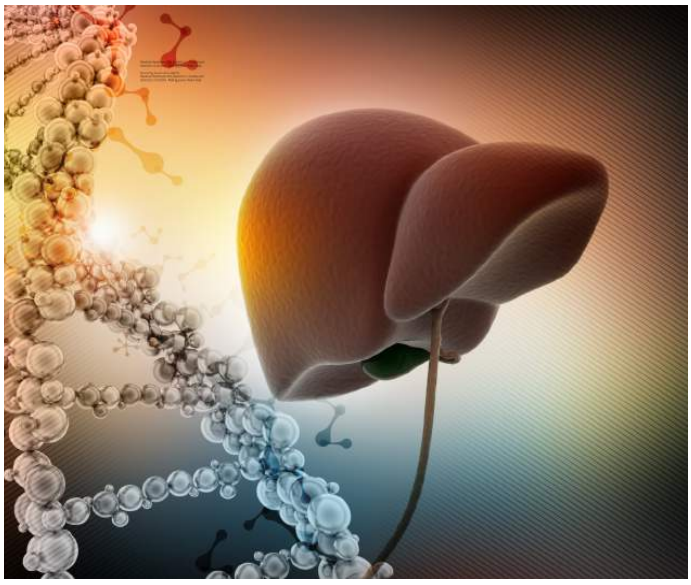
I find myself asking why some people don't make an appointment immediately and clear the virus forever …. remember liver disease is deceiving where you feel ok right up to the point where you fall off the cliff and it's all too late.

You can go to your GP and get it organised or make an appointment with your liver clinic or call your haemophilia treatment centre – call now. If you need any assistance or just want to talk give Graham or myself a call at HFQ (confidentiality guaranteed). If you have a roadblock to treatment HFQ can help knock it.

Dave.

Statins Reduce Cirrhosis in HIV / HCV

Researchers in the USA have reported that treatment with statins decreases the risk of progression to liver cirrhosis in people with HIV and hepatitis C virus (HCV) co-infection. The protective effect of statins was most evident in people with normal liver function.



This is the largest retrospective study of HIV/HCV co-infected individuals to examine the effect of statin drugs on cirrhosis development and it demonstrated that statin drug use in patients with HIV/HCV co-infection and normal liver function decreased the risk of cirrhosis.

Approximately a fifth of all people with HIV have a co-infection with HCV. Liver disease is a leading cause of serious illness and death in people with HIV/HCV co-infection. Statins have an anti-inflammatory effect, the researchers wanted to see if statin therapy reduced the risk of progression to cirrhosis in people with co-infection.

6000 people with co-infection were included in the study. In addition to statin use, data was collected on metabolic risk factors, including obesity, diabetes, hypertension and low HDL cholesterol. Individuals were stratified according to their liver function (ALT below/above 40 IU/L).

2265 people developed cirrhosis, an incidence of 6 per 100 person-years. They were significantly less likely to be on Anti Retroviral Therapy nor have a CD4 count greater than 350. People with cirrhosis also had a significantly shorter period of time with viral suppression than those without cirrhosis.

Metabolic risk factors were highly prevalent. Over 50% of the cohort had hypertension or low HDL cholesterol and 16% had diabetes.

The research found that for every 1% of time on statins, it was associated with a decreased risk of cirrhosis. A CD4 count below 200 cells/mm3 was associated with a 200% increase in the progression to cirrhosis, regardless of liver function. Participants whose viral load was undetectable significantly reduced their risk of progression to cirrhosis.

The researchers concluded that the study demonstrated that statin use in an HIV/HCV co-infected population with minimal liver dysfunction was associated with a reduced risk of progression to advanced liver disease.

Edited for size from an article "Statin drugs decrease progression to cirrhosis in HIV/HCV co-infected individuals" by Oliver NT1, Hartman CM, Kramer JR, Chiao EY. Published in AIDS August 2016

Health Updates

New Approach to Identify Carriers of Haemophilia A

It is difficult to recognise the FVIII gene mutation with simple genetic tests. Chinese researchers analysed two generations of a family, where the son had haemophilia A and the daughter was a suspected carrier. They identified a new and simple method to identify women who may be carriers of the haemophilia A gene.

They used a multifluorescent PCR technique & a seven short tandem repeat (STR) markers (STR's are repetitive sequences of about two to five DNA letters) found in the factor VIII gene, to conduct a linkage analysis of the family. From this, they could identify the probability of the faulty gene being passed to the next generation which would have identified the girl as a carrier.

Their results showed that for the seven STR markers, the group of genes in the son and in the mother were identical. The sister carried the same group of genes as her brother, so the researchers concluded that the STR markers were informative for analysis and could differentiate pathogenic and healthy group of genes so they should be able to identify a girl child as a potential carrier of haemophilia A.

From: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4950737/

The European Medicines Agency (EMA) Review Factor VIII Products

The EMA has started a review of factor VIII-containing products to evaluate the risk of inhibitors developing in patients initiating treatment for haemophilia A, the review follows earlier studies suggesting that inhibitors develop more often in patients receiving recombinant factor VIII than in those receiving plasma-derived factor VIII products.

The review will assess data from the *NEJM* study together with all other relevant data on blood-derived and recombinant factor VIII medicines. They will consider the implications of these data for previously untreated patients with haemophilia A, and whether there is a need for risk minimisation measures or other changes to the marketing and prescribing of these products.

EMA has previously addressed the risk for inhibitor development with recombinant factor VIII products. A 2013 study found that 30% of previously untreated children with haemophilia A developed antibodies but the EMA concluded that the evidence did not prove an increased risk. A second review in 2014 also reached this conclusion.

From: http://www.ema.europa.eu/docs/en_GB/document_library/Referrals_document/Factor_VIII_31/Procedure_started/WC500209984.pdf

Doctors Simultaneously Treat Patient's Acquired Haemophilia A and Prostate Cancer

Researchers in California reported the case of a 66 year-old man with acquired haemophilia A who was treated for it and prostate cancer simultaneously.

The patient went to the hospital because of pain and swelling in his right thigh. He was diagnosed with a hematoma in his right leg, which was removed by surgery. However, following the operation, he bled excessively and on further analysis, he was diagnosed with acquired haemophilia A.

Further investigations showed the cause of his acquired haemophilia A was locally advanced prostate cancer. Based on his haemophilia and his overall critical condition, he was given only hormonal therapy to treat the cancer. After a 35-day period of treatment, and a two-day intervention against minor bleeding, he was discharged.

At the three months follow-up, no more bleeding episodes were recorded, there were no factor VIII inhibitors in his blood, and factor VIII activity was increased to 170 percent.

The researchers said this patient's case illustrates that simultaneous treatment of underlying cause (in this case prostate cancer) along with immunosuppressive therapy can result in a favourable outcome in acquired haemophilia A.

From: http://www.jchimp.net/index.php/jchimp/article/viewFile/32461/pdf_201

Haemophilia Study Points to Strategies to Encourage Physical Activity

Physical activity used to be seen as risk for bleeding, so people with bleeding disorders may have avoided it. However physical activity is recognised as a vital part of the health maintenance, and the WFH says it can actually help with treatment effectiveness and the prevention of bleeding.

Japanese researchers set out to identify strategies to encourage physically activity because lack of activity in older people can add to haemophilia-related complications as well as increasing the risk of osteoporosis, diabetes, hypertension, etc.

They reviewed ways to change behaviours and raise awareness of the importance of physical activity. They found that education, trusting relationships, and promoting intrinsic motivation all contributed promote independent participation in physical activity.

The study concluded that many haemophilia patients find it difficult to be physically active even when an exercise program was shown to be potentially beneficial.

The researchers said that it is critical to have individualised, tailored exercise programs and that if the benefits and risks can be carefully explained, people with haemophilia can plan individual approaches to physical therapy and improve their health.

From: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4876843/

Important Dates for HFQ Members

HFQ Board Meetings 3rd Tuesday of each month

Women's Brunch 9 October @ Café 63

Pain Workshop 14 October 2016. 9.30am @ RBWH.

OBE's For men living with a bleeding disorder. 1st Wed of each month.

Haemophilia Awareness Week & Red Cake Day 9 – 15 October 2016

Regional Meetings Meetings timed to coincide with QHC visits & on request. Please check for the next event in your area.

HFQ Youth Camp 28 – 30 October 2016

AGM 8 November 2016 7pm Venue TBC. Sharan Caris (Manager of HFA) speaking

HFQ Community Camp 14 – 16 April 2017. Sunshine Coast Recreation Centre. Currimundi.

Please check our facebook page and website for details. Or call Graham on **04 1970 6056** for more information

Women's Brunch

Let them eat cake!

Back in June we had a brunch get-together for women in south east Queensland affected by bleeding disorders. This event was well attended and many women there found it a useful way to meet others and said it was a great success. HFQ learnt some things we need to act on with respect to hospital parking and how families can access LCCH in a less stressful way and the women talked about their experiences with bleeding disorders as well as the upcoming HFA Women's & Girls Project.

The next one is on Sunday 9 October to coincide with Haemophilia Awareness Week at the same location (Café 63 in East Brisbane), as before, so if anyone is interested in taking part in the next Women's Brunch, please contact Graham to confim catering numbers.

Brunch is a special time for women in the bleeding disorders community to grab a coffee and have a relaxed chat over food; and to get support and help from each other. It's an opportunity to explore ways woman maintain their engagement with their families and communities of choice. Hopefully there will also be an update on the HFA women & girls project and an opportunity to identify the sort of programs and support you want from HFQ and to let us know what how you can help us achieve this.

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
Ph: (07) 3017 1778 E: info@hfq.org.au