the FACTOR

Issue 42

Autumn 2015

Newsletter of Haemophilia Foundation Queensland

Red Run Classic Annual Fundraiser

The Red Run Classic (RRC) is our biggest fundraiser of the year. Funds raised will provide programs and services for the bleeding disorders community in Queensland and across the nation.

RRC is a fundraising run/walk for Haemophilia Foundation Queensland and Haemophilia Foundation Australia. We invite all members and friends of HFQ to help make this a successful event. You can run or you can volunteer. You can also encourage others to take part. We expect hundreds of women, men, teenagers, children and families to have fun while raising money for our cause.

If you are a serious competitor, the course is timed, so make the Red Run Classic one of your big events, or you can walk with your family and friends for a fun social morning. If you want to help behind the scenes volunteers are also needed.

Do you like a challenge?

Are you looking to achieve a PB? Why not use the Red Run Classic as a great event to achieve your personal goals, be that as a runner, or as a supporter of HFQ. It takes more than our members to raise the funds we need. Get your family and friends involved to help us reach our fundraising goal. You can set up your own Everyday Hero, and encourage your friends to support you by donating to HFQ. All donations over $2 are tax deductible and every dollar raised allows us to change a life of someone with a bleeding disorder.

Race Information

The race begins at 8am on Sunday 17 May and all participants will receive a Red Run Classic commemorative medal. It will start and end at New Farm United Junior Soccer Club. Race bibs will be available

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Inside this issue:

Red Run Classic *Continued...*

for collection from 7am on race morning. A race pack will be emailed to participants by Friday 15 May.

Registrations can be made online until 15 May, or on the day of the RRC but please note; registrations taken on the day will incur an additional $5 fee.

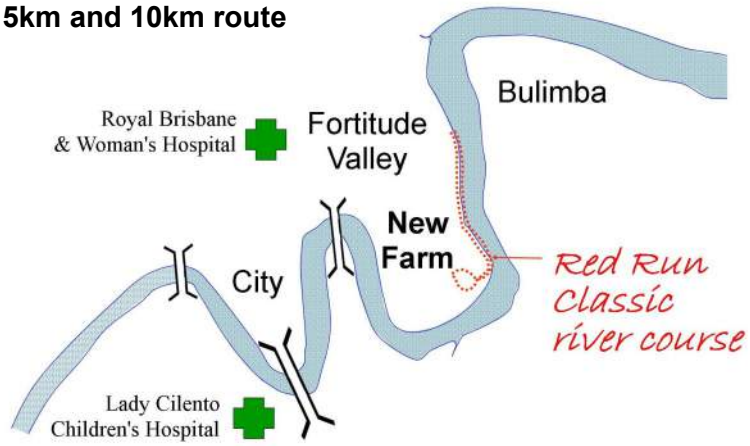
Route

The route meets and finishes at New Farm and follows the river from New Farm up to Teneriffe and back. Each circuit is 5km long. Registrations and Race Bib collection from 7am on the day.

It doesn't cost a lot to enter;

Adult	$30
Child (6-17 Years) ...	$10
Student/Concession ...	$20
Family (2A, 2C) ...	$70
Corporate Team / Team of 4 Adults (4A)	$110

5km and 10km route



Stay up to date!

Like us on Facebook for all the latest race information. http://www.facebook.com/RedRunClassic

Need more Information?

For any questions or further information, please email the Red Run Classic team at ncoco@haemophilia.org.au

Or contact Graham at the HFQ office on 0419 706 056 or email him at: info@hfq.org.au

We would to thank the Lord Mayors Suburban Initiative Fund and Central Ward for their support, our print sponsor BMAG and Supporter CHEM Events.

Special thanks to New Farm United Junior Soccer Club for the use of their grounds.

ABOUT HFQ

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

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

Members of HFQ are entitled to benefits, including subsidies on:

- **Medic Alert bracelets (50% discount)**
- **Electric Shavers (up to $75 off)**
- **Supportive footwear (75% off)**
- **Discounted Movie Tickets**

HFQ Management Committee

President	... ...	Mr David Stephenson
Vice President	...	Mr 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 Contact Details

ADULTS CLINIC (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)	3646-8769

CHILDRENS CLINIC (LCCH)

Dr Simon Brown — Haematologist	3068-1111
Haemophilia Resident	TBA
Joanna McCosker – Clinical Nurse Consultant	043 8792 063
After hours—call switch and ask to speak with on-call haematology consultant or present to the emergency department	3068 1111
Wendy Poulsen — Physiotherapist	3068-1111
Moana Harlen — Senior Psychologist	3068-4180

HAEMOPHILIA CLINICS

RBWH

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

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

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

LCCH

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 (no direct number yet)

OUTREACH CLINICS

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

From the President

Hello everyone, I hope this edition finds you and your family well. As most of you will be aware we had to defer the community camp at the last minute due to Cyclone Marcia. The new date is 28 - 30 August

Remember 1-3 October is the 17th Australian & New Zealand on Haemophilia & related bleeding disorders conference, more information on this can be found on page15.

This month I want to give you an idea of what is happening in one corner of research in relation to Haemophilia. This one is interesting as it could be applied to many diseases. A recent article describes how treatment could start in the womb:

Using mice, the idea of exposing treatment factors to the developing foetus suggests possibilities of boosting the success of therapies after birth.

Our immune systems are pretty good at identifying and destroying foreign material. Once we've encountered a particular invader, our immune cells mount a quicker response should it ever turn up again. This is the rationale behind vaccinations.

This mechanism can cause problems when we want the body to accept foreign material, but this isn't always the case. In the 1950s, a group of researchers at University College London discovered that exposing the immune system to foreign material in the womb can have the opposite effect.

The team was grafting skin from one strain of mice to another. The new skin tended to get destroyed by the recipient animals' immune systems. But when the group injected cells from the donor mice into developing fetuses, the mice that were born were much more likely to accept the skin graft. It seemed they had been primed to the foreign cells while in the womb, and developed a tolerance. Sébastien Lacroix-Desmazes at INSERM, the French national institute of medical research in Paris, and his colleagues wondered whether triggering this priming effect might help treat inherited conditions such as haemophilia where the I immune systems of about one-fifth of people with haemophilia develop antibodies that render the protein ineffective.

To see if priming in the womb would make any difference to this immune response, Lacroix-Desmazes's team attached parts of factor VIII to another protein that enabled it to cross the placenta between mother and fetus. The group then administered this to pregnant mice lacking factor VIII. Other similar pregnant mice received no treatment.

Once the pups were born, the team treated all of the offspring with a factor VIII therapy. The mice treated while in the womb were much more tolerant of the protein – on average, their immune systems produced 80 per cent less antibody against it than the control group.

We are still some way off using these therapies in people, says Mike McCune at the University of California, San Francisco. We don't know the ideal dose for a fetus, when it should be used or whether it would have any untoward effects on either the mother or the baby, he says.

"We know precious little about the immune system of the human fetus and the human newborn," says McCune. "The third trimester is a total black box of human fetal development, because we have no way to study it."

Sing Sing Way, an infectious disease physician and scientist at the Cincinnati Children's Hospital Medical Center in Ohio, agrees that it is early days. "The study shows that this approach can work in mice, but does little to say how it may actually work as a therapy or preventative strategy for humans." However, both say exploring the idea of fetal immune therapy is worthwhile.

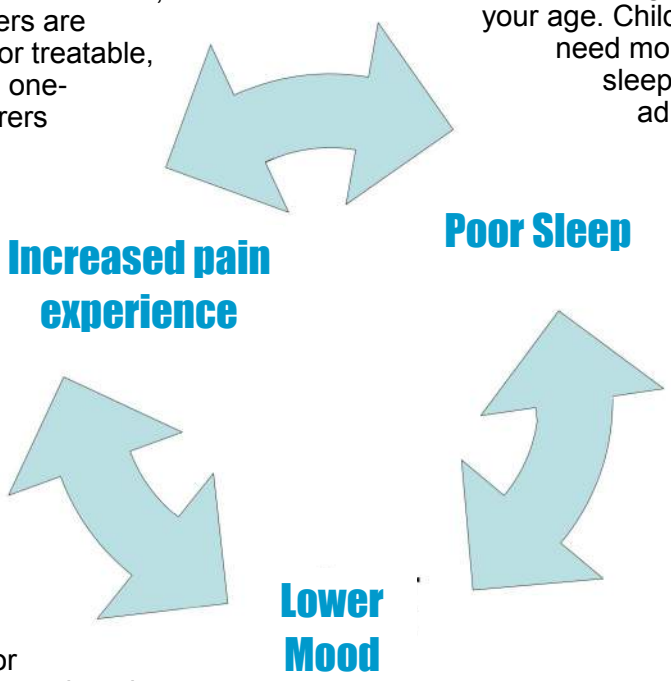
David Stephenson, President HFQ

.....Advocacy, Health promotion, Support

Journal reference: Science Translational Medicine, DOI: 10.1126/scitranslmed.aaa1957
Source http://www.newscientist.com/article/dn27042-treating-inherited-disease-could-start-in-the-womb.html#.VPLmUYYmKJK

The Beauty of sleeping!

13 March 2015 was World Sleep Day (http://worldsleepday.org/). It is an annual event sponsored by the World Association of Sleep Medicine, to raise awareness of sleep disorders and highlight the burden that they place on society. According to the website, most sleep disorders are preventable or treatable, yet less than one-third of sufferers seek professional help. Sleep problems constitute a global epidemic that threatens health and quality of life for up to 45% of the world's population.



In a time-poor modern society, sleep is often sacrificed in the pursuit of more "important" things like work and family. However, research consistently shows that poor quality and duration of sleep—which may be caused by sleep disorders such as obstructive sleep apnea, insomnia, or restless legs syndrome—poses a serious threat to one's physical, mental, emotional and social health. In other words, sleep is essential for general physical health, restoring energy, repairing injuries or illness, growth, psychological well-being and mood, attention, concentration, memory, work performance, and getting along with others. As a clinical psychologist, I often educate my clients on the vicious cycle between sleep, mood and pain. In treatment, one of the first things I do is to get my clients to address any sleep issues. Back to basics, I call it.

The three elements of good quality sleep are:

a. Duration- The length of sleep should be sufficient for the sleeper to be rested and alert the following day.

This varies according to your age. Children need more sleep than adults.

b. Continuity- Sleep cycles should be seamless without interruption. Many sleeping disorders cause us to wake up several times in the middle of the night.

c. Depth- Sleep should be deep enough or sufficiently sound to be restorative and refreshing. There are difference stages of sleep and we need to get sufficient amounts of REM (rapid eye movement) sleep and stage 3 and 4 of non-REM sleep.

What to do if you think you have a sleep problem

If you find yourself struggling with any of these elements over a prolonged period and your daytime functioning is being affected despite trying various methods to improve sleep, raise your concern to your GP. Your GP may be able to offer some advice or refer you to a sleep clinic or sleep specialist. If your sleep issues stem from psychological reasons such as stress and depression, he may refer you to see a psychologist. As mentioned above, many sleeping disorders can be treated using a combination of methods and you don't have to suffer in silence.

Please see these websites for more information on sleep.

www.sleepoz.org.au/

www.sleephealthfoundation.org.au/

www.snoreaustralia.com.au/

www.sleep.org.au/

See also page 11 for an article written foir younger people.

Dealing with fears of hospitalisation.

There is a question that many parents of a child with a bleeding disorder ask about their child's haemophilia treatment and broader hospital involvement. Should they (the parents) be around and involved with their young children's treatment, and does the nature and degree of their involvement as a parent make it better or worse for their child? This question is often asked by parents when dealing with intensive and sometimes painful medical procedures.

There have been studies that show that the facial expressions of anxious mothers made children more nervous when they were heading to surgery. This finding can be reframed to say that the emotional state of the mother is very important and making mums and dads feel confident about what's about to happen will enhance your child's experience.

Angela Mackenzie is a paediatrician and former consultant in pain management at the Royal Children's Hospital in Melbourne. Angela was doing some research in oncology and one of the things she observed was how distressed parents felt watching their children suffer. At the same time she was seeing lots of children who had developed a fear around medical procedures.

Angela says children gradually become aware that they are in a body. You may notice a child sitting in a stroller and then suddenly discovering their foot—ah!—and they starting to play with it. They develop this gradual awareness until it progresses to a stage where children think of their body as a bag of skin holding everything in. They then have an innate fear of their body being harmed, or damage to their body, which is a very sensible protective mechanism.

So we should be careful about how we handle our children's hospital experiences. The prevailing wisdom used to be that it was kinder to hold a child down and get a procedure over with. And even if the child doesn't know why it's so frightened or doesn't like coming to hospital and doesn't like having needles, there seems to be this implicit memory within the body of something having happened.

So how should parents think about (and put into practice)

ways to help their children be less threatened by what is being done to them? There are two key things you can do. Accept that for some parents it can be a complete nightmare having a child go through a significant or serious illness, but it's important to keep those feelings separate from your child. Even though they're going through invasive medical procedures where they have needles and tubes and all sorts of things done to them, you can affect the procedure but you can support you child during it.

The second thing is to understand that children are programmed to watch for things that might be threatening or dangerous to themselves. They watch our faces, they listen to how we talk, even the tone of our voice, and they even watch limb movements. In fact they watch all the adults' behaviour and attitudes and emotions including the clinical staff, so that they can get a sense of how they should be in this situation.

So as parents you can influence how your children experiences their hospital visit and treatment, because children watch and learning from you as the important adult in their life. They pick up the anxiety in your body…or the tension. As parents you need to let a calmness go through you, not just what you're saying but also how you hold your child. It's no good to say the right thing if your body is saying something different. Children are very good at picking up mixed messages.

It really is about finding a way of soothing your children and helping them experience these situations as warm and comfortable, not fearful. Then your child will internalise your expression of the experience and this will increase their sense of coping, their ability to develop resilience, and even mastering the situation. If you're not sure how to do this talk to Moana or Jo for some tips and pointed of helping your child have a good hospital visit.

Edited for size from a broadcast on The Body Sphere, ABC Radio National, presented by Amanda Smith http://www.abc.net.au/radionational/programs/bodysphere/children-and-medical-procedures/6082244

GP Survey Prize Winner

Prize winner announced!
Brett from Morayfield was the lucky winner of a $100 Bunning's voucher provided by HFQ.

Brett was one of over 100 people throughout Queensland to complete the "Haemophilia, GPs and Healthy Living Survey". A keen artist, Brett has used the voucher to buy spray paints for his projects.

Beryl and Olivia from the RBWH Haemophilia Treatment Centre would like to thank Brett along with everybody who did the survey. We have gained plenty of useful information and opinions to help guide our research into GP utilisation and men's general health care.

Stay tuned for the next phase - We need men of all ages to come and share their ideas and opinions at focus groups.

More details soon.

Social Work and Psychology News

Can you believe that it is already March? The year is already flying by, but Mona and I have a number of exciting plans for projects over the coming year.

Keep a look out for information about the following:-

- A quality of life survey to gather information so that we can better understand the most important issues within the haemophilia community
- A number of workshops regarding understanding and Managing Pain
- A workshop about enhancing relationships and about effective communication.

We are currently recruiting participants to attend our first workshop for women who carry the severe haemophilia gene. It will be held on Friday May 1st at the Kedron Wavell Services Club beginning with lunch at 11:45am and finishing with a light dinner at 7pm. Please contact Maureen or Mona on 36 46 8769 for a flyer or for more information. Women from regional areas are encouraged to attend. We are happy to discuss funding issues. Please feel free to tell others about the workshop as we may have lost contact with some members of the community.

We are also involved in planning, in conjunction with our physiotherapist Rebecca Dalzell, a trip to LIFETEC at Newmarket. Lifetec offers a range of support and information to help people to remain safe and independent in their own home.

We have booked a visit, which will be led by an Occupational Therapist, from 10am on Wednesday 15th of April at Level 1, Reading Shopping Centre, Cnr Newmarket and Enoggera Rd at Newmarket. Come along and enjoy a chat and a free coffee and cake with us. You can RSVP to Rebecca or Mona or me.

Don't forget to call us if you need information about other issues including Patient Travel if you live outside of the Brisbane area.

We are also happy to discuss any psychosocial issues with you. I am in the office Monday to Thursday. Dr Mona Chong, an experienced psychologist is in the office on Fridays. Mona provides expert counselling and referral for people in the haemophilia community.

Maureen Spilsbury
Ph 07 3646 8769

Editors Note: It's great to have Bec back as part of the Physiotherapy team. Bec has an article on stretching the hip muscles on page 17.

Haemophilia Brothers jumping for joy!

Following a traumatic labour, Allyson Hill couldn't understand why her beautiful newborn son Declan wouldn't stop bleeding after a heel-prick test in the hospital.

While there was a history of haemophilia in Allyson's family, she had been tested for the blood disorder as a teenager and was told she was not a carrier.

But just days after experiencing the elation of becoming first-time parents, Allyson and her husband Dean Blaxall received shattering news. Declan, who turns eight this week, was severely haemophiliac.

Allyson and Dean were distraught when the diagnosis was confirmed.

"We were devastated," recalls Allyson. "The emotion is really raw. You get on with day-to-day life, but the emotion always stays brewing under the surface.

"Both Dean and I were really into sport, and my first thought was the sport implications. But then, as it unfolded, I realized that sport would probably be the least of my worries." Meanwhile, after agonizing over whether or not to have a second child, Allyson and Dean decided to expand their family.

"I felt that it was important to give my child a sibling," says Allyson. Shortly after his birth, Allyson and Dean learnt that their second son Connor, now aged six, also has haemophilia.

The couple's third child, four-year -old Siobhan, does not suffer from the disorder, although she is a carrier.

As the carrier of the disorder, Allyson admits she can't help but feel responsible.

"It's not a choice that you make.....But, of course, because you carry the gene, you do feel guilty," she says.

The first few years of Declan's and Connor's lives were incredibly worrying for their parents, who found themselves watching over the boys every minute of the day, constantly checking for cuts and any signs of bleeding.

As time went on, however, the family learnt to manage the boys' condition. Today, Declan and Connor enjoy happy, active lives.

Like most boys their age, Declan and Connor enjoy playing outdoors, despite the risks their condition presents. Woman's Day sourced a trampoline with a safety enclosure and padding from Rebel Sport, so the fun-loving youngsters could jump around in a safe environment. And there's no doubt the boys, along with their younger sister, Siobhan, are having the time of their lives on their tramp.

"I would have been so fearful that the boys would fall off a trampoline, but with the safety enclosure around it, I can relax," smiles Allyson. "They're so excited about it.

If you are thinking of getting a trampoline

Trampolines have gained significant popularity in recent years. However, in a study published in the June 2003 issue of the Canadian Journal of Surgery, Dr. Brian Black, a paediatric orthopaedic surgeon, documents the high risk of orthopaedic injury in children between the ages of two and sixteen associated with trampoline jumping. During a twenty-one month time frame, eighty children were seen at the Winnipeg Children's Hospital for orthopaedic injuries sustained while jumping on a trampoline. Approximately half of the injuries occurred at a neighbour's home, and in only 10% of the cases was an adult supervising the trampoline use. One third of the children sustained their injuries while playing on the trampoline mat with other children.

We asked the Qld Haemophilia Clinic team about trampolines and they suggest;

- No more than 1 person should be on the trampoline at any time.
- Children younger than 6 years should not use the trampoline.
- Children should not use the trampoline without adult supervision.

A long time HFQ member and man about town Jamie is promoting SpringFree trampolines as there are no springs to get caught on and cause bleeding. James has arranged for HFQ to get a donation for every trampoline sold through us so if you are thinking of buying one please talk to HFQ first and we'll give you the reference number that gets us some funds while you get the fun.

Original article written by Jackie Brygel rand educed for size and editorial comment.
First published in Womans Day, September 24 2007. Reprinted by HFA at http://www.haemophilia.org.au/documents/item/108

Life Series Workshop 1

Women who carry the Haemophilia Gene

1 May 2015 from 12 noon to 8 pm
Kedron Wavell Services Club Kedron.

This 2 part workshop is designed to start the conversation about the issues you may face carrying the haemophilia gene.

Part 1: 11.45 am – 4.30 pm
Lunch (provided) followed by networking, small group discussions and life sharing by other women who have walked the journey.

Part 2 : 4.30 – 7.00 pm
Seminars by medical speakers followed by Q & A

A light dinner will be provided for all attendees from 7.00 to 8.00pm

Medical speakers will provide presentations on Genetic and IVF issues. Partners and extended family members are encouraged to attend part 2 of the workshop.

Please indicate your early interest for catering and organising purposes.

Please RSVP to Maureen or Mona on 07 3646 8767

The life series are developed by the Queensland Haemophilia Centre, supported by Haemophilia Foundation Queensland and funded by a :"Changing Possibilities in Haemophilia" Grant from Novo Nordisk

HFQ Members Survey

As an organisation HFQ seeks to look at our whole membership rather than focusing on medical matters. We have just completed our first survey of members and their needs.

We asked quality of life type questions so that through the answers we could better understand and respond to the needs of our members. We probably asked to many questions and they were not always easy to answer correctly so we thank the nearly 80 people who returned the survey to us.

The responses show that people with bleeding disorders face challenges in income, relationships and public knowledge of their bleeding disorder. The burdens they cope with include mobility issues, pain and discomfort, and anxiety & depression.

Our survey asked similar questions of all members, wether they had a bleeding condition or were a sibling, or a carer. This comprehensive approach has resulted in our gathering a more detailed picture of the issues people with bleeding disorders in Queensland and their loved ones face.

One of the surprising findings was that 40% of respondents reported having pain that was strong enough to interfere with their daily lives some or all of the time . Such a result shows that bleeding disorders can impair quality of life, not only by the experience of pain but also through decreased mobility, anxiety and other health conditions.
The lack of knowledge by GP's and the general community can also lead to increased problems. 12% of respondents said their GP's knowledge was poor. 32% felt they were stretched because of the bleeding disorder in their family and 24% found it difficult to discuss the bleeding disorder with people outside their immediate family.

Although 75% of those surveyed were working only 25% were full time and 23% were retired or unemployed which is considerably more than the general community so it was no surprise that 15% of respondents found it a struggle to meet their family needs on their current income. We'll continue to unpack the survey and a report of it's results will be included in the next issue of the H Factor.

Back to school — Bright lights or the Blues?

So your back at school. Is it a good year for you or is it causing you some concern? Is you mum or dad more anxious than you about your going to school?

When you're younger, your parents may be concerned about you getting injured. They may also want to tell the teacher about your condition, so they can also look after you.

School can be a difficult time if you have a bleeding condition and sometimes the teachers are not sure what to do either. There are some good resources for you and your parents to use in this situation. Check out Haemophilia Foundation Victoria's school kits (http://www.hfv.org.au/resources/) for haemophilia and von Willerbrand if you need some information to take to school.

Some teachers worry that you could bleed to death from a minor cut or scrape. They may not understand the signs of an internal bleed and your need for immediate attention. You are going to have to help them as well as yourself. If you know your having a bleed tell your teacher and follow the plan your parents have prepared for this situation. If the teacher is busy, try to remain polite but insist this needs attention if that is what has been agreed.

The Qld Haemophilia Centre staff and HFQ can help you or your parents with other resources and information to take to school.

Most of all it is important to be positive about school. You should try and look forward to learning and participating at school, do what you can and have a good time.

If you're doing your own infusion, you may want to talk to your parents about keeping a dose of factor at school, so they can then ask the school about safe storage and so they know about the syringes and things. Don't use your condition as an excuse to get out of doing things, but be sensible and tell your teacher if an activity could cause you harm. School is the place we learn things so that we can have a great life when we become adults.

What are Bones?

We all have bones. If we didn't, we would be like jellyfish!

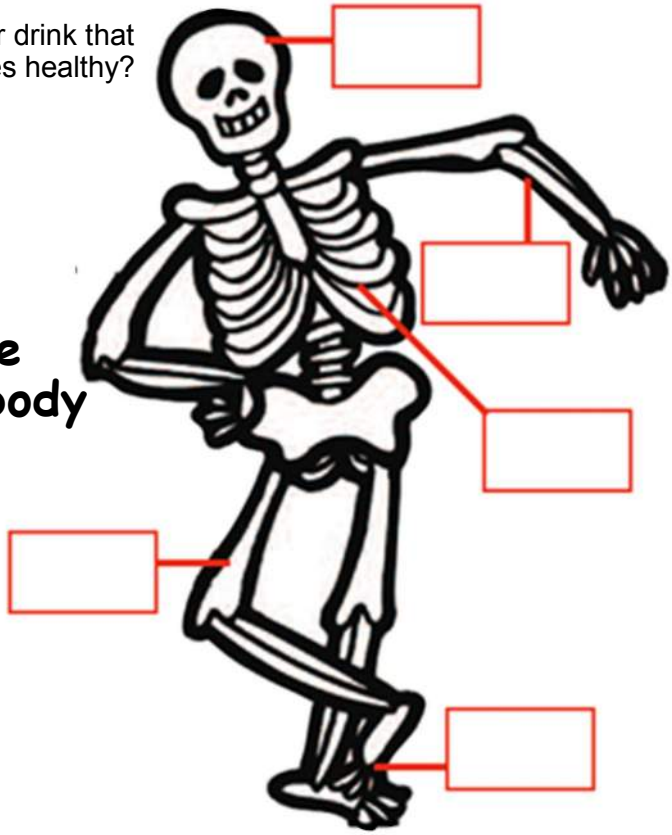
Bones are living, growing and changing parts of our bodies. Bones make up the frame work of our bodies, this is called our skeleton. Babies' skeletons are made up from more than 300 parts, but by the time we become adults we only have 206 bones! Some smaller bones join together to make one bigger bone. Bones also protect the softer parts of our bodies; one of these is the skull which is like a natural helmet protecting the brain.

How can we look after our bones?

You need to look after your body to stay healthy. It is important especially when you have haemophilia to have strong bones and muscles! We can do this by eating healthily, getting lots of exercise and protecting our bones!!

What can you eat or drink that will make your bones healthy?

Can you identify the different body parts on the skeleton?



7 tips for a good night's

When your mom's mobile phones battery runs down, she charges it. And that's what sleep does for us, too! A good night's sleep gives your body rest and stores up energy for the next day.

But many of us are not getting enough sleep to fully recharge. Kids ages 5 to 12 years old need about 10–11 hours of sleep each night. So if you need to wake up by 7 a.m. in time for school, you'll want to hit the sack by 8 or 9 p.m.

It may be fun to stay up late watching TV or playing games, but if you don't rest, you may get sick more and miss play time with friends! Not getting enough sleep can lead to more colds, flu and stomach aches. That means missing school and being stuck inside the house.

Sleep also helps you get better after an illness, injury or surgery. That's why rest is so important if you've had a bleed. Sleep lets your body focus on fixing itself.

You know you're not getting enough sleep if you:

- Feel sleepy after you wake up.
- Sleep late on weekends and days when you don't have school.
- Get tired during the day and wish you could take a nap.

Here are seven tips to get a good night's sleep:

1 Get moving! All that time on the playground and playing with friends can help you sleep longer at night.

Go to bed and get up at the same time every day, even on weekends.

2 Don't play with video games or a mobile phone after you get in bed. It's tough for your body to wind down afterward.

3 Ask Mom or Dad to read a book with you every night. Having a routine like this helps your body know it's time for bed.

4 Don't eat big meals right before bedtime. Try having a warm glass of milk or a healthy snack instead.

5 Don't drink sugary sodas, especially in the afternoon or night. Many sodas contain caffeine, which can keep you up and make you jittery.

6 Ask your parents to help make your bedroom feel cosy. A cool, dark and quiet bedroom helps you fall asleep.

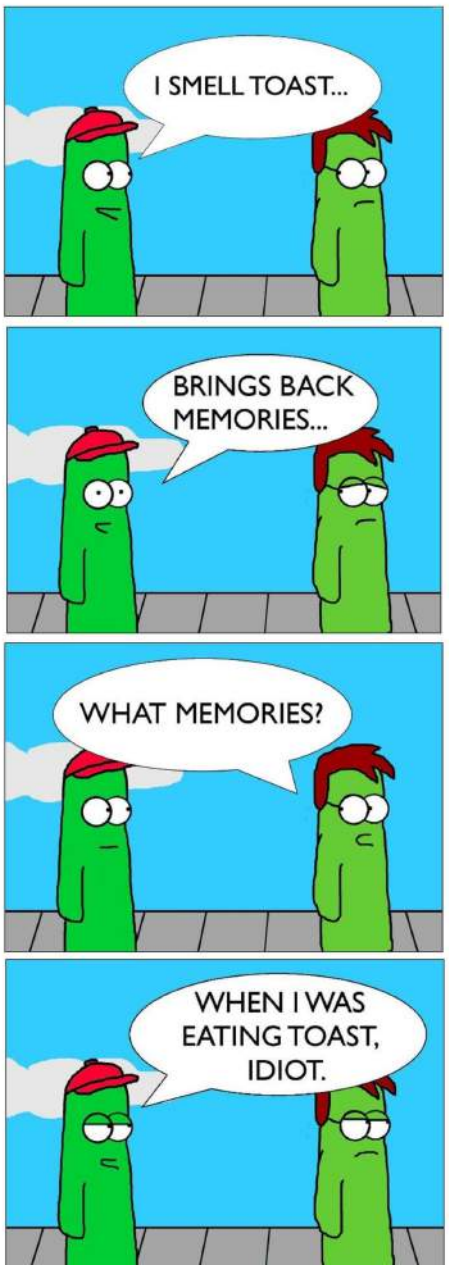
7 With this advice in mind, you're on your way to getting a great night's sleep—every night!

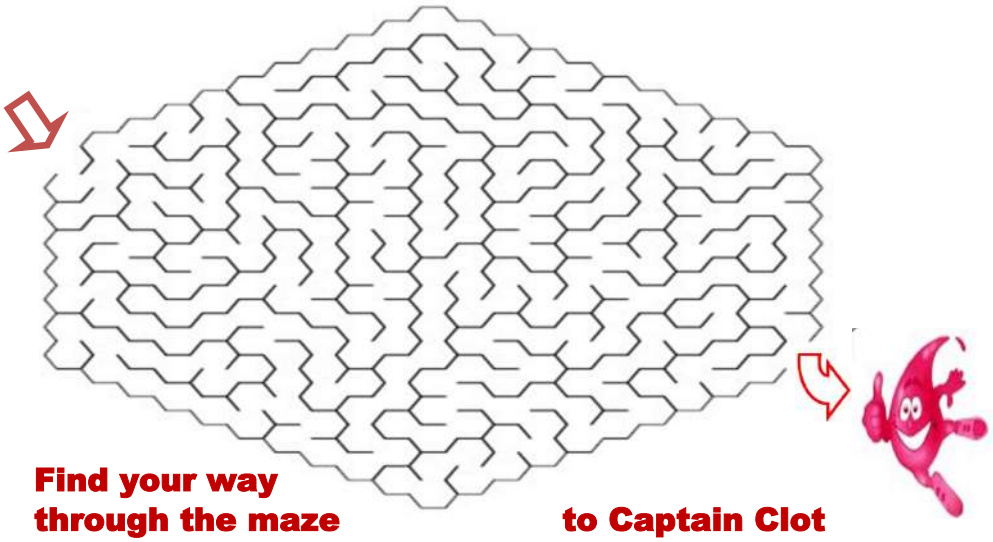
First published in Hemaware February 2015 as Hey, Sleepyhead by Kadesha Thomas Smith

The Slobs

by Conor Birkett

First published by the Irish Haemophilia Society.
https://www.haemophilia.ie/content.php?id=7&article_id=698&level3_id=738





Find your way through the maze to Captain Clot

The HFQ Office Relocation

The HFQ office has moved a lot over the years. Regretfully the moves continue. At the time Liz left and Graham took over we had just moved to a business centre which was very central (Fortitude Valley) but very small and didn't allow for volunteers to visit or help out in any way. In January we moved again. We are now in Teneriffe, collocated with the AIDS Council and the room has a spare desk and storage facilities. this means that for the first time in over a year we have been able to unpack and access all the resources and equipment HFQ owns on behalf of its members.

Did you know that we have a small library of books and other resources on bleeding disorders? These are available for members to borrow. We also subscribe to the Haemophilia Journal and Graham is happy to send articles to members on request. If you ever google a topic related to bleeding disorders and you end up with an abstract from Haemophilia Journal, we can provide you with the full article. As part of the library service, if there are any books or DVD's etc on or related to bleeding disorders that you know of and would like us to purchase to add to the library please let Graham know.

Current books include; Injection of Life (autobiography of board member Robbie Weatherall); Achieving the Extraordinary (50 years of bleeding disorders in Victoria); Living with Haemophilia (Guide for families); My Pet Virus (autobiography of Sean Decker US comic); and Success as a Haemophilia Leader. We also hold current journals and reference books on nursing practice and also other medical conditions some members experience, especially HepC and HIV. We have identified a couple of DVD's we are currently sourcing including "Factor 8: The Arkansas Prison Blood Scandal," and "Bad Blood", but we are adding to the library all the time so please ask Graham if there is a book or video you are after.

The office is a place where the paid staff work from and where our volunteers help us organise the events and activities of the foundation. Our current home is likely to be temporary because it is on the 1st floor and there is no lift access making it difficult for members with mobility issues to access. Longer term we want an office that is on the ground floor or wheelchair accessible. If you are aware of any low cost office space, please let Graham or a board member know.

OBE's *(newer, better, more informative)*

OBE's provides support for men with coagulation based bleeding disorders in Queensland who have been around for a while. In the beginning OBE's stood for Old Boys Essentially and while it is not age specific, most members are men over 40.

This year Erl has organised for meetings to be held across Brisbane and he has also organised some with talks about issues that may interest you. So this year some OBE meetings will also have a presentation from someone who is a health professional or who is involved in haemophilia care.

The challenges OBE members face varies, like their disorder and their age etc., because of this and because OBE's is a state wide group many members have different life experiences and viewpoints. The meetings are a safe place to explore these differences as well as the similarities. They find it's often helpful to talk with other people who are facing similar challenges.

OBE's meets monthly in SE Qld for a low cost or subsidised meal and as mentioned, occasional guest speakers will address various topics of interest to the group. The meetings usually provide a chance for people to ask questions, discuss issues and seek input from other members. This years talks are on; Wills

Continued on next page ⟶

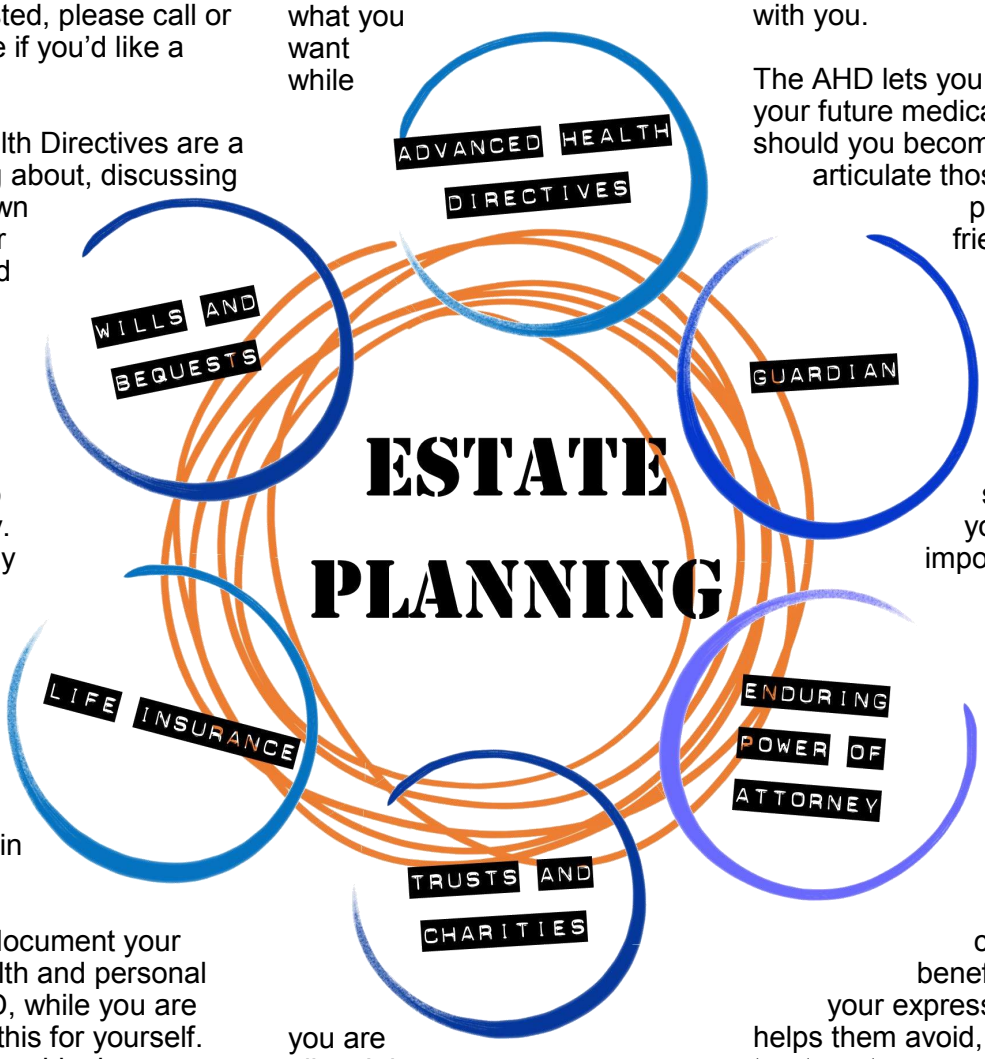
Advanced Healthcare Directives

At the recent OBE's meeting Maureen Spilsbury spoke to the participants about Advanced Health Directives (AHD's). Her talk and material is being made available to the OBE's and anyone interested, please call or email the office if you'd like a copy.

Advanced Health Directives are a way of thinking about, discussing and writing down your wishes for health care and Treatment, should the time come when you are unable to speak for yourself due to illness or injury. There are many reasons and several ways of doing this and all directives are state specific so we only covered the AHD used in Queensland.

You can only document your wishes for health and personal care in an AHD, while you are still able to do this for yourself. Once you are unable, because of injury or advanced illness such as dementia, to complete an Advance Health Directive, then your appointed decision maker, in partnership with your treating doctor/s and those close to you such as family and/or friends have to make decisions for you which may be contrary to what you actually want.

The Advance Health Directive is sometimes called a 'Living Will' because it concerns itself with what you want while you are alive. It is a written statement regarding your wishes for your own future health care. An AHD can be made now by anyone who has the capacity to do so and is only used if, at some point in the future, you become incapable of making health care decisions for yourself (due to illness or injury). It needs to be reviewed by a doctor to ensure it is medically viable and the social work team at the QHC's are happy to start that discussion with you.



The AHD lets you have a say in your future medical treatment should you become unable to articulate those wishes. Your partner, families, friends and carers will often value the opportunity to discuss and better understand what your wishes are so talking about your wishes is as important as writing them down. This will help them to accept your decisions if you should ever loose capacity to do this for yourself. Hospital and clinical staff also benefit from knowing your expressed wishes as it helps them avoid, or reduce treatment responses you don't want.

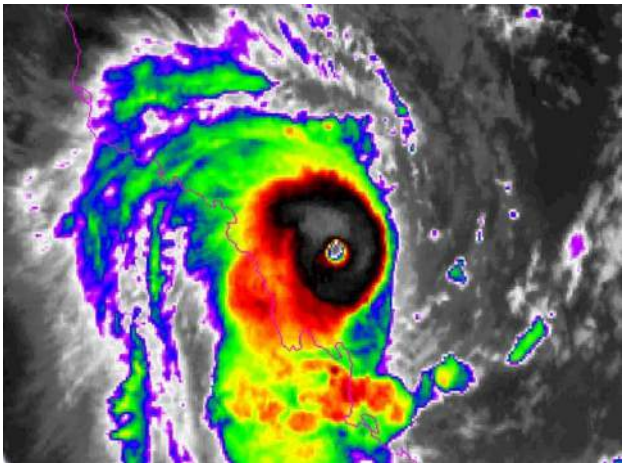
If you'd like a blank copy of a Qld AHD, or more information, or to discuss how your can express your own wishes, please talk to Maureen or Mona on 07 3646 8769

and the ways you can make your wishes known while alive; Standing up for your health needs when it's not the haemophilia centre staff your dealing with; and also a look at what treatments are coming on-stream in the next while.

OBE's also produces an occasional broadsheet that is mailed to its members so you can keep up with the conversation even if you can't attend a particular meeting. If you'd like to go on the contact list or want more information call the HFQ office or speak to Mona or Maureen at the adult haemophilia clinic.

New Dates for Community Camp

The HFQ Community Camp was planned for the weekend of 22 February. The same weekend that Cyclone Marcia making her way south and was expected to sit over Noosa and make for a very wet weekend. After much deliberation we made a decision to postpone the event.



Everyone registered to attend was informed and there was a universal sense of disappointment, so we are very pleased to let you know that we have secured a new date (28 — 30 August) and the camp is on again.

This means that registrations are open again, so if you couldn't make the first date please check your diary and come along. The camp provides a safety-focused, peer supervised, fun and recreational experience for people with bleeding disorders and their families.

Our community camp is not just for young families, it provides an opportunity for anyone affected by haemophilia and other bleeding disorders to reconnect, have fun and exchange social support with other adult and child participants. Our scheduling includes time for rest and revitalisation and we adjust the camp program based on who is attending.

Although families usually spend the majority of their time participating in activities together, adult- and child-only time is also scheduled. The camp can accommodate the immediate family of the person with a bleeding disorder, including non affected siblings.

The new dates hopefully mean more members can attend so please put the weekend aside and let Graham know if you want to attend. We always try to make the weekend a low cost relaxing event for you to take a break and recharge amongst other people who know what it's like to live with a bleeding disorder.

HFQ has been committed to providing a retreat experience for people affected by haemophilia for a long time now and the need has not diminished. We are proud to have been able to and continue to provide summers of joy, confidence, support, and hope for these people and their families.

The Community Camp is appreciated and cared about by campers and their families alike, but part of what makes each camper's experience so wonderful is the program's ability to allow these people to gradually come to accept the differences that might exist for them due to their bleeding disorder. We have people tell us that camp has helped them to accept who they are and to engage in all the varied experiences they now enjoy with peers from school, their community, and whichever social groups they become a part of.

Campers sleep in family units grouped around a pool or individual cabins nearby (all units have fridges). Most of the time, families are together and supervision is the responsibility of the parents or caregivers. Medical support is not avalable on-site (Nambour Hospital is one hour away) so parents are expected to provide regular treatment-related care to their children as required.

With the new dates set we are reviewing the camp program and we really need help to make this a great weekend for everyone so if your able to volunteer your time, it will make the community camp memorable as well as safe and secure. There are many different volunteer positions so if you are over 17 years of age and think you have what it takes to be a camp volunteer please call and talk to Graham.

Aus & NZ Bleeding Disorders Conference

The 17th Australian & New Zealand Conference on Haemophilia and Related Bleeding Disorders will be held at the QT Hotel, Gold Coast from 1-3 October 2015. The theme for the conference is "**Facing the Future Together**".

Quite a few HFQ members attended the WFH World Congress in Melbourne last year so we are looking forward to a good HFQ presence at this Conference where we will discuss and debate issues and follow up on ideas and connections made.

The conference will bring together people with bleeding disorders and their families and carers, as well as health professionals, policy makers and industry. It is a great opportunity to learn more about care and treatment in Australia and New Zealand, and around the world, and to plan for the future.

If you would like to attend then please go to Visit www.haemophilia.org.au/ conferences for more information. If you need assistance, please contact Graham at the HFQ office as the board is offering some help to people wanting to attend. We would like to see a representation of members from across Queensland and also representing the various elements of our community (affected and infected individuals, all conditions etc.)

The conference program has topics and issues to interest everyone including the following and more:

- Living well with bleeding disorders
- Best practice treatment and care and how this is measured and monitored
- Supply and safety of treatment products, including long acting clotting factors
- Family planning
- Youth matters
- Helping children live with a bleeding disorder
- Improving your joints
- Women's health and bleeding issues
- Understanding von Willebrand disorder
- Managing pain
- Hepatitis C treatment and care – including new treatments
- Living well with HIV
- The global bleeding disorders picture

The program will include people living with bleeding disorders as experts as well as health professionals and others presenting from different perspectives. HFQ hope to offer side meetings and social opportunities for older members (OBE's), new families, youth, siblings and carriers of the gene. This will only happen if we have enough interest from our members and if time permits within the conference schedule. If you are willing to help at the conference itself or to host one of the proposed side events please let Graham or a board member know.

The conference will be held at the QT Hotel in Surfers Paradise (www.qtgoldcoast.com.au) and special prices starting from $190 per room per night have been negotiated directly through the hotel but only if reservations must be made through HFA. Other accommodation is available nearby.

The conference itself already has some planned events. Thursday 1 October is the Welcome & Exhibition Opening. This is a free activity providing a chance to see the exhibition and meet people before the conference. On the Friday of the conference there will be a nonreligious Remembrance Service offering a time to remember friends and family, and the people we have cared for in our community, who have died. There is also the Conference Dinner that night.

The dinner has always proved itself to be an informal and fun way to join your fellow delegates and talk and share experiences. Dinner tickets must be purchased in advance - no tickets will be available during the conference or on the night.

On the Saturday there are specially planned men's and women's breakfasts. Come along to hear an interesting speaker and share your ideas and experiences with other men or women! Like the conference dinner, you will need to book and pay for your ticket in advance.

Young people are also encouraged to attend the conference and participate in the mainstream program from ages 16-30. Youth under the age of 18 years will need to be accompanied by an adult. There will be a special activity for youth as well.

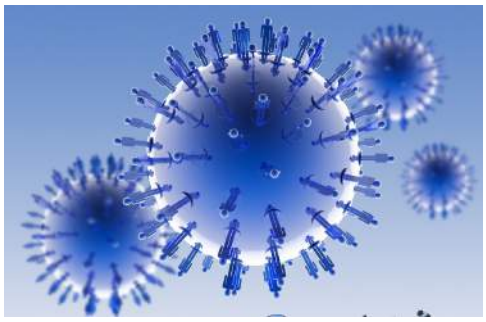
The conference is also calling for abstracts for presentations to be included in the main conference program or to be included as a Poster in the Poster Exhibition. It's not restricted to clinical practice and care, they also want presentations from people living with or affected by bleeding disorders or treatment complications.

Please see *www.haemophilia.org.au/ conferences* for the abstract submission form and more information.

HFA Submission to Parliament on Hep C

People with inherited bleeding disorders in Australia have had a long and difficult history with hepatitis C and treatment and the Australian Haemophilia Foundation submitted a response on our behalf based on the feedback many of our members passed on the HFA.

In their submission HFA reminded the government that in 2004 around 1350 Australians with bleeding disorders were living with hepatitis C. Until 2004 most people with a bleeding disorder were reliant on human-plasma derived clotting factor concentrates as the only treatment for their bleeding disorder. Some of our members infused these concentrates several times a week, it was like having unsafe sex with thousands of people so these concentrates were an extreme risk for HCV infection.



HFA estimates that 20 to 30 years on, the surviving people with bleeding disorders around Australia who have hepatitis C are now at risk of developing advanced liver disease or dying from hepatitis C related causes so the new curative hepatitis C treatments for surviving people with bleeding disorders and hepatitis C is an urgent priority.

They recommended that accelerated access to the vey new and somewhat expensive Direct Acting Antiviral treatment should be made available to people with bleeding disorders and hepatitis C as a matter of urgency.

They also asked that governments find ways to reduce the burden of out-of-pocket health care costs to individuals with bleeding disorders and hepatitis C. This is because having both a bleeding disorder and hepatitis C is a "double whammy". With haemophilia, many older people have developed severe arthritis in their joints and experience pain and disability. This often means they only address immediate and obvious health issues and sometimes ignore liver health because of the out-of-pocket health care costs which are substantial, while their income has often been reduced because they have been forced by their health to reduce or stop working from their mid-thirties onwards.

HFA also asked that the National Hepatitis C Strategy be revised to:

- Include people with complex co-morbidities, including people with bleeding disorders and hepatitis C, as a priority population
- Include disability as a guiding principle in access and equity
- Incorporate models of care for complex co-morbidities in special populations, enabling people with bleeding disorders to access targeted and co-ordinated services for their hepatitis C management.

Currently we are not mentioned in the National Strategy as there are so many more people living with hepatitis C acquired by other means and our numbers are reducing as they age. HFA pointed out that members of our community affected by hepC cannot wait until they are sicker still or on the transplant list for effective treatment. Curing their hepatitis C now could make an enormous difference to their life experience and that of their partners, carers and family. However, in order to achieve this we need targeted and accessible services embedded in the National Hepatitis C Strategy to ensure that this approach is implemented nationally. The recognition of the special needs of people with complex co-morbidities, such as those bleeding disorders and hepatitis C, or disability would help that along.

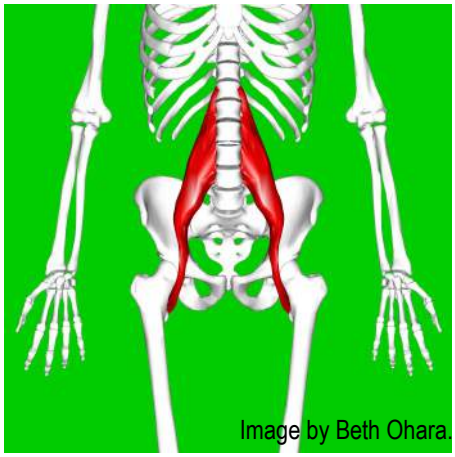
Finally HFA asked for a wide community campaign resourced at a national level to address fear of transmission, discrimination and the negative image of people with hep C. Because hep C, like HIV is now something from the past, not all our members may realise the enormous psychological impact the infected blood supply had on our community and continues to have on those still infected.

Being infected through their treatment products has left many with a distrust of the healthcare system. A lot of members were given an unclear message at diagnosis, and have been confused about their hepatitis C status. They and their family may have experienced stigma and discrimination. For people with a bleeding disorder and hepC, this has resulted in extreme caution about disclosure which results in a high demand for psychosocial services and peer support. It can also impact on health-seeking and which could result in inadequate care which is becoming an increasing issue as some grow older and start to access aged care services.

If you'd like to read the full submission please go to the HFA website where it should be published by time this magazine goes to press.

Stretching the Psoas (hip) Muscle

In Haemophilia care, attention is often given to joints, where 80% of spontaneous bleeds occur. The flow on effect of joint restrictions on neighbouring body areas should not, however, be overlooked. The Psoas muscle is an example of a muscle that can become tight and can have a significant impact on function and daily life. This muscle is deep within the groin, attaching from the pelvis and spine onto the femur and its primary job is to flex the hip.



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For those who have restrictions in knee and ankle range of movement, hips can become flexed effecting gait and leading to a stooped posture. This can mean that the hip muscles, namely the Psoas muscle, are not taken through full range. If not given the opportunity to lengthen they can contract over time and tighten. The more forward flexed the posture, the further forward the centre of gravity, effecting balance, and increasing falls risk. This can also put more strain on the back, and can potentially increase the risk of Psoas bleeds.

Psoas bleeds are serious, and can take months to fully resolve (NB if you ever suspect you have a Psoas bleed contact the treatment centre immediately). Long after symptoms have gone there can be residual tightness. This can predispose the muscle to being 'overstretched' suddenly during normal daily activities, and potentially re-bleed. Ongoing tightness can also lead to postural changes and the outcomes mentioned above. It is very important to ensure that full range of hip extension has been regained post bleed to avoid these complications.

Stretching the Psoas muscle is simple, quick, and effective, and can be easily incorporated into a regular routine. For those with significant knee and ankle arthropathy even simply spending some time lying on your stomach can help to stretch out that area. To get a greater stretch you can push up on your arms. For those who are able, stretches can be done in standing in a lunge position. It is important the stretch is felt in the front of the groin, and not in the back. Always draw in your lower tummy and slightly tuck your bottom under to keep the spine in a neutral position. Stretches should be done for at least 30 seconds. Gradually sink into the stretch as you go but never push into pain.

So what is the conclusion – Don't forget your Psoas muscle! Make 'tummy time', or stretching, part of your daily routine, and help avoid some serious complications.

If you would like more information, or would like an assessment of your muscles and joints, please call the QHC Physiotherapists:

Bec Dalzell (adults) – (07) 36468135
Wendy Poulsen (children) – (07) 30685615

Editors Note: Bec works Wednesdays and Thursdays from 8am - 4pm
You can call her and Michael for an appointment on her number and leave a message on other days.

Psoas major muscle.
Illustration by: en:Anatomography
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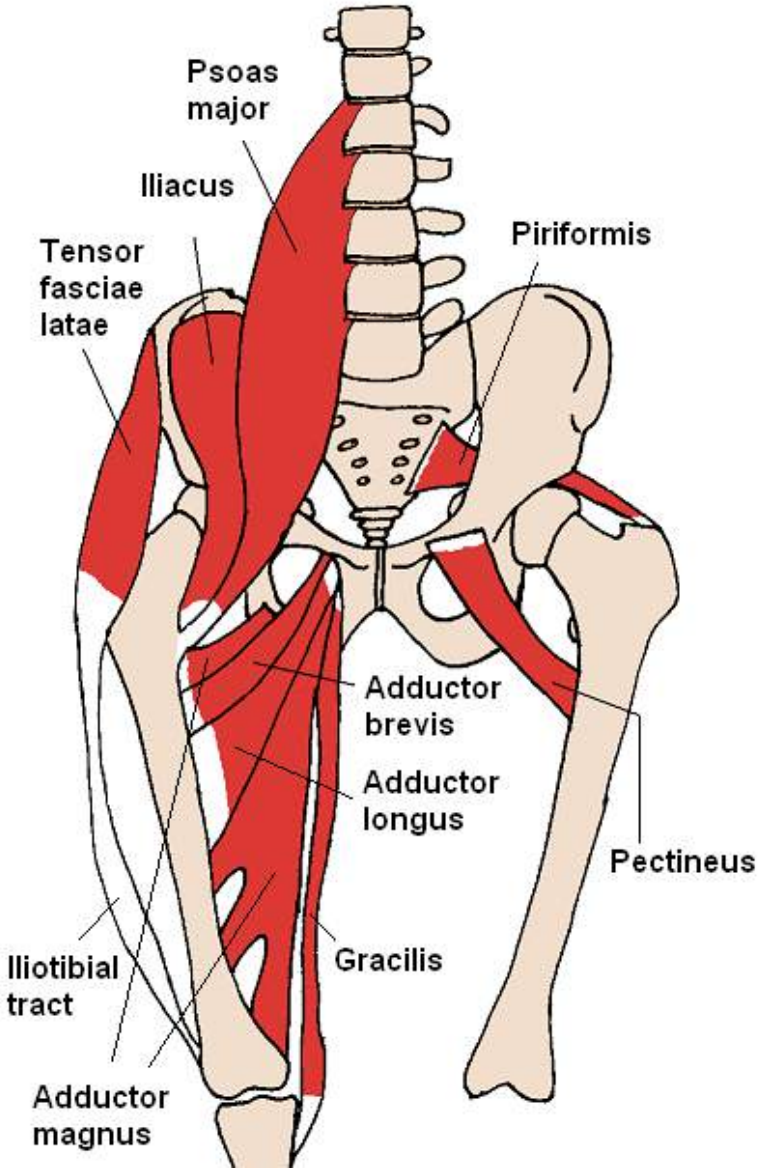

Health Updates

Change in Dispensing HIV Medications in Australia

Issued March 2015

Important changes to HIV s100 dispensing are due to come into effect from 1 July. From then patients with HIV will be able to have their s100 scripts dispensed from community pharmacies and not just hospital pharmacies as is the case now. There are still a few arrangements to be finalised and we will update you with more information as it comes to hand.

US trial of long-acting coagulation factor VIIa-CTP to treat hemophilia

Originally Published February 2015

An application has been made to the US FDA to study a long-acting version of coagulation Factor VIIa for the treatment of haemophilia A or B patients with inhibitors.

Currently, due to Factor VIIa's short half-life, treatment requires multiple infusions. Pre-clinical animal studies of the product demonstrated its longer duration of action and significantly increased survival.

The applicant says a longer acting product could change the Factor VIIa market by permitting children and adults to easily self-administer at home on a prophylactic basis.

Liver-directed lentiviral gene therapy in a dog model of hemophilia B

A recent animal study investigated the efficacy of liver-directed gene therapy for hemophilia B. Gene therapy using lentiviral vectors targeting factor IX was well tolerated and provided a stable long-term production of coagulation factor IX in the dogs and no genotoxicity was detected with these lentiviral vectors. These findings suggest that this therapy may be an attractive candidate for the treatment of haemophilia.

Gene therapy found effective in haemophilia B

Originally Published November 2014 by Reuters Health.

Ten patients with severe haemophilia B have remained cured of the disorder for as long as three years thanks to gene therapy, according to a report in the New England Journal of Medicine.

The study updates an earlier one from 2011, in which six volunteers were successfully treated with various doses of the treatment that uses a virus to insert genetic material into the liver. The four additional patients received the highest dose.

The problem is that the genetically engineered virus that delivers the cure is really difficult to make and better methods to produce the treatment are desperately needed.

The therapy seemed to have no serious side effects and is could eliminate the need to give patients injections of factor IX every two or three days.

Coinfected People With Hep C May Have to Switch HIV Meds to Take Simeprevir

Originally Published March 2015

People who are coinfected with HIV and hepatitis C virus (HCV) hoping to take the new HCV drug Simeprevir may need to change HIV medications to avoid drug-drug interactions.

Seventy-seven percent (103 out of 133) of the individuals on a Simeprevir trial had to switch ARVs before beginning treatment. More than 30 percent of those taking a protease inhibitor were not able to switch.

Smoking Increases Risk

Originally Published January 2015

Smoking may double the risk of mortality for HIV positive people according to results from a large study of people who have been on ART for more than one year.

The life expectancy of a non-smoking, HIV positive, 35 year-old male is similar to that of the general population, BUT the life expectancy of a similar male who smokes is 8 years shorter.

The investigators suggest this is because the reduction in life years lost to AIDS has steadily diminished, while at the same time the impact of smoking and other life-style risk factors is likely to increase, as HIV positive people live longer and age.

Anti-HIV Agent may work in a Vaccine

Originally Published February 22, 2015

Scientists have announced the creation of a novel drug candidate that is so potent and universally effective, it might work as part of an unconventional vaccine.

The study shows that the new drug candidate blocks every strain of HIV-1, HIV-2 and SIV (simian immunodeficiency virus) that has been isolated from humans. It also protects against much-higher doses of virus than occur in most human transmission and does so for at least eight months after injection.

the new drug candidate binds to two sites on the surface of the virus simultaneously, preventing entry of HIV into the host cell.

Using MyABDR.

Did you know that in our member survey 37% of respondents were not using MyABDR and 20% didn't know what MyABDR was? Of those that did it was clear that the people with bleeding disorders used the web based version (56%) more than the carers who were using the phone Ap to look after a child with a bleeding disorder (54%).

Of the people who said they were NOT using it;

⇒ 7 hadn't heard of it or weren't aware of it

⇒ 2 people said it didn't cover their condition or didn't give them back the information they wanted

⇒ 7 said they were not treating and didn't need it

⇒ 2 people were not computer literate; while another person owned up to being slack and not making time to start using it *(thanks for your honesty)*

⇒ 3 were on a trial with different recording methods and a 4th person was using another recording method; and

⇒ 8 had problems either signing in, experiencing glitches, finding it hard to load or access

If you didn't know about it or where unsure about it please consider using it. It will be around for a long time as it is now part of the national ABDR system and you can use MyABDR to record home treatments and bleeds and to manage your stock at home. The app and web site link directly to the Australian Bleeding Disorders Registry (ABDR). The ABDR is the system used by our Haemophilia Centres in Queensland for the clinical care of our members.

MyABDR is available to all people with bleeding disorders who have been diagnosed with haemophilia A, haemophilia B, all types of von Willebrand Disease (VWD), or other factor deficiencies including fibrinogen, platelet dysfunction, acquired factor VIII inhibitor, acquired von Willebrand Disease and some vascular disorders.

So if you're using factor or other treatments and not using MyABDR, please consider it. If your computer naive we can help you with that or you can use a paper based version. My ABDR is free. If you've tried it before and had problems, please try it again, there is a 24 hour support line to help you get past those difficulties. Their number is 13 000 BLOOD (13 000 25663).

MyABDR should make life easier for you, your family and the staff at the Queensland Haemophilia Centre (QHC). It offers a secure app for smartphones and a computer website. There is also a MyABDR paper-based Treatment Diary as an alternative.

MyABDR makes it quick and easy for you and your family to record treatments and bleeds, stocktake and update contact details. It is less relevant if you're not using factor but it will still help you record bleeds so that you can refer to it when discuss your condition at your next appointment. It works both ways too, your bleeding episodes and any treatment information will be at your fingertips - on your smartphone or your home computer as well any other concerns so it helps you and the QHC manage your care.

It also means that the QHC can keep track of what is happening for you or your family and see if there are any problems or if treatment plans need adjusting. Statistics from the system will also help HFQ as well as specialist clinicians, researchers and other advocates, study trends and patterns and work to improve treatment and care.

You may have heard from some members about problems with MyABDR, but this was probably the early version and those bugs have been fixed so just as different people use different version of MyABDR, every one of us experiences the system differently. Of course we need to know if there are still issues so please tell us if there are problems with the app, what the problems are, whether they are ongoing or whether they have been resolved.

MyABDR

Quick, simple steps to record treatments

- Bleed details can be added to treatments
- Body map to help identify bleed location
- Areas for detailed notes
- Treatment plan details can be viewed online
- Reports of treatment and bleed histories on web site version
- Easy to use inventory section to manage stock at home
- Family logins to switch between multiple family members
- Updatable height and weight, contact and delivery address details
- Secure and private.

More information can be found at http://www.blood.gov.au/abdr.

Important Dates for HFQ Members

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

Red Run Classic 17 May 2015

Community camp 2015 We've rebooked Noosa North Shore Retreat for 28 – 30 August 2015

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

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

Youth camp 2015 This is booked for 30 October 20 – 1 2015. More details will be in later issues.

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

Haemophilia Awareness

Haemophilia is often used as a general term for all inherited coagulation bleeding disorders. We don't know how this came about but we do know that until the general community has some knowledge about inherited bleeding disorders it will be difficult to explain the various differences between them.

This is why it is really important that all members do what they can during World Haemophilia Day (17 April) and Haemophilia Awareness Week (11-17 October) to let their local community know about these events and the various bleeding disorders associated under haemophilia. You could also raise some funds at the same time. If you would like some promotional materials and ideas for running a local event please let the office know.

We can only support our members with funds raised through these general community appeals so we need to take these opportunities to educate them and to seek donations so that those people doing it hard because of their bleeding disorder can get the support they need.

You don't have to do a lot. It can be as simple as wearing an HFQ polo shirt ($40 from the office) putting up a poster in your office or local school or helping with the Red Run Classic or Bunning BBQ fundraiser. Your presence at these events raises awareness in itself. You could also tell your story or submit articles to The 'H' factor.

Please think about it and do your bit for bleeding disorder awareness.

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