the FACTOR

Issue 38
Autumn
2014

Newsletter of haemophilia Foundation Queensland

Inside this issue:

Presidents message	2	Colouring Competition	11
Managing Pain	4	School Attendance	13
ICE	5	Osteoporosis in kids	14
Looking at Lonliness	6	Treatment anxiety	15
Communication	7	Subclinical joint bleeds	16
Smoking Stinks	8	HIV & HCV updates	18
Genetic News	10		

President's Message...

Hi everyone

I know some in our community have had significant health issues since our last publication and I hope you are all on the mend. It's interesting to hear personal experiences from people, many of which are good news stories of great treatment and service from different medical teams across the state. Unfortunately we do still come across some stories where the patient experience could have been significantly better. Things don't always go to plan for many reasons. HFQ represents issues and advocates for appropriate outcomes in these situations.

You have the right to provide feedback – either positive or negative. Queensland Health has a clear policy that allows you to lodge a complaint in person, over the phone or in writing to the Complaints Coordinator of the health service . They will ensure that your feedback is confidential, documented and shared with the staff or service involved in your care. If something is wrong, act quickly and voice your concerns, if you're not being heard then escalate to the person in charge – be clear and calm which might be a big ask when you're in the middle of a stressful event.

Remember the Haemophilia Treatment Center is a phone call away during office hours and may be able to assist. It was refreshing last time I attended emergency after hours at the RB&WH where the first person to see me said …" we have been told to listen to you as you know a lot about your condition" ….. just brilliant!

If you have exhausted all options and not satisfied you can contact Health Quality and Complaints Commission. is an independent organisation that reviews and investigates health complaints

So my key message to you is to firstly advocate for yourself and secondly escalate immediately if you're not being heard.

Contact details:
Qld Health Patient/Staff Liaison Officer 07- 3646 8216 or RBWH-Feedback@health.qld.gov.au
Consumer/Patient Feedback brochure. http://www.health.qld.gov.au/rbwh/docs/plo-brochure.pdf
Qld Health Compliments & Complaints http://www.health.qld.gov.au/hospital/complaints.asp
Health Quality & Complaints Commission http://www.hqcc.qld.gov.au/Pages/Home.aspx

All the best ….

David Stephenson

President HFQ…..Advocacy, Health promotion, Support

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 fulltime Coordinator 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 211 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)**

HFQ Management Committee

President	... ...	Mr David Stephenson
Vice President	...	Mr Howard Mitchell
Secretary	... ...	Mrs Sarah Hartley
Treasurer	... ...	Mr Peter David
Members	... ...	Mr Craig Bardsley
		Mr Robert Weatherall
		Mrs Leanne Stephenson
		Dr John Rowell
		Mr Adam Lish
		Mrs Eva Turek
		Mr Erl Roberts

HFQ Delegates to HFA

Mrs Sarah Hartley Mr David Stephenson

About The H' Factor

The 'H" Factor is published four times each year by HFQ. We occasionally send important information and updates on local and relevant events for people affected by bleeding disorders to subscribers of our email list. If you would like to be on the HFQ Email List, please register your interest by sending through an email with the subject title The 'H' Factor email list' to info@hfq.org.au. You can be removed from the list at anytime.

Graham Norton
HFQ Manager & The 'H' Factor editor

Queensland Haemophilia Centre Contact Details

ROYAL BRISBANE AND WOMEN'S HOSPITAL

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

ROYAL CHILDRENS HOSPITAL

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

HAEMOPHILIA CLINICS

RBWH

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

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

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

RCH

Phone Joanna about appointments

Banksia Outpatients — Dr Simon Brown — Thursdays at 2.30pm

OUTREACH CLINICS

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

Book through Joanna at RCH and Beryl at RBWH

LADIES

A good place to visit if you want to read some well-written personal stories of women with bleeding disorders or feel connected with other women worldwide. *http://mygirlsblood.org*

Managing Chronic Pain

Adapted from an article originally published in Hemaware by Heather Boerner May 2009

For some haemophiliacs, pain can feel like an enormous force is crushing your joints. That's how many people know they are having a bleed—usually in a target joint, though you can also get spontaneous bleeds, too.

Other times it can be a phantom—pain caused by nerve stimulation in a joint that regularly bleeds. Something will trigger the nerve, and you will experience a body memory of crushing bleeds from the past.

For others, the pain can become a constant, throbbing ache that can stop you doing things and keeps you stuck at home. For people with inherited bleeding conditions who grew up before the advent of prophylactic clotting factor, one or two bleeds a week for most of their life is not uncommon. Typically into target joints such as the knees and the joints become damaged and arthritic.

The pain of acute bleeds will eventually subside when you treat with factor. In contrast, with arthritis the pain can be more persistent. It takes an hour or more for some of our older members with severe haemophilia to get out of bed because of related arthritis. So pain control is a valuable thing, with it under control you can perform everyday chores like grocery shopping; or go out and watch sports or socialise. When not under control pain can stop you doing things and increase isolation.

Chronic pain can permeate every part of your life. Pain can get so overwhelming that it affects people physically and emotionally, as well as financially, but if you take action you can live life with a lot of it's problems managed or resolved.

Confronting the Pain

Pain can be the primary problem people with inherited bleeding conditions have with their disorders, more than finding time to infuse or anything else. This is especially true for children with inhibitors, in which the bleeding is poorly controlled, or with some of the older guys, who grew up without early prophylaxis.

Physically, pain is exhausting, preventing people who live with it daily from accomplishing all that they want. It can cause you to lose focus at work or school. It also disturbs your sleep. Chronic bleeds can mean limited mobility or even confinement to your home.

Making plans for dinner and a social occasion can become a logistical act of timing medications perfectly so that you are energetic and pain-free enough to enjoy the event. When not timed perfectly or if the pain persists you can feel like you're not contributing equally with those you socialise with.

There can also be a financial cost to chronic pain. Long-term absenteeism at work because of bleeds can end up with you not being able to work or being in and out of work. That can mean losing income - negotiating CentreLink to get the support you are entitled to (and need) can be an arduous journey that some people find frustrating.

For students whose classwork is constantly interrupted and who fall behind in school, the pain can forces them to defer exams or plans for going on to higher education at uni or TAFE.

Emotionally, pain is associated with an increased incidence of depression, anxiety, irritability, anger and even grief. For many people, the overwhelming feeling is frustration as they feel stuck at home and isolated, especially when responsibilities hang over you and you feel bad about yourself for not being able to do what is expected. With reduced social activities there will be fewer opportunities to get involved in the lives of others and feel good about yourself.

Pain Killers

Aspirin exacerbates or causes bleeding, while other painkillers can aggravate liver conditions so because these medications can be a bad fit, codeine and opioid based painkillers are often prescribed for people with haemophilia. However, pain can be undertreated, because of misunderstandings about pain treatment and because people can panic when it comes to painkillers, especially opioids.

They become worried about becoming addicted, or oversedated by the medication, and doctors are also concerned about misuse and many do not prescribe them properly for people with bleeding conditions. But there are healthy ways to take painkillers and the staff at the Queensland Haemophilia Centres are an excellent place to start the discussion on what will work for you and they can refer you on to pain specialists.

Talk to your treatment team about your pain and what might work for you because once the pain is validated—once it's proven that the person has an untreated pain issue and is given the medically appropriate amount and type of medication—the pain can be Controled and the symptoms usually recede or go away.

Having a Good Day

Fortunately, there are other ways to cope with pain that don't involve medication. You could use a pain log where you record the date, time, medication use and pain rating for each instance of pain. That way, you can discover behaviors that may cause pain and change them to increase your pain-free days.

Distraction also works. For instance, some people relieve pain by settling in for an episode of their favorite TV show, or play online video games which can also help combat feelings of isolation and loneliness. These activities can restore a sense of control that the pain takes away.

There are also some emerging alternative treatments such as acupuncture which can help alleviate arthritic pain in people with hemophilia. Other people have found visualizations, self-hypnosis, meditation or even very gentle yoga can relieve some pain.

When you find what works for you most of the time, you gain some control over the pain and the stress becomes less because you know that if things get rough, you can look forward and know you'll have another good day soon.

Rest, **ICE,** Compression, Elevation

In recent years there has been a closer look at the benefit of using ICE as part of the treatment for bleeds. There was an article presented at the 2012 World Federation conference that in general terms indicated that the use of ICE, to some degree, hindered the clotting process. This was a controversial article as ICE has been a key component in treatment for decades – everyone will have come across the term RICE (Rest, ICE, Compression, Elevation) This article left questions and doubts in the minds of many. What followed was a second article in 2013 that looked again at ICE treatment. The following points are the take home messages from the second follow-up article for me:

* Much of the original articles evidence was from test tube research - what happens in the body is more complicated than this and this new article explains some of this well.

* Ice can be used to help control the inflammation caused by bleeding. This inflammation causes damage to the joint so is important to control.

* Many people find ice eases the pain of a joint bleed. Some of those with arthritis however are reluctant to use ice and say it can be painful. A small number have even indicated they use heat on bleeds for pain relief. If this is the case it is important to know and understand if the pain and swelling is arthritis or in fact a bleed.

* There is a strong warn against use of heat on bleeding because it could worsen inflammation as well as bleeding. It may feel nice at the time but may make long term damage worse.

* If ice is making your pain worse you should fist check that it is not too cold or on for too long, but do not continue to use something which is making pain worse.

NOTE – Ensure you talk to your treating medical team for expert advice before making treatment decisions.

LIVING POSITIVE IN QUEENSLAND (LPQ) STUDY:

Collecting Peoples Stories. We are looking for Participants in Regional Queensland

Researchers from the University of Queensland And University of New South Wales, IN PARTNERSHIP WITH Queensland Positive People, Positive Directions, Queensland Association for Healthy Communities and Queensland Health are Undertaking an exciting QUEENSLAND SPECIFIC qualitative Longitudinal research Project to better understand people's experiences of living with HIV, aging and social communities In REGIONAL AND RURAL Queensland.

The study will involve face to face INTERVIEWS ONCE A YEAR FOR UP TO THREE YEARS. Interviews will elicit Information on social networks, work and economic status, experiences of discrimination, relationships including sexuality and prevention issues, health behaviours and future plans, experiences of aging and health/other Service providers and particular issues related to regional location.

The study will GIVE VOICE TO THE COMMUNITIES of people living with HIV and AIDS across Queensland, with the aim to be better address their needs now and going into the future. The findings will INFORM PLANNING FOR SERVICE DELIVERY MODELS that are appropriate for the positive people living in different areas. Participants' WELLBEING & CONFIDENTIALITY are our paradigms. This Study adheres to the Guidelines of the ethical review process of The University of Queensland.

If you are interested in being part of the study, or have some questions, PLEASE CONTACT US.

THANK YOU

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RBWH Social Work / Psychology News

Loneliness – the silent killer!

Did you know that loneliness is twice as unhealthy as obesity for people aged over 50?

University of Chicago Researcher John Cacioppo (the world's leading expert on loneliness) and his colleagues recently released the findings of their study where they tracked more than 2000 people aged 50 and over a six-year period. They found that the loneliest were nearly twice as likely to die than the least lonely. In fact, loneliness increases the chance of premature death among older adults by 14%! They found that loneliness disrupts sleep, increases depression and lowers one's overall feeling of subjective well-being. Loneliness also increases stress, blood pressure and weakens the immune system.

What is loneliness?

Loneliness is a subjective feeling of powerful social or emotional isolation and disconnection. It is not objectified by your martial status, number of relationships or friendships. While being lonely means different things to different people, it seems to be about not feeling connected in a meaningful way to others, to the world, to life. For older adults, changes in loneliness has been linked with changes in marital status, living arrangements, social networks, and physical health.

What does this mean for me?

If we hope to have a happy and healthy (physical and emotional) life in our later years, the findings suggest that we have to develop and deepen social connections with people around us.

What's the first step?

One psychologist, Dr Hall, argues that giving up self-judgment for your loneliness is a good first step. I do agree with her that self-blame, name-calling ("It's all my fault", "I am a social outcast") because you are lonely is ineffective and erroneous. Rather, Feeling lonely in the absence of meaningful connections is normal and acceptance that loneliness is a part of the human condition can help you put your energy into creating solutions.

And the next steps?

Another psychologist, Dr Winch, has suggested three ways to focus your efforts.

1. Intimate Connectedness: Having people in our life with whom we can be ourselves and who make us feel good about who we are.

These could include your family or close friends.

2. Relational Connectedness: Having mutually rewarding face-to-face friendships that we engage with on a regular basis.

These could take the form of social contact over lunch/ coffee, sports or other activities.

3. Collective Connectedness: Feeling accepted as part of a group, a team, or a community.

These could include being an active member of the haemophilia community (I know lots of people have benefitted from the OBE meetings, camps and such) and other interest groups such as walking/ gardening/ Men's Shed etc or voluntary groups.

It can be difficult to take steps to connect to others, so start with baby steps, like calling up a contact that you have not seen for a long time. Give yourself the chance to connect with others; give others a chance to enjoy your friendship.

Good luck!

Dr Desdemona Chong (Mona)
Advanced Psychologist
RBWH (Fridays) Phone 07-3646 8769

More information can be found on these websites:

http://www.psychologytoday.com/blog/the-squeaky-wheel/201402/loneliness-increases-chances-early-death-14

http://www.theguardian.com/science/2014/feb/16/loneliness-twice-as-unhealthy-as-obesity-older-people

A message from Maureen

***An important message from the RBWH Queensland Haemophilia Centre Staff

The Team at the RBWH Haemophilia Centre would like to strongly recommend that you take part in the use of myABDR being promoted by the HFQ in this newsletter.

The project is an important development and an innovative way to enhance care by improving the recording of bleeds and treatments in a way that will be easily (and automatically) visible to all members of the team, that is, affected people and the treating team.

MyABDR will also improve communication between families and local Haemophilia teams. We hope you can make time to attend the training session and look forward to working together on this important initiative which will further optimise care for individuals with inherited bleeding disorders in Australia.

Happy New Year everyone!! I think you will agree that this year is already flying. Mona and I are now fully "back on deck" after Christmas breaks and look forward to working with you throughout 2014.

I have recently recommended joining a Men's Shed to a number of community members. Go to amsa@mensshed.net and have a look at this great "Ozzie" initiative. It's a great "social" extension of the "old backyard shed" and you can read all about it and find the location of your closest shed in the "Find a Shed" section. You can also call them on 1300 550 009.

Please let us know if you have any exciting ideas about psychosocial programs/workshops you would like us to consider facilitating this year. We are hoping to conduct some research to better understand the current needs of the community and are always keen for your feedback about your information/support needs. I have included a few points on communication which I hope that you will find interesting below.

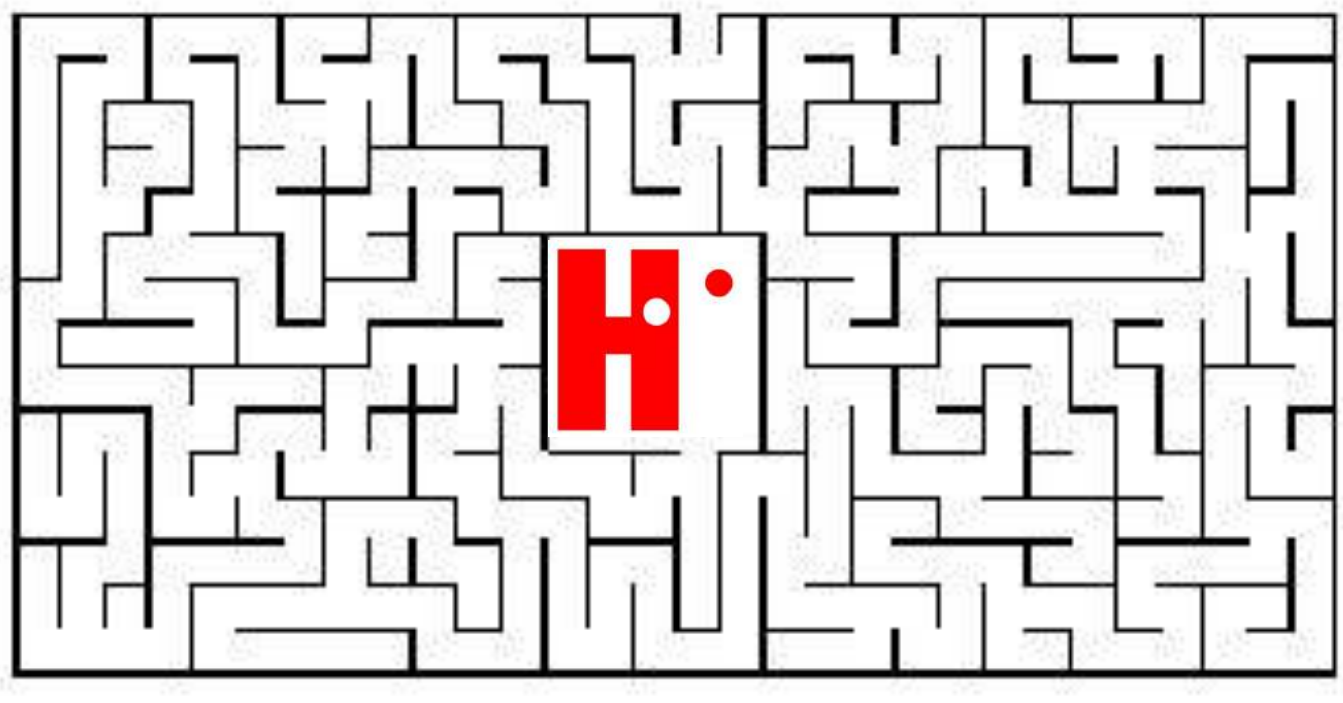
Assertiveness is the style of communication which expresses our point of view while still respecting the views of others. It's easy to confuse assertiveness with aggressiveness. Mona and I are hoping to do a workshop later in the year which looks at "Your Rights and Responsibilities in the Health Care Setting" and will cover the area of assertiveness. In the meantime go online to cci.health.wa.gov.au and have a look at the easy to navigate fact sheet about the topic in the Resource section. Alternatively give me a call and I will email or post a copy to you.

Communication is important in all areas of life. George Bernard Shaw wrote, *"The single biggest problem in communication is the illusion that it has taken place"*. Please let the Haemophilia Centre staff know if you have been given a date for surgery or if you have an unexpected Department of Emergency Medicine visit or and inpatient stay. We may not always be told that these things have or are happening even at the RBWH. Leave us a message if we don't answer the phone or if it is after hours. We will try to get back to you to follow up as soon as possible. It's important to leave your current phone details as well. Advising us of surgery dates and travel dates well in advance will help to reduce stress as the date gets closer.

Please give me a call if you want to talk about these issues or any other.

Maureen Spilsbury Advanced Social Worker – Haemophilia (Monday to Thursdays) ph 3646 8769

Follow the maze to HFQ



Smoking Stinks!

Adapted from an article in Kids Health *http://kidshealth.org/kid/watch/house/smoking.html#cat20074*

Smoking is one of the worst things kids or adults can do to their bodies. Yet every single day about 3,900 kids between the ages 12 and 17 start smoking.

Before high school most students don't smoke — only about 1 in 16 does. And most high school students don't smoke either — about 1 in 5 does (that means 4 out of 5 don't). But why do those who smoke ever begin?

There's more than just one answer. Some children may start smoking just because they're curious. Others may like the idea of doing something dangerous — something grownups don't want them to do. Still others might know lots of people who smoke and they might think it's a way to act or look like an adult.

Fortunately, fewer people are starting smoking than a few years ago. Maybe that's because more and more people have learned that smoking and tobacco use can cause cancer and heart disease.

But sometimes kids can't really think that far into the future to worry about an illness they might not get for many years.

So let's talk about the problems that might affect young people more quickly:

- bad breath
- yellow teeth
- smelly clothes
- more colds and coughs
- difficulty keeping up with friends when playing sports
- empty wallet — cigarettes and tobacco products are very expensive!

Let's find out more about cigarettes and tobacco...

What Are Smoking and Smokeless Tobacco?

Tobacco (say: tuh-BA-ko) is a plant that can be smoked in cigarettes, pipes, or cigars. Tobacco contains nicotine (say: NIH-kuh-teen), a chemical that causes a tingly or pleasant feeling — but that feeling only lasts for a little while.

Nicotine is also addictive. That means that if you start to use nicotine, your body and mind will become so used to it that you'll need to have it just to feel OK.

Anyone who starts smoking could become addicted to it. If you're addicted to something, it's very hard to stop doing it, even if you want to. Some kids get addicted right away. And adults are often addicted, which is why so many of them have a hard time quitting smoking.

Why Is It So Bad for You?

Cigarettes kill thousands of Australians every year. You know those rubber bracelets that were created to bring attention to different causes like haemophilia? A US Campaign for Tobacco-Free Kids created a red one with the number 1,200 on it because hat's the number of people who die each day in America due to smoking.

The nicotine and other poisonous chemicals in tobacco cause lots of diseases, like heart problems and some kinds of cancer. If you smoke, you hurt your lungs and heart each time you light up. It also can make it more difficult for blood to move around in the body, so smokers may feel tired and cranky. The longer you smoke, the worse the damage becomes.

The Other Cost of Smoking

Using tobacco eats up a lot of money, too. A pack of cigarettes costs over $20, on average. That means, even if you buy just one pack a week, you'll spend $1040.00 in a year. Some people smoke a pack a day, which adds up to $7,300! That's a lot of computer games and clothes you could buy instead.

What's It Like?

Usually, people don't like smoking at first. Your body is smart, and it knows when it's being poisoned. When people try smoking for the first time, they often cough a lot and feel pain or burning in their throat and lungs. This is your lungs' way of trying to protect you and tell you to keep them smoke free.

Also, many people say that they feel sick to their stomachs or even throw up. If someone accidentally swallows chewing tobacco, they may be sick for hours. Yuck.

What if My Friend Smokes?

If you have friends who smoke or use tobacco, you can help them by encouraging them to quit. Here are some reasons you can mention:

- It will hurt their health.
- It will make their breath stinky.
- It will turn their teeth yellow.
- It will give them less endurance when running or playing sports.
- It's expensive.
- It's illegal to buy cigarettes when you're underage.

If you think it will help, you could copy articles like this one, or find them on line to give to a friend who smokes. They may be interested in learning more about the dangers of smoking.

But people don't like to hear that they're doing something wrong, so your mate might also get be a little angry. If that happens, don't push it too much. In time, your friend may realise you are right.

In the meantime, it could help to talk with a parent or a school counsellor if you're worried about your friend. When your friend is ready, a grownup can help him or her quit for good and there is also Quit Line a phone counselling service on 13 QUIT (13 7848) which a free and anonymous service. If your friend decides to quit, lend your support. You might say it's time to kick some butts!

World Congress Free Funding for Youth Registration

Full funding is available for you to attend the 2014 World Congress in Melbourne!

WFH World Congress – being held in Melbourne May 11-15 – is your chance to catch up, connect and hang out with other young people affected by bleeding disorders, as well as an unique opportunity to learn more and have fun. The Congress is a great chance to take part in the largest international meeting for the global bleeding disorders community.

As a member of the HFA Youth Community, we'd like to invite you to a special, once-in-a-lifetime Youth Meet N Greet weekend just prior to the start of Congress. The Youth Meet N Greet runs from Saturday 10 May - Sunday 11 May and will finish just in time for the Congress Opening Ceremony. There is also a Thursday night dinner to conclude the congress.

The Youth Meet N Greet will be facilitated by Purple Soup and will include many exciting activities.

If you are aged 18-30 and have a bleeding disorder or are a carer, partner or relative of someone with a bleeding disorder, you are eligible for full funding for the Congress (including registration, travel and accommodation expenses) from the Haemophilia Foundation Australia (HFA). ***Complete and return the attached form to register for funding before the 7th March.***

Visit www.wfh2014congress.org to find out more about the Congress

HFA Youth Meet N Greet: **Saturday 10 May until Sunday 11 May**

WFH Congress: **Sunday 11 May until Thursday 15 May**
Congress dinner: **Thursday 15 May (night)**

Never! a Crossword...

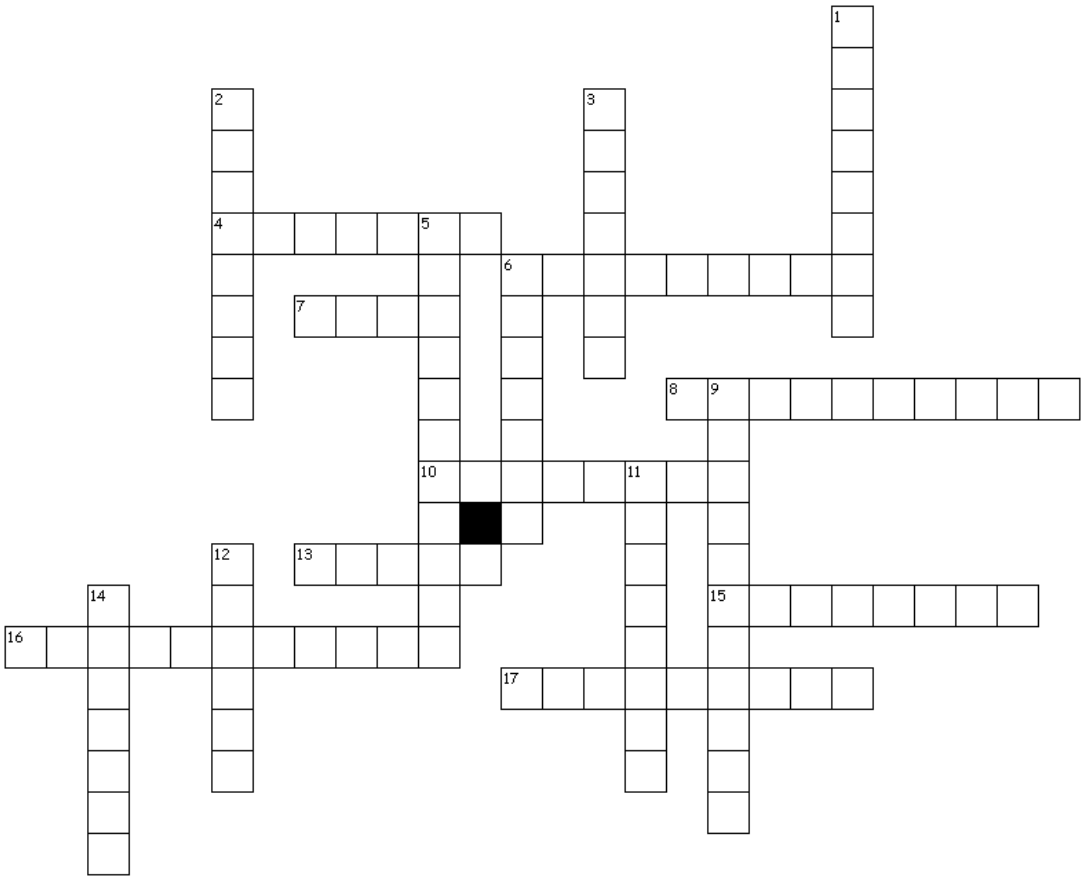
Here's our first Haemophilia Foundation Queensland Crossword. Some of the words are complicated so you might have to work it out together but give it a go. The answers are printed upside down at the bottom of the page.

Across

4. large molecules that are an essential part of all living organisms, especially blood and antibodies.
6. change from flowing to solid
7. blood that stops flowing
8. structures that determines the sex of a person
10. activity requiring physical effort
13. It goes round your body and sometimes has a missing factor.
15. disc-shaped cell fragment found in the blood
16. a measure taken in advance to prevent something dangerous
17. a thing which inhibits

Down

1. an abnormal condition affecting the body of an organism
2. a indication of a condition of disease
3. treatment intended to relieve or heal a disorder
5. administered into a vein
6. someone who can pass on a bleeding disorder
9. a medical condition in which the ability of the blood to clot is severely reduced
11. the introduction of a new



Hemophilia gene therapy trials start delivering the goods

Adapted from an article in Heamaware By Sarah Aldridge Originally Published September 2013

In gene therapy trials for people with haemophilia, different vehicles are competing to carry the packages. Currently, viruses lead the field, delivering healthy genes to cells that can begin producing normal levels of factor protein.

Many believe gene therapy is about to deliver the goods. Preliminary results from a UK clinical trial in the show that several patients with severe haemophilia B, or factor IX (FIX) deficiency, no longer need factor product & a few infuse less often.

But gene therapy is not quite ready for routine administration. Clinical trials for haemophilia A, or factor VIII (FVIII) deficiency, are a few years down the road. Those for FIX are testing ways to manage immune responses. And none of the gene therapy clinical trials has yet to include children.

Creating the perfect package

Gene therapy entails correcting a genetic defect by inserting healthy genes into living cells, which then produce functional levels of the missing or deficient protein and haemophilia is a good candidate for gene therapy.

The FIX gene is easier to work with than the FVIII gene for several reasons. It's not an enormous gene, in contrast to the FVIII protein, which is large; and is coded for by a sizable gene and travels a complicated path in cells before it can be secreted into the bloodstream. Although FIX is normally made in the liver and modified by liver cells, other tissues can make it following gene therapy.

Another advantage of FIX is related to inhibitor, or antibody, formation. It doesn't seem to set off alarms with the immune system quite as easily as FVIII does. Lastly, FVIII is typically bound to von Willebrand factor so all the things that make it a little bit more complex to make as recombinant protein also make it more complex to express in gene therapy.

Viruses provide speedy delivery

Viruses are some of the most reliable ways to carry healthy genes into the body. Like express mail, they are sent to a specific site. They then latch onto receptors on cells, taking over the cells' machinery and instructing them to produce factor protein. By genetically altering these viruses, researchers have been able to insert the desired gene, which is then carried to the site where it is produced.

Currently, the adeno-associated virus (AAV) is out-competing-other courier viruses to carry the FIX gene. AAV serotype 8 has an affinity for the liver—that's where FVIII and FIX proteins are normally produced. The procedure is simple: The patient is given a single infusion of the vector-containing gene through a peripheral vein in the arm.

Results from the UK study show that prior to the trial, the first six men in the study were on various prophylaxis regimens. Now, four of them have stopped. The two patients on the highest dose express factor levels between 3% and 6% and that means they moved from a diagnosis of severe haemophilia to moderate haemophilia. Hardly any of them have had a bleeding events and some have returned to favourite outdoor activities, including cricket, hiking and soccer. One even ran a marathon.

Detours and obstacles

AAV is a common virus that infects humans, so the older you are, the more likely you have been exposed to it. It's possible that if older patients have been exposed to AAV, their immune system would wipe out the delivery system and they wouldn't get the same efficacy. Also; although the UK patients from the have maintained stable FIX levels for three years, long-term stability is an unknown.

In hot pursuit

Gene therapy trials for other factor deficiencies are coming down the road. Researchers are using an AAV vector for FVII and for FVIII. The first FVIII clinical trials using an AAV vector could be tried in humans within a couple of years, so it's coming closer. When we eventually get the perfect package to deliver healthy genes we're going to have some truly transformative -therapies that will to come out of all this research.

Tretten Approved for Genetic Clotting Disorder

a rare condition that could otherwise be life threatening

By Scott Roberts *HealthDay Reporter*

MONDAY, Dec. 23, 2013 (HealthDay News) -- Tretten (coagulation factor XIII A-Subunit recombinant) has been approved by the U.S. Food and Drug Administration to treat a very rare blood clotting disorder called congenital Factor XIII A-Subunit deficiency.

People with the genetic disorder do not make enough Factor XIII, a blood component that promotes clotting. Tretten, a human recombinant produced in yeast cells, makes up for this deficiency, which could otherwise be life threatening, the FDA said Monday in a news release.

Tretten was evaluated in a clinical study of 77 people with the disorder. Administered monthly, it was effective in preventing bleeding in 90 percent of recipients. Side effects included headache, extremity pain and pain at the injection site. No study participant developed abnormal clotting, the FDA said.

The product was developed and is produced by Novo Nordisk, based in Denmark.

http://consumer.healthday.com/circulatory-system-information-7/hemophilia-news-371/tretten-approved-for-genetic-clotting-disorder-683345.html

Colouring Competition

"What's your dream" Colouring In Competition REGISTRATION

Full name of the child: _____

School/Organisation (if applicable): _____

Postal Address: _____

Postcode: _____ City: _____ Country: _____

Phone: _____

E-mail: _____

Date of birth _____/_____/_____ Age as of 1 April 2014: _____

I agree with the terms and conditions (for full terms and conditions visit www.haemophilia.org.au)

_____
Signature (legal guardian)

Categories and ages
This Colouring In Competition is open to children from any country in the following three categories:
Category 1: children aged under 4 years
Category 2: children aged 5 to 8 years
Category 3: children aged 9 to 11 years

Only one entry per child will be accepted

Prizes

	Children aged under 4 years
1st prize	Toys r us voucher or nominated toy shop voucher in your country to the value of A$200
2nd prize	Toys r us voucher or nominated toy shop voucher in your country to the value of A$150
3rd prize	Toys r us voucher or nominated toy shop voucher in your country to the value of A$100

	Category 2: children aged 5 to 8 years
1st prize	IPod Nano or Apple voucher for the equivalent value + $50 itunes voucher. Total value $219A
2nd prize	IPod Nano or Apple voucher for the equivalent value + $20 itunes voucher. Total value $189A
3rd prize	IPod Nano or Apple voucher for the equivalent value. Total value $169A

	Category 3: children aged 9 to 11 years
1st prize	IPod Nano or Apple voucher for the equivalent value + $50 itunes voucher. Total value $219A
2nd prize	IPod Nano or Apple voucher for the equivalent value + $20 itunes voucher. Total value $189A
3rd prize	IPod Nano or Apple voucher for the equivalent value. Total value $169A

Closing Date
The colouring in sheet and registration form must be received by 1 April 2014 to -

HFA
"What's your Dream" Colouring In Competition
1624 High Street, GLEN IRIS VIC 3146 AUSTRALIA

Or scanned in colour and in a pdf document emailed to hfaust@haemophilia.org.au

School is ~~not always~~ Kool

(or Why your kids may not want to go to school)

Adapted from an article that appeared in "The Conversation" by Adjunct Associate Professor Sue Roffey

There has been a lot of news about schools and the quality of education recently. Prime minister Abbott wants to improve Indigenous school attendance; but failure to attend school is not just a problem for children in the bush. The issue of school attendance can arrise in your own family because the list of vulnerable students whose school attendance is at risk includes children who have periods of illness or hospitalisations.

There are many things that push children and young people out of school and that pull them towards other things and each child will have multiple motivations that require differentiated responses but understanding this 'Push and Pull' framework can help you apply it to what may be going on for your child.

'Push' factors come from what is happening, or not happening, in school that makes students not want to be there. Feelings are critical. No-one learns well when they are scared, anxious or overwhelmingly miserable.

Being bullied or being a “low achiever” can make coming to school scary. Multiple failures, missed lessons, comparison with more able peers and fear of ridicule can be threatening. Being asked a question they can’t answer or to read aloud when they struggle with literacy can have the same effect for some students.

Sometimes being confused or having a negative school experience will push students away. It can take effort to try to “fit in” and sometimes this becomes too much. Students need to feel a sense of safety, a sense of belonging to help them want to attend. Keeping a child out of school can suggest they are not wanted there and does nothing to boost their motivation. Positive emotions and motivation from knowing people believe in them and see themselves as learners can encourage school attendance.

'Pull' factors are the things that are happening, or not happening, at home that stops school from being a priority for your child. Ill health, family loss or sibling sickness can keep young people at home. They want to keep an eye on things and may feel responsible for keeping members of the family well and these problems at home make school feel unimportant.

Poor attendance in young children may be the outcome of parental health issues. Your child can’t or won't want to go to school if no-one gets them up and dressed. It can add to not 'fitting in' and if children (and sometimes parents) get into trouble for being late it can start to be easier to not go at all.

Thinking about the 'Push and Pull' Framework can help you understand your own child's reluctance to attend school and help them overcome it. In order to be aspirational, your child needs confidence and you can provide this support. Their school needs to be a place where they feel they belong and what happens is relevant and you can ask the school to help provide this. If you child has been out of school for some time, talk to the school about a plan for re-integration that takes account of your child's perspectives and needs.

You can discuss bleeding conditions at with them at home and how to minimise their impact on school attendance. Talking to the haemophilia social workers may help you find a way for your child to accept family (and their own) health conditions; and develop their personal and interpersonal qualities as well as academic abilities.

It’s okay to make mistakes. Not everyone is a perfect parent and not every child is an A-grade student - and we don’t need to be. We need to show our children that school can help them reach their own potential, whatever this is.

ARE YOU A VICTUM OF HABIT?

consider this...

Prophylaxis treatment has been available for a while but is still not embraced by adults.

If on-demand treatment is what you've been used to, you will adjust your lifestyle and perhaps the job that you do to the amount of activity your body can stand. What we face in this new age of a larger availability of products is the choice to lead a more active life.

You, along with your treating doctor should make the choice between on-demand and prophylaxis treatments, improve your quality of life today.

Osteoporosis In Kids With Bleeding Disorders

Adapted from an article by Sarah Aldridge Originally Published February 2014

Osteoporosis, a disease usually linked to old age and old bones that become thin and brittle, is showing up in kids with hemophilia. Oosteoporosis is still rare in children, but pediatric haemotologists are finding it more often than they would like to and are working at defining at-risk patients and developing standard protocols for screenings and preventive measures. Until then, parents can increase their awareness of pre-existing conditions or behaviors that may predispose children for osteoporosis. Understanding the body's need for calcium and vitamin D as children grow can help parents create a proactive plan for their kids so they can build better bones.

Bone Building

The skeleton provides a strong framework to keep organs in place, and for attachment of ligaments, muscles and tendons. Its bones are like miniature construction sites, where building and demolition teams work round the clock. The osteoblasts are the cells that build bone; the osteoclasts remove it. Ideally, the builders should outnumber the destroyers from childhood until young adulthood. Their goal is to amass as much bone as possible, called peak bone mass, by the time a person is 25–30 years old.

Hormones, gender, genetics, diet and exercise all affect bone mass. Boys' bones tend to have more mass and density than girls' bones. During the teenage years, hormones kick in, causing growth spurts and sudden increases in bone density. This is a very pivotal time for kids to be accruing bone mass, which is essential for the rest of their life.

Bone mass and density are increased through weight-bearing exercises, such as weight lifting, that force muscles to pull on your bones. Bones also need vitamins and minerals to stay strong. Vitamin D is a partner in bone building because it helps the body absorb calcium. Calcium is also needed to build bones and teeth and maintain their strength.

Vitamin D and calcium can be obtained in a variety of foods and also through vitamins and supplements. Dairy products are loaded with calcium, as are some types of fish and other foods, including produce such as green leafy vegetables, like broccoli.

The Link Between Hemophilia and Osteoporosis

Certain circumstances associated with hemophilia can increase a child's risk of developing osteoporosis. Top among them are the periods of inactivity when a child is recovering from a bleed or surgery. At this point they are often immobilised and even a few weeks of immobility can lead to decreased bone mass. When they get back on their feet they'll gain some bone mass back, but when bone development is interrupted, it increases the risk of osteoporosis.

Another perhaps surprising contributor is the fear factor. Osteopenia, or thinning of the bones (a precursor to osteoporosis) may be due to kids with hemophilia having reduced activities, either because parents are overly protective, or the kids themselves are protective as they get to the teen years. Without this activity a lot of bone never gets put on.

A 2004 study of 19 children with severe hemophilia in Melbourne, Australia, showed that those with the most damage from bleeds into their ankles and knees also had significant loss of bone density in the lumbar (lower) region of their vertebrae. The most likely explanation for the decreased bone density was lack of physical activity, specifically weight-bearing exercise. Screening for osteoporosis was recommended for at-risk children with hemophilia who had joint damage from bleeds.

Patients with inhibitors, antibodies to infused factor product, are at higher risk for osteoporosis. Because their bleeding is often not well controlled, they can develop target joints. The influx of iron and other components of the blood irritates the membrane lining the joint (the synovium), this can lead to synovitis, a chronic condition in which the synovium becomes inflamed and thickened, prone to even more bleeding. Synovitis, in turn, can impair bone growth.

Chronic inflammation, especially from synovitis, can cause the release of a protein produced by the immune system that activates osteoclasts, increasing the rate of bone destruction as the body steals calcium from your skeleton.

Then there's the issue of weight gain. Being overweight taxes joints and limits range of motion in children with hemophilia. A 2004 US study showed that nearly one-third of the boys and teens treated at the hemophilia treatment centers (HTCs) they surveyed were overweight or obese. Australian rates are not far behind and we know that obesity definitely leads to inactivity, which then can make osteopenia worse.

Healthy Bone Basics

Having healthy bones means getting back to basics—good nutrition, plenty of exercise and daily exposure to some sunshine (for the vitamin D). Experts say it's more beneficial to boost kids calcium intake through diet, than supplements or vitamins. You need a balance of calcium phosphate, magnesium and vitamin C which you get through different foods. An 8-ounce glass of milk at breakfast, a piece of string cheese at lunch and a 6-ounce cup of yogurt at dinner supply the 700 mg of calcium needed by most children.

But vitamin D is different. Now that people are slathering on the sunscreen, it's hard to tell if you're truly absorbing your 15-30 minutes daily dose of vitamin D in the great outdoors. Although there are vitamin D-rich foods, such as salmon and tuna, and foods fortified with it, including orange juice and cereal, it can be difficult to reach the recommended daily amount through diet alone.

Approved Activities

Prophylaxis has opened the door to a wide array of approved activities. A 2009 study in Pediatrics concluded that in boys with severe hemophilia who were on prophylaxis could participate in high-impact sports, such as running and skateboarding, without producing any more bleeds than low-impact sports, like golf and swimming.

That may mean letting your kids do some bone-building activities, within reason, after school. The haemophilia centre

Message from Moana (Senior Psychologist Haemophilia Royal Childrens Hospital)

Is your child anxious about his haemophilia treatment?

Here is a great way to help him to relax.

Diaphragmatic breathing technique

Diaphragmatic breathing or tummy breathing is a stress reduction technique that helps individuals to relax their body. Proven health benefits include lowered: blood pressure and stress hormones (adrenalin, cortisol) which allow the body to return to a relaxed state.

- Get your child to lie on their back on the floor. To make it more fun place a foam cup or a small soft toy on their belly or they can just place one hand on their tummy and one on their chest.
- Then ask them to breathe in slowly through their nose so that their stomach inflates like a balloon. He should see the cup or toy rise up higher. Place your hand above the cup and ask him if he can make it touch your hand when he breathes in. The trick is to keep the chest still and only expand the abdomen.
- Ask him to watch the toy go down slowly has he breathes out.
- Lay down next to him so you can model how to do it. Then see who can push the cup up the highest.
- Practice at least 3 times

This is a new skill and will require daily practice for it to become more automatic so that it can be applied in anxiety provoking situations when needed. When teaching, keep it light and fun.

Try playing fun games that require the child to take deep breaths such as blowing bubbles without trying to make them pop – take a deep breath then blow very slowly so you don't pop the bubble.

If you would like more intensive help with treating your child's anxiety please feel free to make an appointment to see me. No cost is involved.

Dr Moana Harlen
Senior Psychologist Haemophilia
Royal Children's Hospital
Ph: 07 3646 7937
Email: Moana.Harlen@health.qld.gov.au

Osteo In Kids...

Continued from page 14

physios should be able to identify some activities your child can do to stay active within the constraint of what's going on with their particular joints.

Walking is a good weight-bearing exercise for children and running is usually fine when kids are young and play rudimentary games of soccer and cricket. It's when the games get more competitive and contact occurs, such as during junior igh and high school, there is a higher likelihood of injury or bleeds.

Lifting weights, on the other hand, is a bone-healthy activity more suitable for teens and young adults than younger children. The muscles attached to the bones pull on them, creating resistance. "That provides a form of stress on the bone, which stimulates it to form more bone. Again, it is best to consult the physios who may recommend ellipticals and NordicTracks over treadmills, because of their gliding motion.

The schoolyard favorite, the skipping rope, receives praise from many physiotherapists because there's probably nothing better for building bone density than jumping and landing. But kids with ankle or knee issues should avoid that steady pounding. Instead, they could reap similar rewards by dribbling a basketball.

What's this thing called 'Subclinical joint bleeding'

The topic of subclinical joint bleeding, or microhaemorrhage, remains a subject of debate, with experts divided on whether it exists and, if so, whether it contributes to joint damage. Although the concept has received considerable attention in recent years, it is hardly a new one, having first been reported in 1981 by Pettersson, he and his colleagues found that three subjects with radiologic evidence of joint abnormalities had never reported a single episode of haemarthrosis. The investigators concluded that 'changes in a joint can be produced by repeated subclinical bleeding'

The presence of unrecognized subclinical haemarthroses was suspected in the US Joint Outcome Study, in which 65 boys <30 months of age with severe haemophilia A were randomized to factor VIII prophylaxis or enhanced episodic therapy and followed up for 5 years. In general, the number of bleeding episodes was highly correlated with the MRI score, but this was not true for every subject. Some children who had no clinical evidence of haemarthrosis had MRI-demonstrated joint damage.

Other researchers have also confirmed the phenomenon of subclinical joint bleeding. In an analysis of bleeding frequency and arthropathy, den Uijl *et al*. found that 28% of patients with mild haemophilia and a zero ' annual joint bleeding rate' had damaged joints, some of which were sufficiently impaired as to require orthopaedic devices. In a single-centre retrospective cohort study of 26 haemophilia patients on prophylaxis, Olivieri *et al*. found that five (19%) had worsening MRI findings without experiencing a single episode of joint bleeding. Finally, in a study designed to assess the efficacy of escalated-dose prophylaxis in young boys, Kraft *et al*. found that 31% (20/65) of ankles, knees and elbows with no history of clinically reported bleeding had soft tissue changes on MRI. Furthermore, deposits of iron which normally result from bleeding was detected in 26% (17/65) of these joints.

The massive proliferation of smaller blood vessels that occurs after an episode of joint bleeding may provide one explanation for subclinical bleeding. The walls of these new vessels are often defective, predisposing to the continual leakage of blood into the joint cavity]. Alternatively, intra-articular blood has been shown to adversely affect cartilage in the absence of inflammation – in other words, without clinically evident pain and swelling.

Source (edited) *http://onlinelibrary.wiley.com/doi/10.1111/hae.12375/abstract*

European Haemophilia Safety Surveillance project (EUHASS)

In 2008 a project commenced to gather information from Haemophilia treatment. Reports of all adverse events were gathered at least once every 3 months with a 12 month report from each participating centre. Information included a range of stats – number of patients treated with each product, any adverse events like inhibitors in previously untreated patients (PUP's), infections, deaths, poor efficacy etc.

In the first 4 years, 75 centres participated with a total of 32 659 patients with inherited bleeding disorders and 11 757 patients were treated with one of 63 different clotting factor concentrates during the period. A total of 970 events were reported. 101 were acute or allergic reactions, of which 9 were anaphylactic reactions. There were no transfusion transmitted infections. There were 104 thromboses of which 63 occurred within 30 days of concentrate exposure. 208 malignancies and 324 death were also reported.

Inhibitors developed in the first 50 exposures in 108/417 (26%; CI22-30%) PUPs with severe haemophilia. So there were no statistically significant difference in the rate of inhibitos between the different concentrates.

The good take home message here is that there were no significant differences between the currently used recombinant concentrates and the rates of inhibitors observed are similar to those reported by previous studies but no differences in inhibitor rates between the different currently used recombinant concentrates were seen.

Editorial summary by David Stephenson – from abstract report 7th Annual Congress of the European Association for Haemophilia and Allied Disorders, 26–28 February 2014, Brussels, Belgium

Motorcyclist's near-death experience...

Haemophilic youngster underwent life-saving surgery at Mafraq Hospital after suffering skull fracture

A 20-year-old Emirati haemophilic motorcyclist, a victim of a fatal crash, underwent a life-saving surgery at Mafraq Hospital.

He suffered severe head trauma as he was not wearing a helmet when he crashed, thereby also suffering a right-side skull fracture and intracranial bleeding.

He lost 70 per cent of blood by volume, according to hospital sources.

“The risks increase significantly when the rider has a serious blood disorder like haemophilia. The patient is lucky to be alive, ” said Dr Fawzi Al Ayoubi, Consultant General and Trauma Surgeon, Chief of General Trauma at Mafraq Hospital.

A two-hour blood transfusion procedure was needed to help stabilize the patient’s condition in combination with haemostatic agent recombinant factor VII.

Dr Al Ayoubi said, “Blood disorders, especially hereditary disorders like haemophilia, are common in the Gulf. That’s why it is important to raise awareness and bring attention to the risks for those Emiratis and their families living with blood disorders.

Haemophilia is a genetic disorder in which blood does not clot easily and is the most prevalent form of inherited bleeding syndromes (IBS) in the Arab region . The disease only occurs in males.

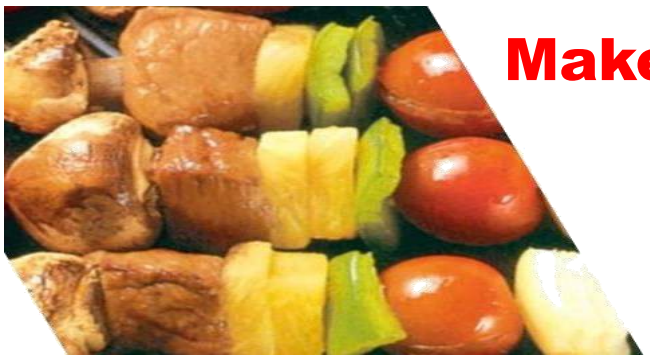
Symptoms of this disorder are excessive bleeding and easy bruising. Bleeding can occur on the body’s surface and the signs include nosebleeds for no obvious reason, heavy bleeding from a minor cut or bleeding from a cut that resumes after stopping for a short time.

“People with haemophilia have a tendency to bleed longer after an accident or injury. Therefore, they need extra protective gear when taking part in high risk activities. In this case, the patient had not taken the basic precautionary measure, which is applicable to everyone – always wear a helmet when riding a motorcycle”, Dr Al Ayoubi added.

Wearing a helmet correctly can reduce the risk of death by almost 40 per cent, and the risk of severe injury by as much as 72 per cent.

Published Wednesday, January 22, 2014

http://www.emirates247.com/news/emirates/emirati-motorcyclist-s-near-death-experience-2014-01-22-1.535648



Make your own Kebabs

Ingredients

440g can of unsweetened pine-apple pieces
2 tablespoons salt-reduced soy sauce
1 clove garlic, crushed
1 teaspoon grated ginger
500 g beef, steak or other meat such as pork, lamb or chicken
1 green capsicum
1 onion
1/2 punnet cherry tomatoes
10 mushrooms

Utensils

10 wooden or steel skewers
Shallow dish
Mixing bowls
Measuring spoons
Strainer
Chopping board and knife
Spoon
Grill or BBQ
Can opener

Method

1. If you are using wooden skewers, soak them in water for at least an hour.

2. Drain the pineapple pieces and save the juice.

3. In a bowl, mix together 1/3 cup pineapple juice, soy sauce, garlic and ginger.

4. Trim off any fat you can see on the meat.

5. Cut the meat into cubes. Put meat in a bowl.

6. Pour the juice mixture over the meat. If you have time allow to stand for 1/2 to 1 hour.

7. Chop the capsicum and onion into cubes. Cut the mush-rooms in half.

8. Thread the kebab sticks. First a piece of meat, then pineap-ple, capsicum, onion, cherry tomato etc.

9. Grill or BBQ kebabs for 8-10 minutes. Turn kebabs over once or twice until cooked.

The new epidemic - HCV & HIV coinfection

Adapted from an article by Graham Stocks that first appeared in Positive living August 2013
http://napwa.org.au/pl/2013/09/the-new-epidemic-hepatitis-c-and-hiv-coinfection

New cases of hepatitis C (HCV) are still being seen largely amongst people who inject drugs (PWID). However, in recent years it has become more recognised that HCV can also passed on sexually and that a disproportionate number of people living with HIV (PLHIV) are also living with HCV.

Between 2004 and 2008, the Australian Trial in Acute Hepatitis C (ATAHC) found that around 30% of those who had recently acquired HCV were also HIV positive, and that 15% of those new HCV infections were attributed to sexual activity .

In Australia, around 13% of PLHIV are also living with HCV. This estimate is similar in the USA, while in Europe up to 25% of PLHIV also have hepatitis C.

In her International AIDS Society 2013 Conference plenary lecture, Karine Lacombe from the Université Pierre et Marie Curie in Paris, claimed that HIV/HCV coinfection constitutes a new epidemic, and provided an overview of the harmful and synergistic effects of having both.

Put simply, having both viruses complicates your clinical care considerably. The combination increases the chance of liver fibrosis and impairs Natural Killer (NK) cell anti-fibrotic activity. End-stage liver disease is the highest cause of death in people who are living bi-virally.

But it's not all bad news. Treating HIV can restore your anti-HCV T-cell response (a good reason to initiate it early), and unlike HIV, HCV is a curable disease because it doesn't integrate into the host genome, so there are no archived mutations.

Plus, when you add the new first generation direct-acting antivirals, protease inhibitors boceprevir and telaprevir, to standard treatment peginterferon and ribaviran it can shorten treatment time and you've got a better chance of curing the HCV.

Results of trials with second generation protease inhibitors are also very encouraging. Both naive patients and relapsers showed an 80% sustained virological response with simeprevir and almost 90% early virological response with faldaprevir.

Treating people with HCV to reduce new transmissions is a real possibility in the near future, however this is a monumental task as globally around 185 million people are living with the virus.

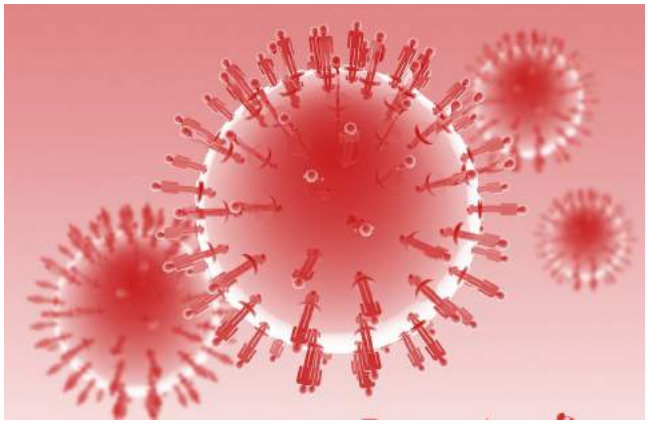
A range of newer drugs are also in the pipeline, and hopefully some of these will be eventually licensed for use.

Treating and clearing HCV infection still results in a health burden, as there is an increased risk of liver cancer, specifically hepatocellular carcinoma. So, ongoing care and monitoring of liver health is essential.

Another presentation on HCV and HIV coinfection amongst gay and MSM was delivered to the IAC conference by Thomas Martin on behalf of a team from Chelsea and Westminster Hospital in London.

He began with a fairly gloomy overview. Having both infections reduces spontaneous clearance rates of HCV (PLHIV account for only 20% of all cases). HCV RNA set points tend to be higher which increases the chance of transmission. Having both also increases the chance of progressing to cirrhosis faster. And while treatments are improving, there is still a reduced success rate among PLHIV.

Liver disease is a major non-AIDS cause of death among PLHIV, accounting for 9% of all deaths in the largely treated D:A:D Cohort (2009 to 2011). Viral hepatitis infection (mainly HCV) was the main contributor to these deaths.



HIV Relapse

HIV Relapse in Patients Thought Virus-Free Spurs Researchers to Push More for Cure

January 7, 2014
Reuters: Relapse of 'cured' HIV patients spurs AIDS science on

"Scientists seeking a cure for AIDS say they have been inspired, not crushed, by a major setback in which two HIV-positive patients believed to have been cured found the virus re-invading their bodies once more. True, the news hit hard last month that the so-called 'Boston patients' -- two men who received bone marrow transplants that appeared to rid them completely of the AIDS-causing virus -- had relapsed and gone back onto antiretroviral treatment. But experts say the disappointment could lay the basis for important leaps forward in the search for a cure..." (Kelland, 1/2).

Date Claimer

For guys from 8 and 18 years of age with an inherited bleeding disorder.

Fun activities from Swinging logs to Commando Cable Crossing to Rock Climbing and a High Adventure Night Walk. *For info check out their website www.emugully.com.au*

Lock in the weekend & talk to Graham if you'd like to come along.

NB: All boys attending are permitted to bring along one parent.

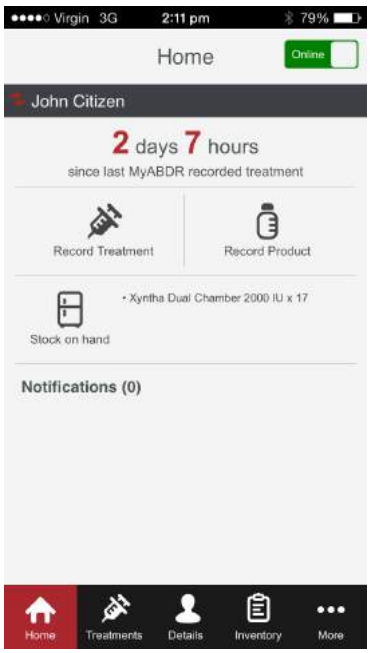
HFQ 2014 Youth Camp

22 August for Emu Gully Adventure

myABDR update

Suzanne O'Callaghan, Haemophilia Foundation Australia

MyABDR is being released at the end of February 2014.



This exciting new online tool is a quick and easy way to record home treatments and bleeds, stocktake and update contact details using a secure app for smartphones and/or a computer web site.

It's a two-way system with the Australian Bleeding Disorders Registry (ABDR), the system used by Haemophilia Centres for clinical care of their patients. When you are in mobile phone range or online with your computer, your entries will upload directly to your record in the ABDR at your Haemophilia Centre. It also draws on your ABDR record for information like your treatment plan.

Prefer paper to online? A paper-based MyABDR patient treatment diary has been developed alongside as an alternative.

WANT TO KNOW MORE?

Introductory sessions about MyABDR and how to use it will be held in Brisbane on Monday 10 March – see **www.haemophilia.org.au/myabdr** for more information

Printed start-up packs will be available from your Haemophilia Centre and to download from www.blood.gov.au/myabdr in March 2014.

Need help to get started? Phone 13 000 BLOOD (13 000 25663) for the myABDR help desk.

HOW TO REGISTER?

Registering on the app

Download the app from the App store (Apple) or Google Play (android). Register online by CREATING AN ACCOUNT.

Registering on the web site

Go to **www.blood.gov.au/myabdr** and click on NEW USER? CLICK HERE TO REGISTER.

You can register on the web site for both the app or the web site – your account will work on both.

After you register, your Haemophilia Centre will process your access to MyABDR.

When? You can register any time after **28 February 2014**. Before you can use MyABDR, you will need your registration approved by your Haemophilia Centre. In Queensland your Haemophilia Centre will begin processing access to MyABDR on 10 March 2014 when training for Haemophilia Centres and the community has taken place.

WHAT DID THE FOCUS GROUP THINK?

A national group of people with bleeding disorders have tested the MyABDR prototypes from home and in a small group workshop. Their comments? They particularly loved:

"Having the details of their treatment and stock on their phone and all in one place."

"How easy it was to record."

"The quick summaries of their last treatment and stock on hand on the home screen."

MyABDR is a collaboration between HFA, the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of Australian governments.

MyABDR