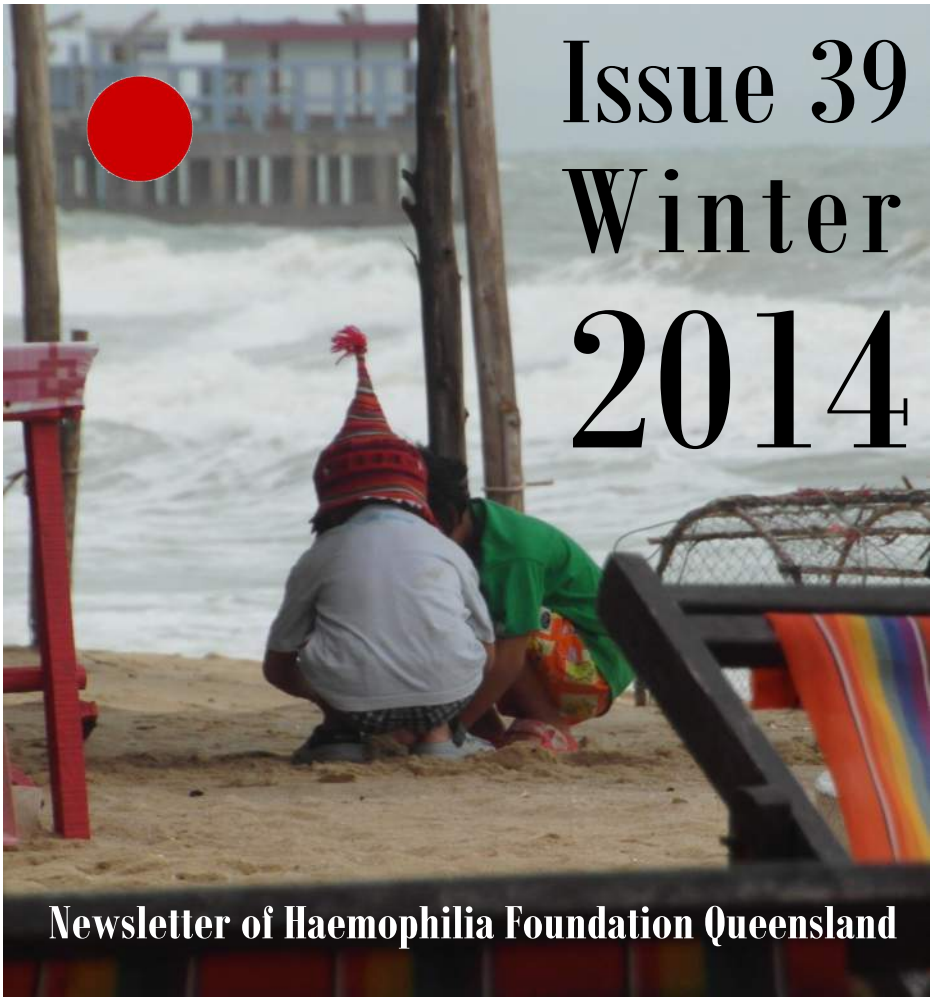
the H FACTOR



Issue 39
Winter
2014

Newsletter of Haemophilia Foundation Queensland

President's Message

World Congress 2014 was a wonderful event bringing together 4300 people from across the globe – medical, patient and industry. It was impossible to attend all sessions so you had to pick topics of interest. Research strategies continue to evolve in using factor VIII and factor IX therapy in persons with haemophilia- longer acting and genetic engineered products.

New approaches to Hepatitis C management were presented and the list goes on. Women with bleeding disorders were included, one woman said "I don't think there are words in any language to describe what's it like to be able to sit down with a woman who knows what I'm going through," she said. For any women out there check out http://mygirlsblood.org

An important aspect of any congress is the connections people make with each other, from simply new or renewed friendships to discussions on patient outcomes between medical professionals. One interesting observation discussed by several physiotherapist's was the concept of micro bleeds (the bleed you may have when you don't think your having a bleed) They noticed damage to ankle joints of youth who were on prophylaxis, but the question

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Inside this issue:

President's Message Continued...

continues on next page

remains unanswered if this is a micro bleed as it's never been conclusively detected by imaging techniques.

It was great to see one of our Treatment Center staff on stage talking about one aspect of the Australian experience. Beryl Zeissink, Royal Brisbane & Women's Hospital talked about the divide between older and younger people who have Haemophilia. Older people are problem solvers, independent, resourceful and resilient. They've dealt with lots of change, and they support Haemophilia groups.

Younger people generally don't know what their older peers have endured and are sometimes less involved, and many haven't met other people who have Haemophilia. They don't see the need to attend a clinic, and are often not able to recognize a bleed.

"What both groups share is hope—for younger generations and for themselves"

All the best ….

David Stephenson

President HFQ…..Advocacy, Health promotion, Support

Book Group to Explore Pain

I have been reading a book entitled "EXPLAIN PAIN" by David Butler, and Dr Lorimer Moseley. David was a speaker at the recent World Federation of Hemophilia Congress in Melbourne. He provided an entertaining and thought provoking presentation in a session entitled **Multidisciplinary Management of Chronic Pain**. David is the Director of the Neuro-Orthopaedic Institute and senior lecturer at the University of South Australia. In the introduction to the book the authors write;

"There are many myths, misunderstandings and unnecessary fears about pain. Here are two important things we know about explaining pain: the biology of pain can be easily understood by men and women in the street, and understanding pain biology changes the way people think about pain, reduces its threat value and improveheir management of it".

I am interested in hearing from anyone who might like to meet regularly over a cuppa as a small group, to learn more about the information in "Explain Pain". Give me a call on 07 3646 8769 if you are interested and we can discuss the "When and Where".

Maureen Spilsbury
Advanced Social Worker - Qld Haemophilia Centre RBWH

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 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)**
- **Discounted Movie Tickets**

HFQ Management Committee

President	... ...	Mr David Stephenson
Vice President	...	Mr Howard Mitchell
Secretary	... ...	Mrs Sarah Hartley
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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
Ph: (07) 3338 5604 E: info@hfq.org.au

Queensland Haemophilia Centre Contact Details

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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

The Children's Hospital is Moving.

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

The "Why, What and How" of Clinics

This newsletter the staff at the QLD Haemophilia Centre at the RBWH have written some short pieces about the benefits of attending clinic. Mick our physiotherapist, Mona our Psychologist and our nurses, Beryl and Olivia share their thoughts.

We would all agree that Public Hospitals are becoming increasingly busy. Waiting lists at all Outpatient Departments continue to expand and time and room availability is limited so our goal is to optimise the time you set aside to see Dr. Rowell and the team.

Mona has written some tips on how to make the most of your time at clinic and has outlined some useful strategies to use before, during and after the session, to get value for your effort. Olivia and Beryl have outlined the value of being able to accurately provide feedback about your health and your response to treatment products and Mick reminds us of the importance of regular assessment of joints and mobility.

Clinics are generally organised every six or twelve months depending on individual situations. If you have significant issues or upcoming surgery etc... it may be more useful to attend more frequently. Sometimes attending one clinic session can sort issues which can't easily be dealt with by phone. Feel free to give us a call if you think that you are overdue to be seen or if you have issues which need to be addressed at a clinic visit. It might also be possible to see a team member before clinic if it's difficult for you to get in at other times. Give us a call and we will do our best to make the situation work for you. It's also important to update your contact details if you move.

From time to time there are important updates about treatment products or the management of viral issues so it's important to stay connected with the team by attending clinics whether at the RBWH or at our regular Outreach Clinics around the State. Give me a call if there are particular issues which make it difficult for you to attend clinic so that we can look at how we can deal with the situation and provide the support you need. We hope that the clinics meet your needs and would be happy to hear feedback about what works and what doesn't work for you.

Maureen Spilsbury
Advanced Social Worker
ph 07 3646 8769

Water Works

The pool is an excellent place to exercise. Your body is buoyant in water, it puts less weight on your joints & staying in shape can be safer and less painful. But it's still a real workout, as you move through the water, you encounter resistance and that effort builds muscle, which helps to protect your joints from bleeds.

Water workouts are ideal for everyone. If you're new to aquatic exercise, start slowly, it takes time to adapt to new exercise. Ask your physio what exercises you could do and what to expect. A couple of weeks of muscle soreness, for example, is normal. Push on and you'll be rewarded.

Stationary running can be a beneficial exercise, even if you have ankle, knee or hip problems. Strap on a flotation belt or life vest, and you can run in deep water without touching the bottom of the pool. But before your first dip in the pool, talk to your doctor or physio about any necessary precautions.

Some local pools offer community classes such as:

- **Ai Chi.** A pool-based spin-off of tai chi, ai chi uses slow, controlled movements to build strength, balance and stability.
- **Shallow Water Aerobics.** Performed in water that comes up no higher than your shoulders, shallow water aerobics will boost your strength and flexibility as your heart beats at a faster rate.
- **Deep Water Aerobics.** These no-impact cardio exercises work your core muscles, increasing strength and balance, and improving heart health.

Edited for size from an article by Matt McMillen First published by National Hemophilia Foundation of the USA in HemAware (hemaware.org) May 2014 *http://www.hemaware.org/story/water-world*

Why you should attend Clinic

Physiotherapy perspective

It is important that you attend your regular haemophilia clinic appointment, whether this be in Brisbane, or at one of our regional outreach clinics. Regular physiotherapy assessments are important in order to maintain/ optimise movement and function.

Some of the specific aims of physiotherapy within the haemophilia service are to:

- assess joint and muscle function
- provide input as to how to best maintain optimal muscle and joint range, function and flexibility
- advise as to how to improve muscle strength and coordination
- advise how to manage or reduce pain
- provide opportunity for improvement of general fitness and well being through group or individualised exercise programs
- provide advice regarding sport and recreation
- manage, and teach self-management of chronic pain
- help to prevent the detrimental secondary effects of bleeds
- provide functional retraining post bleed
- assist with issues of weight management

The physiotherapist assesses joint range of motion once every twelve months (when patients attend clinic) and keeps a record of these measurements. These measurements are also recorded on a national database (Australian Bleeding Disorders Registry – or the ABDR), and are very useful in getting a 'big picture' of what is happening with haemophiliacs across the country in general. Joint range of motion measurement is an objective way of monitoring joint health over time. Often I find that a decrease in joint range of motion happens slowly, over time and is not immediately obvious to the patient that it is happening.

I see this often with elbows. A patient may have a few bleeds over a twelve month period, none that they would report as "serious". Though the patient thinks they've recovered back to full function each time, there is actually a slight but progressive reduction in joint range of motion. This is a big reason why regular joint measuring is important. It is also the reason why we say *every* joint bleed needs to be rehabilitated promptly and correctively. The term that is often used is "aggressive physiotherapy". Not that the therapy itself is aggressive, but that the prescribed treatment needs to be attended to aggressively. That is, it must be adhered to diligently and rehabilitation taken seriously until full recovery is achieved. Sometimes the physio themselves have to be a little 'aggressive' to make sure the message is being heard!

It is very important also, that we hear at the centre about *every* bleed. This is sometimes perceived as a threat by patients, to their independence in managing their condition, but is very important for best practice to occur. Each health professional in the team brings much experience and knowledge and is here to support patients in order to maintain optimal health and wellbeing.

Outreach Clinic Dates

Townsville 11th Aug **Cairns 12th Aug** **Gold Coast 5th & 19th September**

Nambour 24th Oct **Toowoomba 7th Nov**

For more information on the adult clinics please call Beryl on 3646-7752 or 3646-7751.

The dates for the children's clinic on the Gold Coast is yet to be set but will probably still be September. All other visits are the same as above. Please call Joanna on 3636-9030 for more information.

In Brisbane the children's clinic move to the new Lady Cilento Children's Hospital on the 24th November.
See article on page 11 for more information on tne new Children's Hospital.

How to get the most out of clinic reviews

Psychologist's perspective

Queensland Haemophilia Centre clinic reviews are led by the medical consultant and supported by a multi-disciplinary team consisting of the haemophilia nurse, physiotherapist and social worker/ psychologist. Each team member is trained in their own specialised field and hence, looks at your condition from a different perspective. The ultimate aim of the multi-disciplinary team is to provide comprehensive care to you and your family, so that you can achieve the highest possible quality of life.

You may not realise it, but you are actually the most important person in the clinic reviews. The team can only work with the information that you provide to them. Preparation for the appointment is therefore crucial in order to improve care outcomes. Each clinic review can last up to 30minutes and presents an excellent opportunity for you to clarify your issues and concerns.

Here are some general tips to help you better prepare for your clinic reviews.

Before the visit

- Write down a list of 2-3 questions to ask the team. If you have a number of questions, prioritise them ahead of time to make sure that you have time for the most important ones.
- Be ready to update the team about any changes in your GP/ medical status/ living circumstances etc.
- Also be ready to update the team on any upcoming travels, operations/ surgeries/ pregnancies, relocation as this would require letters and forward planning by the team.
- Bring a current record of every drug/ vitamin and herbal supplement that you are consuming. Include information about dosage and frequency of use.
- Treatment diary (if you are not already using MyABDR).
- If you had a recent bleed, information about the onset, treatment regime, pain levels, outcome etc.
- Dress sensibly if you intend to have your body part examined (e.g. shorts for knee or hip, singlet or top with few buttons for shoulder or elbow problems).

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Monitoring home therapy & bleed management

A Nurse's perspective

Your Haemophilia doctor is responsible for reporting back to the National Blood Authority that clotting factors are being used responsibly and are benefitting and improving the lives of those who need them.

Your clinic appointment is the best opportunity to measure this and check that everything is going OK.

With the free availability of factor concentrates and home delivery, many people manage bleeds successfully at home. However your doctor still needs to know that things are being managed appropriately. For example is that ankle bleed you've been treating actually arthritis or do your doses need adjusting.

You are considered part of your haemophilia team. You have a responsibility to report bleeds that do not settle after 2 treatments to the haemophilia team and also to record what treatment you did and whether it was helpful. Without this information, it becomes difficult for the haemophilia treatment centre to compete for limited health budget dollars from the state and federal governments.

For those people who have regular treatment several times a week in order to prevent bleeds from occurring (also called prophylaxis), you need to report back even if you have very few bleeds. *Recording your regular treatments even if you have no or few bleeds* provides the best evidence that your treatment is working and that it must continue.

The Haemophilia community in Australia has worked hard over time to establish its haemophilia treatment centres. Again this continued support of the treatment centre relies on people actually using it by attending their regular appointments.

When coming to clinic , it can be hard to recall all your bleeds and treatment if they were not recorded at the time they happened. Many people are very used to treating bleeds and know what works for them. However it can be very useful to share this information as there may still be

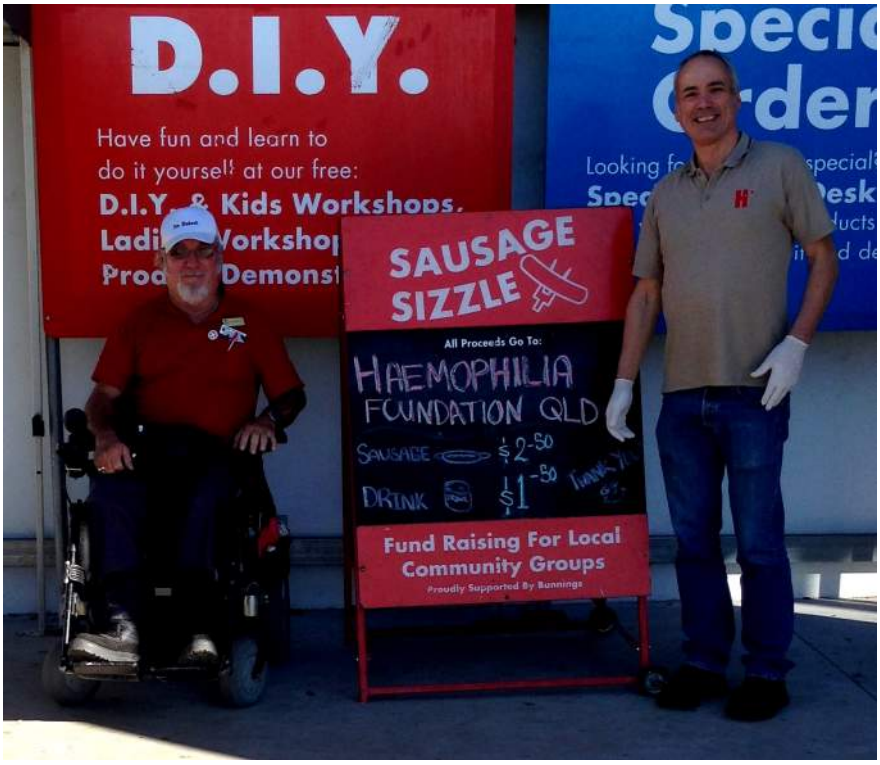
Continued on page 18

Funding the Foundation

Many of you will know that we are at the end of our Queensland Health contract that funds the part time manager position and much of the program work we do such as OBEs and support for members with HIV or hepC. We submitted an application for renewed funding at the beginning of June and we expect to learn the outcome in mid September.

Almost all our other work such as the community and youth camps, welfare assistance, etc., relies solely on other funds, most of which we raise ourselves. That is you, the reader raises it for us, your foundation. It is done through your membership fees, Red Cake sales during Haemophilia Awareness Week (12-18 Oct 2104), BBQ's and our collection jars that members have asked local cafe's and businesses if they would have one on their public counter. As an example of success we recently had a BBQ at Bunnings Rothwell and raised over $500.00, my thanks go out to the members who volunteered to staff the stall on the day and a reminder. We have another BBQ booked for September, so please let me know if you can help with that event.

Last 'Red Cake' haemophilia awareness day we raised over $300.00 from a stall in Mackay last year and Haemophilia Awareness day is in October each year so let me know if you'd like to do something in your local community and I can get resources to you. The collection jars we have are capable of holding over $100.00 in coins. Some members have been very successful in getting them installed in cafés so if you'd like me to send one to you or the name of a business you have permission to send it to, please let me know and I'll organise to have it sent out. We do ask that you take responsibility for checking on it and it's level of fullness, but I can organise it delivery, banking and replacement when full.



Robbie and Graham take a break from cooking snags

We have been lucky in other years to get assistance from other grants such as the Queensland Gambling Benefit Fund which has been generous in it support of our community camps. If you know of other funds or grant program's we can apply for please let the board or myself know. Is is vitally important as there is no guarantee that we will be successful in getting Queensland Health funding this time round. The application we made is restricted to blood borne viruses and STI's which came into our community in the 80's through untreated factor. This is not longer the case and our affected membership is reducing as newer treatments and members arrive. However our needs don't diminish. Many new families experiences a bleeding disorder as a shock and we want to support them in coming to terms with their condition and help them get the supports they need.

This is why we ask for people to officially join the Foundation. It proves our membership base and is evidence of affected families in Queensland. It is why we like to hear about your experiences and needs so we can better advocate for changes or improvements that will help you get the most out of life, so please consider writing something for this magazine or letting a board member or myself know if you have (or know of) needs that we can help resolve or if you know of someone willing to support us financially.

Graham

Ph (07) 3338 5604

JJ's Factor Story

Full story is at: http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/jj.html

Hello! My name is Gerald, but my friends call me J.J. I'm wrote this when I was a nine-year-old boy...Now I'm 13, and I may just write some more when I get around to it. OK, here goes. I have lots of energy. My mom says that I'm funny and fun to be around and she thinks that I have a big heart. My favourite sports are AFL and swimming, but I also like dirt bikes, video games, baseball cards and computers. I'd like to have a horse to ride when I'm older. Pizza is my very favourite food. I guess that's about it for my favourites right now.

I don't tell a lot of people about my 'hidden' medical problem which is haemophilia. I was born with it and it's a problem that will stay with me forever. That is, untill they find a cure, and I am sure that they will someday! Most of the time nobody can see it, but sometimes I get very big bruises because of it, and often when that happens, I can't walk right or move properly. I don't have as many "bleeds" as some kids with haemophilia, because I do have a little of what I need to stop the bleeding...just not enough. The small bleeds I can handle, but those big ones...and those nasty twists to my ankle or knee, they really get me!

Since I was young I've been in and out of hospital lots of times. That's because for a long time, my mom couldn't give me my special clotting medicine. Now that she learned how, we can do it at home so we don't have to go to the hospital nearly as often...just when the bleed is too big for my mom to handle. This is especially good since whenever I was away from school, I would feel sort of left out and out of place when I returned, even though my classmates never teased me about my bruises.

When I was younger, I used to give everyone a really hard time because I was scared, afraid that the IV would hurt. My mom always stayed calm, though, and she would tell me "It's gonna be all right". Now That I am older, I am much braver when I need to get the medicine and it seems a lot easier for me now.

I have lots of friends in school. My best friends are Tony, Daniel and Josh. We all like to play tag. I don't talk to them about the haemophilia since I just know what I can and can't do to keep from getting hurt. My teachers and the nurse at school know about it,

Continued on next page →

Health Word Search

How many of these words can you find hidden in the jumbled letters?

ALLERGY
BACTERIA
BLOOD
BODY
COLD
DISEASE
DOCTOR
EXERCISE
FOOD
HEART
HOSPITAL
HYGIENE
LUNGS
MEDICINE
NURSE
OXYGEN
STRESS
SYMPTOMS
VIRUS
WATER

V	S	F	S	J	A	E	G	S	V	H	S	E	E	Y	L	A	Q
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R	U	Y	I	M	G	G	P	G	O	O	D	D	N	Y	A	Z	X
H	O	S	P	I	T	A	L	R	L	P	A	N	C	R	B	Y	O
K	Q	T	N	Q	U	E	D	D	Q	Y	T	N	H	P	D	O	S





JJ's Factor Story

Continued from previous page

though, because the nurse from the clinic came to school and explained what they needed to do whenever I have a problem.

If I have a bump or feel a bleed coming on I tell the school and the first thing they do is put ice on whatever gets injured. Then they call my mom for further instructions. If I have to have my medicine, my mom comes as fast as she can. It's all worked out fine so far. Except one time a boy chased me with a pair of scissors because he wanted to see me bleed. I made it safely to the teacher, and he got in big trouble for that one. The other kids who know about my disorder are very nice and try to be careful with me. I have been incredibly lucky so far. When they play something that I can't do, they often change what they're doing so that I won't be left out. Isn't that great?

Since I have so many problems when I get injured, I've learned a lot about staying safe. For instance, it is so important to wear your helmet, knee and elbow pads when you're riding a bike or skating on roller blades. I wear my safety gear all the time because I know that they can save my life.

Thank you for taking the time to read my story.

WFH World Congress (Melbourne)

Part 1 - Sessions on Ageing & Pain

On 11 May I was one of over 4300 people who descended on Melbourne for the WFH 2014 World Congress. HFQ had a delegation of people from the Queensland bleeding disorder community attending there alongside hematologists, nurses, physiotherapists, psychologists and social workers from all over the world. The congress had more sessions than anyone could hope to attend and this is a snap-shot of some sessions I attended.

Ageing

People with bleeding disorders are now living long enough to experience the same range of age related conditions experienced by the rest of the population. Our challenge is to find ways to improve quality of life as they live longer. The Haemophilia Centre doesn't have the resources or expertise to be a one-stop-shop for someone's health needs so people with bleeding disorders have to negotiate a wide range of healthcare services.

At the session on ageing speakers offered practical suggestions such as planning early for ageing and staying active through regular exercise. The light bulb moment for me was the **realisation** that the secret of maintaining mobility is to stay mobile – for many people with bleeding conditions that can be painful and chronic pain was named as a major challenge. Several speakers said that with aging it means you live with it longer, it can be hard to ask for help even when it's available because many people have fought their whole lives for their own independence, but accepting home assessment and modifications can be useful. Also check your medications are needed and considering newer ones when available are all sensible ageing strategies as is following a nutritious diet.

Self injection of factor and vein care was also a concern in this session as many people worry about what will happen if they can't treat themselves anymore. 60-65 years of prophylaxis means you may have had 7,500 injections! This make it even more important to keep rotating injection sites to avoid developing hardened veins.

Pain

When body tissue is in danger and action is required, the brain feels pain. The brain uses lots of areas to register pain which is why memories and smells can also trigger it. Pain can cause loss of mobility and poor sleep. 35% of people with Haemophilia in a recent European survey suffered chronic pain.

Chronic pain is not well suited to the "find and fix" approach used in most primary health settings because of its complex causes. The area of the body that feels pain is actually sending danger signals; it's the brain that interprets this as pain. This is why your mental and physical state can influence your experience of pain and why levels of pains are subjective.

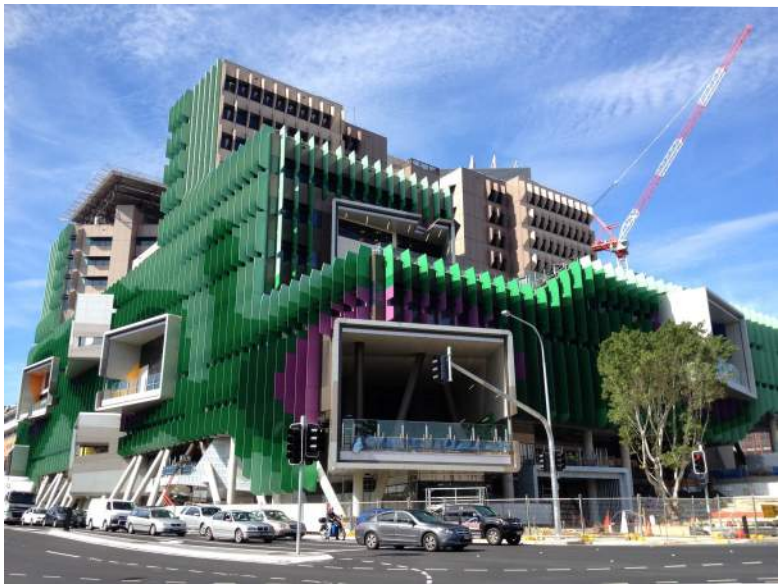
Traditionally, opoid drugs have formed the backbone of treatment for chronic pain. However, many patients worry about toxicity and becoming dependent.

At the session I attended we were told there is a lack of research on the treatment of chronic pain in people with bleeding disorders. However, good pain management should start with a pain assessment and often involves keeping a pain diary so a wide range of factors can be reviewed and responded to. They also made the point that people with bleeding disorders can find it difficult to distinguish between a reoccurring bleed and pain from existing joint damage and should always talk to their centre if they are in doubt.

Physiotherapy also plays an important role in effective chronic pain reduction. Improving movement and posture can have a positive impact on pain. One speaker recommended sports tape as a useful way of tackling pain in people with Haemophilia. Another speaker talked about the role of techniques such as positive thinking and other psychosocial interventions. She also mentioned self hypnosis and stressed the importance of taking medications as scheduled, not just when you're

Lady Cilento Children's Hospital

The new Lady Cilento Children's Hospital will open at the end of the year. It is located next to the existing Mater Children's Hospital in South Brisbane. The construction cost $1.2 billion and the main building has 11 levels of hospital and an additional four levels of underground carpark. You will also be able to access to existing multi -level car parks and it is close to all public transport (bus, train, ferry) and the South Bank Parklands



All specialist services currently provided by the Royal Children's including the Qld Haemophilia Children's Clinic will be available at the hospital, plus there will be new clinics to treat obesity, pain and allergies; a specialised adolescent service; and paediatric renal treatment.

The hospital design is based on the concept of a 'living tree' with a network of trunks and branches leading to several outdoor gardens & terraces that connect the inside with the outside.

It's named after Lady Phyllis Cilento (affectionately known as 'Lady C'). She was born in Sydney in 1894 and studied medicine at the University of Adelaide. She worked in nutrition and paediatrics in Townsville and New Guinea before settling in Brisbane in 1928 where she worked at what was to become the Royal Children's Hospital and in private practise until she retired in the early 1980s.

She was an early advocate of natural childbirth, family planning and having fathers present at the birth of their children, Lady C's ideas were unorthodox to some doctors but many people saw her as a woman, mother and clinician ahead of her time.

The hospital's patient and family-centred care features include:

- provision for a parent/carer to sleep at the child's bedside.
- long-day lounge for families who have multiple appointments and retreatments.
- outdoor pet visiting area enabling patients to see their pets.
- family resource centre with internet access for families to access health information, stay in touch with family and friends or simply rest and relax.
- special overnight rooms for parents/carers who accompany their child or young person to hospital on short notice, such as during a retrieval or emergency.

Phenomenal August

Believe it or not; this is the only time you see this phenomenon in your life.

August, this year, will have 5 Fridays, 5 Saturdays and 5 Sundays.

This happens only once every 823 years.
The Chinese call it "Silver pockets full."

August 2014

Sun	Mon	Tues	Wed	Thur	Fri	Sat
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3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

NATIONAL BLOOD AUTHORITY AUSTRALIA

What the outcome of the NBA tender for recombinant Factor VIII and IX means for patients.

The National Blood Authority (NBA), on behalf of Australian governments, has successfully concluded the tender process for the supply of recombinant Factor VIII (rVIII) and IX (rFIX) products, to replace the contracts for these products which expire on 30 June 2014.

These products are critical for the treatment of Australian patients with bleeding disorders, such as haemophilia. Australia imports these products as they are not made in Australia.

The outcome of the tender gives Australian patients funded access to products equivalent to that available in other parts of the world at a very competitive price and has been highly successful at ensuring a secure supply of essential products for haemophilia patients. The effect on the implementation of these arrangements is expected to provide savings in the order of $50 million per year for product costs, while continuing to ensure a safe and secure supply of these important medicines in Australia.

As a result of the tender process, there will be a change in brand for rFVIII and for the first time there is a new market entrant for rFIX ensuring supply security and clinical choice.

The details of the new supply arrangements for these products compared to the previous arrangement are within the table below.

Imported Product	**New Arrangements** ***Trade Name (Supplier)***	**Previous Arrangements** ***Trade Name (Supplier)***
rFVIII	***National preferred rFVIII product*** ADVATE (Baxter)	
	Xyntha (Pfizer)	Xyntha (Pfizer)
	Kogenate FS* (Bayer) *Not available after a transition period*	Kogenate FS (Bayer)
rFIX	BeneFIX (Pfizer)	BeneFIX (Pfizer)
	RIXUBIS** (Baxter)	

* For patients on active immune tolerance therapy using Kogenate FS as at the time of the tender announcement, exceptional arrangements will be available for continuation of this product for a longer period where this is clinically necessary.

**At the time of implementation of the new arrangements from 1 July 2014, the registered indications for RIXUBIS will include routine prophylaxis, treatment and prevention of bleeding episodes, and perioperative management in adults (18 years and older) in haemophilia B, but will not include registered indications for paediatric patients

Please see the insert; "What does the tender outcome mean for me as a person with Haemophilia A?" for the answers to Frequently Asked Questions from the NBA

Listen up to your health *...but not too much!*

We all worry about our health from time to time, at least to some degree. While we know about our existing conditions like bleeding disorders, some people worry excessively about catastrophic consequences of other seemingly benign symptoms. At its extreme they are called hypochondriacs.

Many of our members already have thoughts, fears and images of a foreshortened future, orphaned children, and opportunities missed; and our future and physical health are inherently uncertain. But hypochondriacs (technically, somatic symptom disorder) immediately assume new or strange physical sensations and symptoms to be catastrophic.

The body is constantly in a state of flux. The heart pumps, blood flows, muscles twitch, lungs inflate, and bowels contract. Strange symptoms come and go. And most pass without conscious awareness as we focus on daily tasks.

Here's a simple task. As you read this, shift your attention to the sensations of the ground or chair pushing up against your body. Chances are you were unaware of all these sensations just moments ago. Attention of the mind can filter in or out internal or external experiences.

The number one enemy of the hypochondriac is Dr Google ("cyberchondria"). They are not searching for information, but for confirmation of their imminent demise and have some self-fulfilling beliefs and worries.

Belief: worrying will help me catch something early.

No, it won't. Worrying will just keep you miserable. Worry itself will not get you any closer to predicting, preventing, or planning for death.

Belief: I can get certainty about my health.

Nope, can't get that either. No amount of checking, doctor visits or Googling, will guarantee that you are well. But the pursuit of certainty can make you miserable.

If you find yourself worrying over or watching for health symptoms, you can your manage health anxiety by developing some healthy guidelines for monitoring your health.

Write down what happened so you can faithfully recall the symptoms and experience to yourself and your doctor next time you see them. Based on your past experience and your written evidence, how long do benign symptoms usually last?

Decide how long you will wait

Continued on Page 19

How to get the most out of clinic reviews

Continued from page 6

- Avoid missing the appointment by planning in advance your schedule. If you really cannot make it, get it rescheduled as soon as possible.

At the actual visit

- Be early or at least on time.
- Remember to bring along any lists or items you have compiled for the visit.
- Be concise in explaining your condition. Answer questions directly and to the point. The team will ask more questions if needed.
- Be honest about your condition. The team is here to help, not to judge.
- Listen and ask questions if you don't understand what is being discussed
- Repeat crucial information back to the team in your own words to make sure you understand it. That ensures information has been communicated effectively
- Speak up for yourself. If you disagree with something, it is ok to point it out and seek clarification.
- Ask for help. If you have a specific concern for a particular team member to address, just say "I need help from XXX".
- Bring someone with you if you need support.
- Bring a note-pad to write things down.

After the visit

- Implement the recommended changes by the team.
- Contact the relevant team member if you have problems with the recommendations.
- Keep in contact with the team if something happens between visits.

Remember that communication is key in ensuring your needs are accurately and promptly addressed.

Dr Mona Chong
Advanced Psychologist – RBWH
Ph 07 3646 8769 (Fridays)

Drug & Alcohol Information for Young People with Bleeding Disorders

As you get older your social life often gets bigger and doesn't always have mum, dad or other family members involved. With this increased social life comes the potential for exposure to activities, such as drinking alcohol and other drug use. Most people use some kind of legal drugs – alcohol, prescribed medications and caffeine are part of everyday life for many of us.

You have to be 18 to legally use alcohol and tobacco in Queensland. The use of recreational drugs, such as marijuana, 'ice', etc., is illegal and can result in serious legal consequences. Using Illegal (illicit) drugs is a part of life for some of the people you may meet as you socialise, so it is important that children and teens know about the impact and possible dangers of alcohol and drugs as much as adults.

There are also additional risks from drinking and drug use to individuals with a bleeding disorder. Did you know that being out of it can make infusions more difficult to perform?

And ***remember that it's always OK to say no!*** Most teenagers don't drink, over half of teenagers (65%) have never had a full serve of alcohol and only 5% drink on a weekly basis. Most teenagers don't use drugs. Over 80% of teenagers have never used an illicit substance.

Drugs, Alcohol & Bleeding Disorders.
Alcohol and other drugs affect the body in a variety of ways. Drug and alcohol use is dangerous for all children and teenagers, but can often be more so for children and teens with bleeding disorders.

Here are some of the negative consequences of drug and alcohol use for someone with a bleeding disorder:

- Drugs and alcohol can impair judgment and coordination, blur your vision, and slow reaction time. If you take drugs or drink alcohol and get hurt, you may have difficulty seeking medical attention or may not be able to explain your condition to others or to medical personnel. If emergency room staff don't know about your bleeding problem, they won't know how to properly care for you.
- When someone is less coordinated and has slow reflexes, it's harder to self-infuse. In addition alcohol is a *diuretic*, which means it causes the body to lose water. This can lead to *dehydration*, making it more difficult to see and find a vein to self-infuse.
- Alcohol acts as a blood thinner in a similar affect to aspirin, even moderate amounts of it can affect blood clotting.

What everyone should know about drug and alcohol use:

- Using excessive amounts of drugs and alcohol can put you in danger. This can include injury, either from loss of balance or consciousness.
- Being drunk or high can weaken inhibitions and judgment and can lead to risky behaviour, like fighting and dangerous stunts.
- Drinking and driving is a crime and is very dangerous, it could lead to you ending up in a car accident, which can greatly increase your risk of injury and severe bleeding.

Many interactions between drugs, including prescribed medications are unknown and can be harmful and even life threatening. However we do know that;

- Alcohol is a depressant drug and can intensify feelings of depression or suicide.
- Excessive use of alcohol can damage the liver. If a person has a virus, such as hepatitis C and is taking antiretroviral drugs, drinking alcohol increases the risk of severe liver damage.
- Many drugs and alcohol can be addictive. Kicking any habit is hard, but adding addiction to that habit makes quitting very difficult. If you find yourself addicted to drugs or alcohol and want to stop, there are programs available to help.
- Taking some drugs (including tobacco and alcohol) by swallowing them can irritate the stomach lining and cause cancer and other health problems.

Paraphrased and edited by Graham from an article supplied by the Drug & Alcohol Coordination Unit of the Queensland Police Service

WFH World Congress (Melbourne)

Part 2 - Dave Reports on Cardiac Risk Factors & Vein Health

CARDIAC RISK FACTORS

People with haemophilia (PWH) are now living longer approaching that of the general population but there is little current evidence based data for doctors to use when confronted with cardiac issues. This will come in time with international experience.

Heart disease is a number one killer, there is some thinking that PWH appear to have a slightly lower risk compared to the general population but there is controversy about this with some older studies indicating the opposite - we have to wait for large population studies of older people with bleeding disorders.

Prevention:

STOP SMOKING - quit today and live.

PREVENT OBESITY - check your BMI

BLOOD PRESSURE - check and manage

CHOLESTEROL - check and manage

PHYSICAL ACTIVITY - work with your physiotherapist even small effort works

There are further issues where doctors are wondering what influence longer acting products might have with higher levels of factor in the blood for longer - could this counter to some degree the possible protective benefits of having a bleeding condition and change cardiac risk factors, again time will tell but there is general suspicion that this may be the case. What does appear to be in general agreement are the risk factors for PWH, which are thought to be the same as the general population:

- HIGH BLOOD PRESSURE - mixed reports indicate this might be higher in PWH - get a check up!
- HIGH CHOLESTEROL - get yours checked!
- DIABETES & AGEING - get a check up.

I was encouraged to see active thinking and investigations from outstanding specialists and although it will take time, this will lead to better understanding with more evidence based protocols to manage cardiac issues in PWH - as opposed tothe largely opinion based approach of today.

Presenters suggested GP & Treatment Centre proactively work together with you to manage not just cardiac but other comorbidities ... most GP's don't know how to handle these issues in PWH

VEIN HEALTH

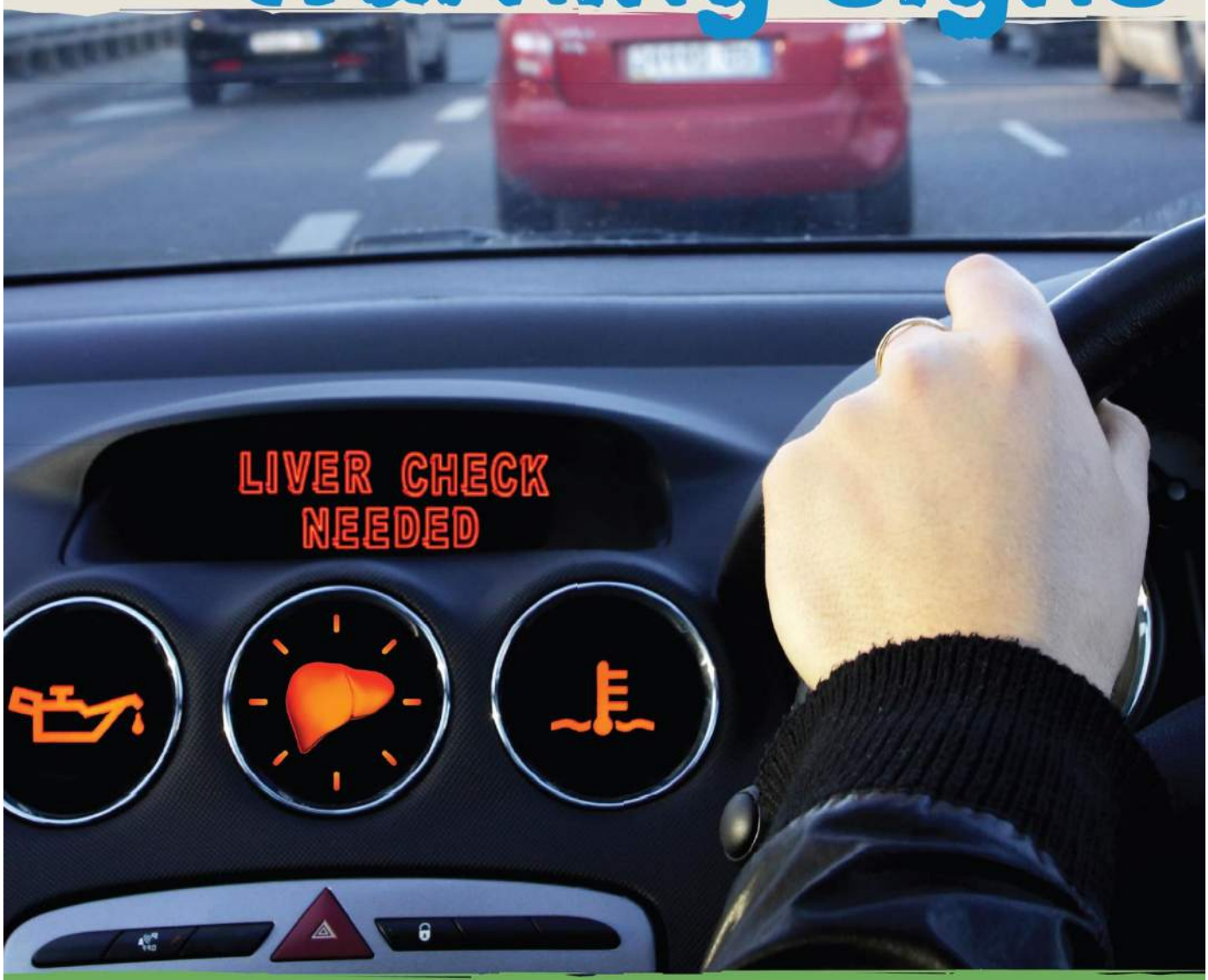
People with haemophilia (PWH) are actually listed as one risk factor for venous access in a condition called DVA - difficult venous access. I imagine we can all relate to times when locating a vein can be frustrating and stressful. The presentation I attended was more for nurses but information was useful. Vein access and the associated issues were discussed. The best veins are often not visible or easily felt but remember each poke is a learning experience and you get better at it. Patient and practitioner accessing veins can be challenging when you have issues of age (young and old), dark skin, pain, scar tissue, obesity and even a phobia or anxiety.

Key messages were:

- Use the smallest needle size possible for the situation.
- Grip and release hands with tourniquet on.
- Warm pacs can help dilate veins and make them more visible.
- Gentle slapping of the vein can help.
- Choose a vein that is easily compressible.
- Don't tell a child it won't hurt.'
- Stress the need for hydration beforehand as this increases volume.
- A level of exercise can assist in showing up veins.
- Numbing cream can assist but takes time.
- An alternative to tourniquet is a blood pressure cuff or even a clip on 'bower constrictor' that you then roll down the arm but caution is required for elderly as this can pop veins with the extra pressure.
- With babies you can use a torch to shine through the skin to show up veins.
- Ports and Pic lines are options but there are risks of infection to consider.
- A practical approach that body builders use is to make a fist or grip or compress a spring to build muscle and in the process veins are significantly improved - talk to your Physio.

If you have any questions issues or concerns talk to your Haemophilia Treatment Centre.

Don't wait for warning signs



If you're living with HEPATITIS B or C (or think you may be), talk to your doctor about a regular LIVER CHECK-UP. It's easy and it could save your life.

WORLD HEPATITIS DAY

hepatitis australia

National Infoline: 1300 437 222

www.facebook.com/loveyourliver.com.au

www.twitter.com/love_your_liver

LOVE YOUR LIVER

www.loveyourliver.com.au

High Hopes for Ending Hepatitis C

People with bleeding disorders and chronic hepatitis C virus (HCV) infection know that the standard weekly interferon injection and daily ribavirin pill can be gruelling. Throughout the typical 48-week regimen, some patients experience many side effects, including feeling like they have the flu. For enduring all that, only 50% clear the virus.

Newer drugs with less side effects that are taken for shorter periods are welcome news. Several such medications are now in later-phase clinical trials or awaiting approval by the TGA. The goal of future HCV therapy will be to find the right combination of medications, ideally in one pill, without interferon which seems to be the main drug that causes those troublesome side effects.

These new treatments are being lauded for their high cure rates (80% to 100%) and their effectiveness in difficult-to-treat patients. They are direct-acting antivirals that disrupt HCV replication process and may not need interferon to work. Depending on a patient's genotype and previous experience with HCV medications, they can be used with ribavirin only and the course of therapy can be as short as one-quarter to half the time required for the previous interferon based regimens. They are not side effect free but they seem to be more effective, take sorter to work and have decidedly less side effects so please talk to your doctor if you have hepC and would like to take action to cure it.

Written by Sarah Aldridge and originally published by National Hemophilia Foundation of the USA in *HemAware* (hemaware.org) May 2014 http://www.hemaware.org/story/hope-hepatitis-c

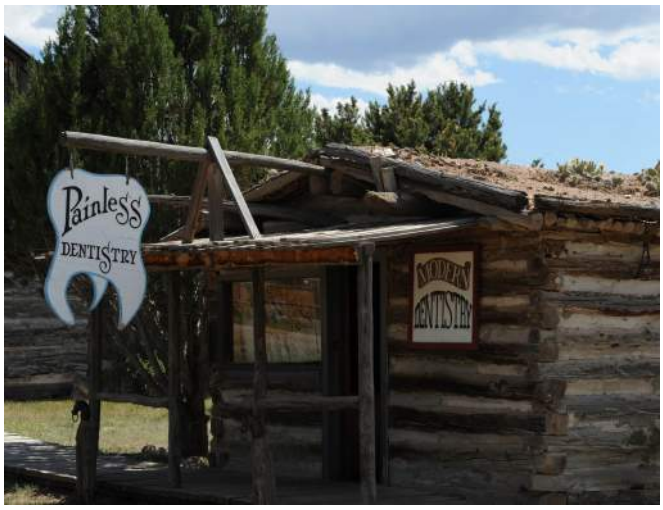
Home Sweet Dental Home

Making dental care part of your family's daily routine takes only a few minutes. Add a couple of annual dentist visits to your brushing and flossing regimen, and your preventive care can pay off in the long haul. Unfortunately, cost and insurance woes can make it tempting to skip those twice-a-year dental check-ups.

Haemophilia and other bleeding disorders don't make you more prone to dental problems. However, avoiding proper preventive care of your teeth and gums can lead to more complicated and costly procedures in the future. Children and adults with haemophilia and other bleeding disorders need an prevention oriented program to maintain good oral health and minimise the risk of complications if dental problems do arise.

For some dental procedures, such as tooth extractions it can be good to start with a consultation with the QHC staff and your dentist, to determine what precautions need to be taken before the procedure.

You also need to do your bit. There is no point relying on the dentist. A preventive dental program should include daily teeth cleaning with a toothbrush and toothpaste, flossing, a proper diet and regular dental examinations.



Most children & adults with bleeding disorders can and should floss so talk to your clinic staff if you've been avoiding it for fear of bleeding gums. If people are not flossing regularly, their gums are more likely to bleed when they start because of bacteria build up between your teeth and gums, leading to irritation, inflammation and bleeding.

As the bacteria are removed on a daily basis, the gum tissue will get healthier and the bleeding will lessen. Your gums may always bleed a little easier than someone without a bleeding disorder, but the goal is to keep the gums as healthy as possible.

For most children with a bleeding disorder, the loss of baby teeth, is not a problem. Teeth should be allowed to fall out naturally to minimise bleeding. Bleeding can usually be controlled with direct finger-and-gauze pressure maintained for several minutes.

Parents should wash their hands, then wrap a small piece of sterile gauze around their index finger and apply pressure to the area that is bleeding.

Continued on next page →

Dental Health

Continued from previous page

A moist, black tea bag can also help because the tannic acid in dark tea helps form blood clots. Place a wet, black tea bag over the area and apply pressure or have the child bite down gently on the tea bag.

If bleeding is persistent, contact the haemophilia centre staff. Severe bleeding & hospitalisation is not common when baby's teeth fall out but it can happen and as you age if severe bleeding occurs, the dentist might recommend a serial extraction next time, such as taking out all four molars when they are loose.

Whether you will need extra factor for a dental procedure will be determined by your haematologist. They will base it on the severity of your disease, your history and the procedure itself, such as an extraction vs. a deep scaling. Deep scaling is a thorough cleaning to stop gum disease from progressing. It is usually performed after the bacteria and inflammation from untreated gingivitis have worked their way down to the foundations of the tooth.

People with inhibitors may require treatment in a hospital setting. People with rare bleeding disorders and von Willerbrands disease should also consult with the QHC and their dentist to discuss their specific needs before any procedure.

Establishing and maintaining a connection with a local dentist provides peace of mind, after all, you can't predict when you're going to need dental intervention. When you do, it's comforting to have a dentist who knows you and understands your needs.

Edited for size from an article by Elizabeth Thompson Beckley and Melanie Padgett Powers Originally published by National Hemophilia Foundation of the USA in HemAware (hemaware.org) July 2008 http://www.hemaware.org/story/home-sweet-dental-home

Vale Lynton Borland (1944 – 2014)

Lynton Borland (1944 – 2014) was a larger than life character who was a member of the haemophilia community. Lynton came from NSW and more recently lived in Toowoomba. He participated in a number of HFQ functions over recent years. He was a magician, puppeteer, jack of all trades and a real "wag".

Lynton was always up for a laugh and had an exhaustive array of jokes even when he was quite unwell. He always had a number of tricks "up his sleeve" and he never left a clinic session without sharing a joke or a magic trick with Qld Haemophilia Centre and RBWH staff. Lynton was a great storyteller who loved to reminisce about his adventures and he had a story for every occasion even when his health was fading.

…Lynton will be sadly missed by HFQ and the staff at the QHC.

Monitoring home therapy & bleed management

Continued from page 6

a technique or tip that can add to what you already know. Also if you tell your team something that helped you, we often use that idea to help others facing similar difficulties. Keeping good records of bleeds and treatments can also highlight the benefits of early treatment of bleeds. Over time it becomes more evident that bleeds treated early generally require less factor.

Olivia Hollingdrake – Clinical Nurse – RBWH ph 07 3646 5727

My ABDR…..

Are you sick of keeping paper diaries?

Have you heard about the "my ABDR" app?

If you want to learn more watch "John" on this YouTube video. Search for "My ABDR" on YouTube or follow this link; *http://www.youtube.com/watch?v=biE-Yy-7fOU&feature=player_detailpage&list=PLwTV8F9r7Dy5UW4Z3nsM0WpxJb0ukJXwC*

Next step download the app to your phone, via I-tunes or google play. Another other option is via the internet. If you need help contact the Haemophilia Centre

It will take a working day or 2 for the haemophilia centre to activate your account. You will receive an email once it is activated

Beryl Zeissink – Clinical Nurse Consultant – RBWH ph 07 3646 5727

Also see back page

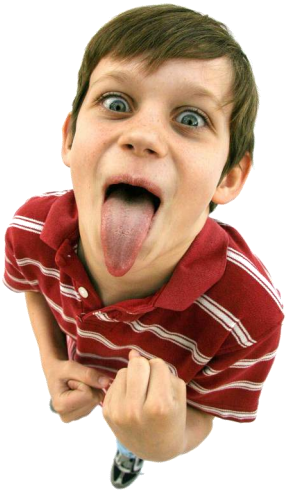
WFH World Congress (Melbourne)

Part 3 - Patient provider perspectives

In the Session we heard from a patient, a healthcare professional, and the audience on 3 subjects.

Adherence to regimes

There was a strong feeling that although patients are ultimately responsible for how they treat, there are a lot of things that can make things more difficult. Sometimes people simply don't want to be reminded about their condition. Many young people feel bullet proof & take risks. People have busy lives which makes taking treatment on time difficult. The memory of painful and distressing injection experiences when you were young can make things harder as an adult. Even though everyone accepts treatment is a patient's choice it can be hard for healthcare professionals not to take lack of adherence personally.



Counselling

Some people see counselling as a sign of weakness. However, bleeding disorders in a family can lead to feelings of guilt, blame and resentment and many people feel better about an issue if they talk about it. For most issues in life we talk to our friends and don't think of getting a professional involved. However, formal counselling has several advantages.

You can talk to people who aren't so close to you that they are personally affected.

It gives you the time and space to think about issues.

There is no judgment in a professional counselling environment.

Talking to other people who have similar experiences can also be an important 1st step in the counselling process. Trained Patient Educators can help puncture the myths that can develop in some peer support groups.

Sexuality and Risk Reduction

Discussing issues around sex can be difficult for everyone involved. Some parents look to the centre staff to raise these issues and vice versa. In reality everyone shares the responsibility. If a young person raises the issue it is likely they have thought carefully about who they are comfortable talking to and that choice should be respected not refused.

Young people can be sexually active younger than either their parents or their centre team realise. Therefore, if problems are to be avoided it important to discuss these issues early. The language young people use when talking about sex, and what they mean by it, changes fast; it's important to make sure you aren't talking at cross purposes.

A good rule of thumb for questions about bleeding disorders and sex is "if you have blood there you can bleed there."

Listen up to your health

Continued from page 13

before seeking reassurance (from the internet, friends, family, or medical practitioners) the next time you notice a symptom, especially ones you've worried about in the past.

Once your time limit expires then make a decision about whether you need to get the symptom checked or whether you can wait a little while longer.

Be willing to sit with uncertainty about your health. None of us ever have certainty about our health. Chasing possible ill-health when you are already managing a known issue like a bleeding disorder takes time away for living and is a high price to pay for your happiness.

Are you really willing to give up your capacity to work, time you would spend with friends and family? Spend energy on things you truly value, rather than wasting it on false alarms. Learn to accept uncertainty about your health. Revel in not knowing when or how other illnesses might come. Focus instead on the times of good or manageable health.

You can decide which epitaph you would prefer when your inevitable end arrives, let's make it: "I didn't see that coming but I lived my life to the full in spite of it."

For more information about how to manage health anxiety, see the Helping Health Anxiety modules at *http://www.cci.health.wa.gov.au/resources/infopax.cfm?Info_ID=53*

Edited for size from an article by Peter McEvoy. Associate Professor of Clinical Psychology at Curtin University in June 2014 with paraphrasing and additional comments by the editor. The original article can be found at; http://theconversation.com/listen-up-hypochondriacs-how-do-you-want-to-be-remembered-27124

Important Dates for HFQ Members

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

Youth Camp Is over the weekend of 22 – 24 August Scholarships are available if cost is an issue.

Fundraising BBQ Our second fundraiser at Bunnings Rothwell is on 23 September. Volunteers needed!

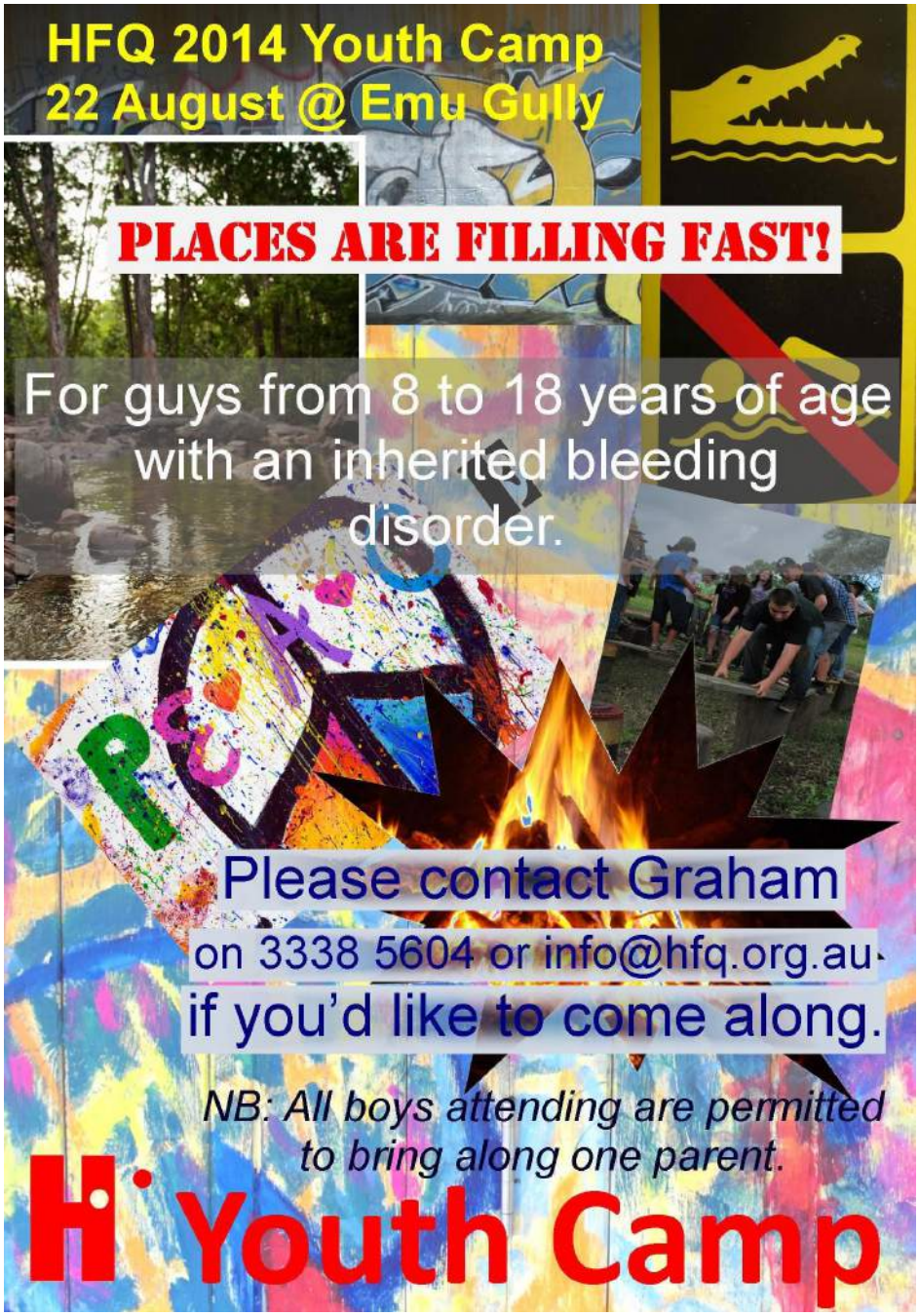
HFQ AGM The AGM and Board elections are in October. Date TBC

Haemophilia Awareness Week 12 – 18 October

End of Year Event This year we are off to Thunderbird Park on 23 November for a Pizza Buffet and laser Skirmish for the more active.

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

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



MyABDR

is now live!

MyABDR is a mobile phone app and website that makes it easy for you to:

- **Record your home treatments and bleed details**
- **Check how much treatment product you have**
- **Update your contact and personal details**

MyABDR links directly with the Australian Bleeding Disorders Registry (ABDR) which is the system used by Queensland Haemophilia Centre staff to manage the treatment of people with bleeding disorders and to gain a better understanding of the incidence and prevalence of bleeding disorders in our state.

When you are in mobile phone range or online with your computer, what you enter into myABDR will upload directly to your record in the ABDR at the Qld Haemophilia Centre. The app also allows you to retrieve information like your treatment plan and record incidents you may want to discuss with your treatment team such as bleeds.

If most people use myABDR we will be able to gather combined information so the NBA can better understand demand for, and to facilitate ordering of, clotting factor product.