

# The 'H' Factor

Issue 33

June 2012

## The Presidents Press

**Inside this issue:**

Presidents Press	1
Haemophilia Awareness Week	5
Kogenate Reconstitution	7
RBH and RCH Social Work News	8
Queensland Positive Speakers Bureau	12
HFQ Wheelathon	15
Latent news from HFQ	18
Youth Camp Notice	20

**Haemophilia Foundation  
Queensland**

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HFQLD](https://www.facebook.com/HFQLD)**

**We are on The Web  
[www.hfq.org.au](http://www.hfq.org.au)**

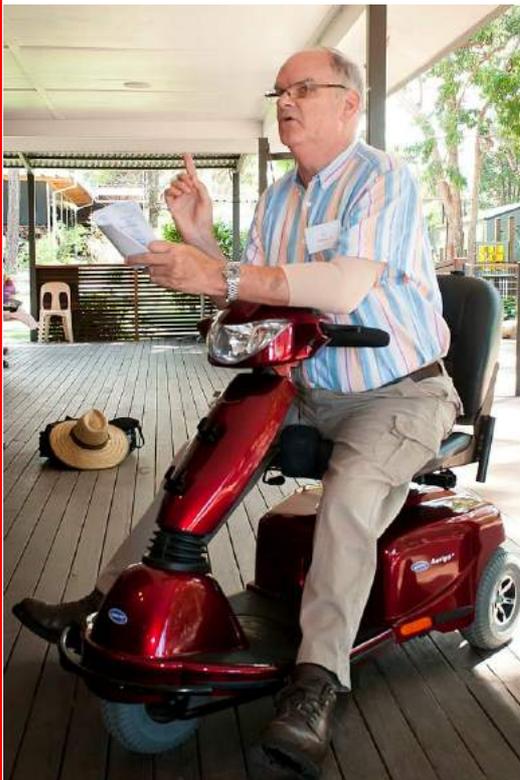
Hi to all where we are already at the end of May, then June and we will be half way through 2012.

In some respects our usual busy schedule in relation to activities generated by Queensland Health has slowed recently. With the lead-up to the State election held at the end of March followed by the appointment of a new Government we then had the appointment of new Ministers and Department personnel.

End of March Election over and we were soon into the Easter weekend and school holidays.

I am a little ahead of myself however, because the weekend following the election was our family / community weekend away and what a lovely venue and weekend away that was.

We had attendance in excess of 90 all arriving to enjoy what was on offer at Noosa Northshore. This venue is situated on probably 10 - 15, maybe even 20 acres (yes I am guessing), with a licenced eating area, coffee shop, breakout areas, with lots of space for the children to run around in including a large bouncing pillow in the



play area. Our accommodation was individual bungalows spread across the acreage - how many acres was that ? which were quite comfortable.

The meals were great with a special dinner presentation on the Saturday evening where we were entertained by a magician and a hoola hoop spinning, fire eating lady. The kids had a go at trying to spin the hoops to. How many hoops at one time did you get up to Craig, I counted at least 10, maybe 15, or was it 20. Have I written this bit before ?

# Presidents Press contd.



Thankyou so much to all who helped put the weekend together, for all who helped during the weekend, to Dr. John Rowell for his attendance and presentation and to all who supported the weekend with your attendance. Liz and I continue our monthly meetings with the Haemophilia Treatment Centre Staff who provide a lot of support to HFQ in the work we do.

The OBE's lunch for May was held at Northshore Riverside Hamilton where we had a guest speaker who kindly gave of her time to discuss with us her own very challenging and rare bleeding disorder. The Women's Group gathered for lunch on the same day at Cruisers at Hamilton Wharf with an attendance of around 12. Good to see that group going so well. This group meets every second month and will next meet on July 4th.

Mid month Liz took a weeks leave and June and I also took a week plus and took a criss-cross journey south on a variety of inland roads. All went well until we arrived at a little place called Dunedoo where we had need to drink the water. Found out later it was bore water - have to tell you it tasted more like boar water and it managed to cause me some problems for a day or two and to curtail our journey South.

Well ! can't complain about the hot weather at the moment - so I guess all we can do is complain about the cold. I can tell you though, it is not as cold here as it is in Armidale at the moment.

We were also entertained over the weekend by dog obedience and police dog training which were extremely entertaining both for the kids and the adults.

And if that was not enough then on the Sunday you could have a great python wrapped around your neck or opt to nurse a croc - this croc was breathing !

Before I go, I must tell you we have had to postpone our charity race day plan which was to be held in October this year at Eagle Farm, we are looking at next year now.

Cheers to all

Erl Roberts President

## New Nurse at the RBWH

Christine has moved to work in haematology research after working with us for about 3 years.

We are very pleased to welcome Jackie Risk to our team. She will be working one Friday a fortnight. Jackie has come from the UK about 7 years ago, and on Australia Day this year she became an Australian citizen. She has a lovely Scottish accent and has worked in haematology for many years.

Regards

RBWH team

## 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 Co-ordinator and is guided by a voluntary Management Committee which meets monthly.

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

**Medic Alert bracelets (50% discount)**

**Electric Shavers (up to \$75 off)**

**Cool Relief patches (special trial offers)**

**Supportive footwear (75% off)**

## DATES TO REMEMBER

August 19th 2012	Cairns Regional Luncheon venue TBC
August 25th and 26th 2012	Youth Camp Emu Gully
September 9th 2012 2pm	HFQ AGM
September 30th 2012	Gold Coast Regional Lunch venue TBC
7-13th October 2010	Haemophilia Awareness Week

## HFQ Management Committee

President	Mr Erl Roberts
Vice President	Mr Howard Mitchell
Secretary	Mr Randal Parker
Treasurer	Mr Peter David
Members	Mr Craig Bardsley Mr Robert Weatherall Mrs June Roberts
HFQ Delegates to HFA	Mrs Leanne Stephenson Mr David Stephenson

## 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
Emma Patterson—Physiotherapist	3646-8135
Maureen Spilsbury—Snr social worker	3646-8769

### ROYAL CHILDRENS HOSPITAL

Dr Simon Brown-Haematologist	3636-9030
Joanna McCosker—Nurse	3636-9030
After Hours—Banksia Ward	3636-7472
Prue Ramsey - Physiotherapist	3636-8506
Mona Chong - Psychologist	3646-7937

## 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  
AND TOWNSVILLE HOSPITALS:**

Book through Joanna at RCH and Beryl at RBWH

# HFA Report

Hello everyone!

As you know the 2012 World Federation Haemophilia (WFH) Congress in Paris is nearly upon us. I am looking forward to attending and hopefully will see some familiar faces there. This is the single largest event where Doctors, Scientist, Healthcare Workers, People with Bleeding Disorders & Haemophilia Foundations from all over the world gather, learn, discuss, debate to contribute to the Global community.

You have the opportunity in 2014 to attend the First World Congress to be held here in Australia. This will be held in Melbourne and all are welcome. The HFA are working hard with the WFH to make sure that this will be an event you will never forget.

World Haemophilia Day activities were held around the country and \$1500 was raised and will be used towards developing world programs. Thanks to everyone who participated.

The new Youth website is currently being designed and developed. Kate Walton, Youth Project Officer is working with the web design company and we hope it will be bright, fun and easy to use. You can imagine there is a lot of work on style, navigation, rules and principles as well as information sections which need to be written as well. Some aspects of the general



HFA website also have to be updated. 'Factored In' will soon be ready for community testing and will be launched in late June.

Haemophilia Awareness Week 2012 and Red Cake Day 7 - 13th October. The theme this year is "Achieving your Dream". Red Cake Day will be incorporated into Haemophilia Awareness Week. HFA will have H logo cupcake transfers made and local foundations will be able to purchase the H so they can use them for their own fundraising efforts during this week.

With the recent product changes we are interested to hear if there are any concerns within the community. Please contact Liz at HFQ to advise but remember that your Haemophilia Treatment Center is your first port of call.

Yours Truly, Leanne and David Stephenson







CHILD & ADOLESCENT SERVICE  
ROYAL CHILDREN'S HOSPITAL

Dear

Re: Kogenate FS Infusions

You are receiving this letter because you have recently changed or are about to change to Kogenate FS™. This is to inform you that the Therapeutic Goods Administration (TGA) has informed Haemophilia Treatment Centres Australia wide of an issue related to the reconstitution of Kogenate FS™.

It is important that the 25gauge butterfly provided with the Kogenate FS™ is used. The filter device is actually in the 25gauge butterfly (that means it is an in-line filter) and not the reconstitution device as with previous products.

No other butterflies you may have used in the past have this filter, so you must use the butterfly provided for filtering to occur.

**ALERT: If you use your old stock of butterflies or use a port then you must inform your Haemophilia Nurse who will organise for you to have separate filters supplied. This can be included with your home delivery.**

It has also come to our attention that some patients are experiencing some difficulty with the reconstitution of Kogenate FS™. This is understandable; as reconstitution is different to previous factor VIII products. Please refer to the Reconstitution Guidelines that are included with this letter.

We request if you have any difficulties with reconstituting Kogenate FS™ that you make contact with the Haemophilia Centre on 3636 9030 ASAP during office hours of 9am to 3:30pm. If the issue becomes apparent out of hours, please ensure that the Kogenate FS™ is kept in a zip lock bag & you discuss this further with the centre. Please do not throw out any product that you may think is faulty, it is possible that some further education in reconstitution is required.

Please contact me if you have any queries.

Kind Regards,

A handwritten signature in black ink, appearing to read 'Joanna McCosker'.

Joanna McCosker

A/Clinical Nurse Consultant – Haemophilia & Bleeding Disorders

Royal Children's Hospital

## RBWH and RCH Queensland Haemophilia Centre

### Kogenate reconstitution with separate filter

#### \*\*ALERT\*\*

- ⇒ **Kogenate FS™ must be administered using a filter.**
- ⇒ **A 25 gauge butterfly with an inline filter is supplied with Kogenate FS™ for routine home administration.**
- ⇒ **Bayer provides a stand alone filter for use when a filtered butterfly can not be used e.g. administration of Factor via an IV cannula or CVAD, IV**

#### EQUIPMENT:

20 Micron inj filter (ICU medical provided by Bayer)

Luer Lock Syringe



#### PROCEDURE:

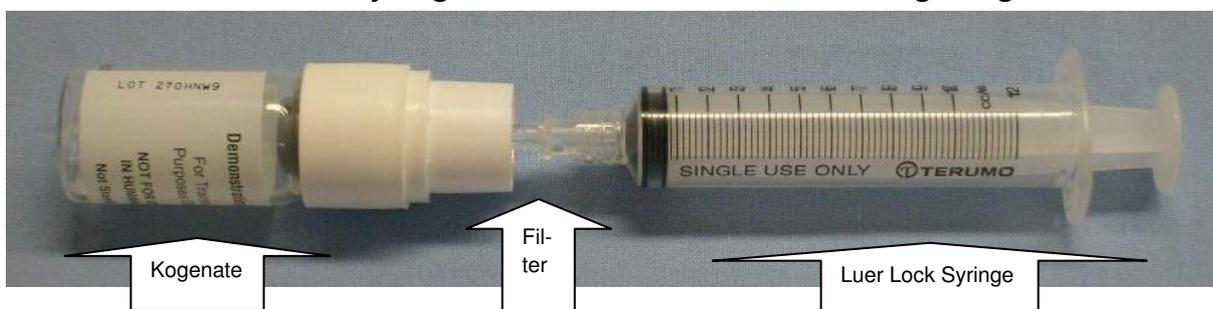
1. Reconstitute Kogenate FS as per manufactures instructions. **During the activation step please ensure that the fingerplate is COMPLETELY depressed, flush with the top of the vial.** It feels like there are three clicks during this step.



2. Attach the luer lock syringe provided directly to the luer lock end of the filter using a non touch or sterile technique as required.

3. **Remove the reconstitution syringe** from the Kogenate BIO-SET bottle

4. Insert new luer lock syringe with filter attached into Kogenage BIO-SET bottle.



5. Withdraw Kogenate FS™ into syringe

6. Detach syringe from Kogenate FS™ BIO-SET bottle.

7. Remove filter and administer Kogenate FS™ as per instructions.

# Social Work News RBWH



Some of their stops include:-

SOUTH WEST: Roma, Charleville, Cunnamulla  
CENTRAL QLD: Rockhampton, Gladstone

DARLING DOWNS: Warwick, Stanthorpe,  
CAIRNS: Cairns, Ingham, Atherton, Innisfail

CENTRAL WEST: Longreach, Birdsville  
MAC-KAY: Mackay, Whitsunday

CAPE: Regions visited will depend on referrals received

WIDE BAY: Gympie, Bundaberg, Hervey Bay,  
Maryborough, Kingaroy

UPPER GULF: Normanton, Mt Isa  
LOWER GULF: Cloncurry

## SOCIAL WORK NEWS – RBWH

### 1. WORLD FEDERATION HEMOPHILIA

Take the time to have a look at the WFH website [www.wfh.org](http://www.wfh.org) for some interesting reading about the following haemophilia related topics:-

The WFH's partnership with the World Health Organisation - WHO

Progress of the Gene Therapy Trial for Hemophilia B

Two Australians who have made significant contributions to the WFH over recent years

The up-to-date program for the WFH Congress which will be held in Paris in July

If you are planning international travel you might want to make a note of the location of the Haemophilia Centres which are closest to your destination, in the WFH Global Treatment Centre Directory (Passport).

You might also want to visit the WFH Facebook page to meet others in the community.

2. MEDICALERT has a brand new Membership catalogue this year with a new and wider range of products including bright and colourful Sports Bands, Swarovski Crystal bracelets and Charm Cable-Link bracelets as well as "funky" Dog-Tag necklets. They also have a wide range of Gold-filled jewellery.

You can call me for a brochure or have a look on [www.medicalert.org.au](http://www.medicalert.org.au) or call MedicAlert directly on 1800 88 22 22.

3. LIFETEC Queensland is a service which provides information, consultation, and education about devices and solutions which can help individuals improve their quality of life and remain independent.

They also provide a range of trips to areas outside of the metropolitan area so have a look at their website [www.lifetec.org.au](http://www.lifetec.org.au) to see if they visit an area near you.

They have access to information about a huge range of resources including the following:-

Emergency call systems – Telephone and non-telephone

Eating and drinking

Dressing

Seating

Transport

Household Aids

### 5. PATIENT TRAVEL SUBSIDY SCHEME

People who live over 50 kms away from the RBWH are eligible for patient travel subsidy if they need to attend certain clinic appointments or be admitted to hospital in Brisbane. Ask your local GP for the appropriate travel forms or give me a call to discuss the process. It's wise to begin setting the paperwork in place as soon as you know your travel dates.

### 6. THINKING AHEAD

Advanced Health Directives – If you become seriously ill or unconscious you may be unable to communicate your healthcare decisions. An Advance Health Care allows you to plan ahead and advise others about your wishes in certain situations.

Enduring Power of Attorney (EPOA) – Establishing EPOA will allow you to appoint an attorney for either personal, health or financial matters should you be unable to do so yourself.

Visit the Justice Department's website for further information about either topic.

[www.justice.qld.gov.au](http://www.justice.qld.gov.au)

# Social Work News RBWH -

Don't forget that the phone number for the RBWH switchboard has changed from (07) 3636 8111 to (07) 3646 8111. Numbers for all of the RBWH Centre staff have changed as well. Simply replace the third number with a "4".

For example, previously my number was (07) 3636 8769 and now becomes (07) 3646 8769

Phone and ask me about the GP initiated Medicare Subsidy for dental and allied health services.

The RBWH has a new mobile phone text messaging system and some people might have recently received text messages from me. I hope it makes it easier than chasing each other by phone for long periods of time. There is no facility for mobile phone users to be able to text a reply as the text is sent from a computer.

Please feel free to call me about any of these topics or call into my office on Level 4 of the Joyce Tweddell Building if you are up at the RBWH for tests or appointments.

Maureen Spilsbury – Advanced Social Worker – Qld Haemophilia Centre

# Social Work News RCH



Hi, my name is Michelle Blewitt and I am currently the part time Senior Haemophilia Social Worker with the Royal Children's Hospital team. I am job sharing with Mona. I have been in this position since the beginning of March and in this time I have been lucky enough to meet lots of our families.

Since graduating in 2002 I have been employed in a number of social work roles both in Australia and the UK. This is my first time working with families affected by Haemophilia and I feel very privileged to be a part of the wonderful team at the Royal Children's and the amazing work that they do.

My role as a Social Worker is to provide support and assistance to Haemophilia and bleeding disorder patients and their families. This can be offered to clients as both an outpatient and inpatient at the hospital. Some of these services include: counselling and emotional support, financial assistance, transport and accommodation assistance or even just as someone to chat too if needed. I work Tuesdays and Fridays and can be contacted on these days on 3646 7937.

# Psychologist News RCH



## Carer Allowance

We have had a few queries about Carer Allowance for children aged over 16.

If you are currently receiving Carer Allowance for your dependent child, it will stop automatically when he/she reaches 16. According to the guidelines stated by Centrelink, one of the basic conditions of eligibility for Carer Allowance for a child over 16 is that "the disability causes a substantial functional impairment". You would need to reapply and have your situation reassessed by Centrelink according to the above criteria.

To find out if you are eligible for this or other Centrelink support, please contact Centrelink (<http://www.humanservices.gov.au> or 132 468) directly as they are in the best position to advise.

## Veins training for our boys – doing it differently

The Team has been working hard this year helping boys transit from ports to veins. Because anxiety around needles is a common issue among children and adults alike, we are in the midst of developing a comprehensive veins training package where our boys (plus mum and/or dad) learn coping strategies to

deal with the psychological issues first, before moving on to the technical side of veins training. This involves having two to three individual sessions with Mona (or an OT/ psychologist if you are not local) and regular phone contact over the training period. I am happy to say that we have had great successes so far. Just last week, three of our boys had successful attempts on their veins. Well done boys! You know who you are!

If you are using a port and would like your child to transit to veins, or if you are already helping your child with venepuncture and would like him to learn to self-infuse, do call Joanna or Mona for a discussion. We are always happy to support your family to achieve this exciting milestone in haemophilia.

Regards

Mona

# RBWH News by Beryl and Olivia

## Home Delivery

For those people who perform factor VIII or IX treatments at home, it is possible to arrange treatment deliveries to your home or office address. Some initial paperwork is required and there are some eligibility requirements that should be discussed. Please make contact with your haemophilia nurse to discuss whether this option is of benefit to you.

## Problems Reconstituting Any Treatment Products?

Are you having any troubles mixing your factor? If for any reason, there is a problem reconstituting your factor it is VER IMPORTANT that you discuss this with your haemophilia nurse. FACTOR should NEVER BE THROWN OUT.

# RBWH News contd.

## SMS Messaging Trial at RBWH

Nursing and Social Work staff are trialling a computer desktop SMS messaging program. We are trialling this, as it seems many people do not have voicemail either activated on their phones or they do not retrieve their messages. We will be able to send SMS messages to you but there is no facility to return these messages, and you will need to ring back.

## Paging Staff

As we now have a new phone board system in the hospital, voicemail messages are no longer able to be notified onto centre staff pagers. In the past, we were able to tell if a message had been left, if we were out of the office. Therefore if your matter is urgent, we will no longer be aware of your call until we are in our office. That means that if your matter is urgent or needs a speedy reply, it is better to have us paged via the hospital switch. The Hospital switch number is 3646 8111.

## Booked Treatment and Clinic appointments at RBWH

As workloads increase and space becomes more limited in the outpatients setting, it is becoming increasingly important that if you have a booked appointment that you endeavour to keep on time. We in turn try our best to also keep on time, however sometimes if patients before you aren't able to keep to time; it affects all the following patients.

If you are unable to attend, we ask that you call 3646 7751 and ask for your appointment to be rescheduled. It is important that you are regularly reviewed either yearly or twice yearly as decided by Dr Rowell.

Also to manage workloads, booked RBWH treatment appointments will be managed more often by the Oncology Day Unit & Oncology Procedure Unit nursing staff. Beryl or Olivia will endeavour to see you at these appointments, but if you want to discuss or have any other haemophilia issues, please ask the nursing staff to have us paged.

## Treatment Diaries

Maintaining home therapy diaries is a very important part of management. For those that are interested there is a phone app/web site that you can use to keep your diaries. This is offered by Pfizer, however information is only accessible by yourself or the treatment centre.

Please see further information in the RCH section about accessing this app.

There is also planning occurring with the Haemophilia Foundation of Australia, Australian Haemophilia Centre Directors Organisation and National Blood Authority to develop another application that will be linked with the Australian Bleeding Disorders Registry.

So those that would find these methods of keeping treatment diaries easier than paper, please discuss with the centre at your next clinic appointment.





## QUEENSLAND POSITIVE SPEAKERS BUREAU HELP REDUCE DISCRIMINATION AND STOP THE SPREAD!

### Who we are

Queensland Positive Speakers Bureau (QPSB) exists to empower and enrich the lives of people living with HIV and viral hepatitis and to provide education to the broader community. The QPSB is comprised of over 45 speakers state-wide and is a not-for-profit collaborative partnership between Queensland Positive People, University of Queensland, Hepatitis Queensland and Ethnic Communities Council of Queensland.

Our professional speakers deliver awareness programs that incorporate their personal narrative - real stories from real people. Sharing the lived experience is a powerful, unique and valuable community education model that is highly regarded. In fact, the feedback overwhelmingly reveals that our speakers influence the dispelling of myths, provide enhanced understanding and reducing stigma whilst providing information to prevent the future spread of the viruses.

### What we can offer

**Education sessions:** Presentations conducted by the QPSB are tailored to suit particular audience requirements. Content, language and format are varied to suit the level of knowledge, age and needs of audience members. Examples of audiences include:

- Health care professionals (eg. GPs, allied health professionals, dentists)
- Government employees
- Corporate employees (eg. aged care facilities, correctional facilities)
- Secondary and tertiary school students
- Individuals in the community

Typical topics that may be covered during the session include (be are not limited to):

- Background information about HIV and/or viral hepatitis
- Treatment & medications
- Transmission & prevention
- Testing
- Confidentiality
- Personal experiences
- Stigma & discrimination
- Community attitudes

**For people living with HIV and/or viral hepatitis:** We provide training, mentoring and support for those living with the viruses to become professional speakers and motivators of change. We offer ongoing professional development through monthly workshops and speakers are remunerated per engagement.

**To book or become a speaker:** Phone 3013 5509 / Email: [qpsb@qpp.org.au](mailto:qpsb@qpp.org.au)

**To donate:** visit [www.givenow.com.au/qpsb](http://www.givenow.com.au/qpsb)

"Her presentation really hit home and I was incredibly moved. I thought I knew a significant amount hepatitis, but hearing the positive speaker talk about topics that were so real for everyone in the audience helped me gain a real understanding of the issues she faces."

*Health promotion worker, not for profit organisation*

# [www.qpsb.com.au](http://www.qpsb.com.au)

## Suppression of HIV using Engineered Stem Cells - a therapeutic strategy

Although there is currently no cure for HIV, the body *does* already contain cells that fight the virus – the problem is, there just aren't enough of them to completely get rid of it. In 2009 scientists at UCLA performed a proof-of-concept experiment, in which they were able to grow these CD8 cytotoxic T lymphocytes (better known as infection-fighting "T cells") from genetically engineered human stem cells. Now, in a subsequent study, they have demonstrated that these engineered cells can seek out and kill HIV-infected cells in a living organism.

In the previous project, the researchers took T cells from an HIV-infected individual, and isolated the T cell receptor within them – this is what allows the cells to identify and destroy cells infected with HIV. They proceeded to clone this receptor, then used it to genetically engineer human blood stem cells. These cells were then placed in human thymus tissue, that had itself been implanted in mice, where they proceeded to grow into HIV-specific T cells.

While the study indicated that it was possible to create genetically engineered HIV-fighting cells in the body, it didn't test how those cells fared against HIV in a living organism. The more recent study, however, did.

This time around, similarly engineered HIV-specific T cells were introduced into infected "humanized mice" – lab mice that have been genetically engineered to carry human genes, cells or tissues. Two to six weeks later, tests were performed on the peripheral blood, plasma and organs of those mice. It was found that not only had the level of HIV in the blood-stream decreased, but the number of CD4 "helper" T

cells had *increased* – CD4s are white blood cells that play a key role in fighting off infections, and they normally decrease in the event of HIV infection.

According to the scientists, these results indicated that the introduced T cells had developed and migrated to the organs, where they fought the HIV infection. They did note, however, that even in humanized mice, HIV may mutate slower than it does in humans. This means that multiple T cell receptors might have to be used, to account for the higher likelihood of the virus mutating in humans. To that end, the researchers have now begun creating receptors that target specific parts of the HIV virus.

"We believe that this study lays the groundwork for the potential use of this type of an approach in combating HIV infection in infected individuals, in hopes of eradicating the virus from the body," said lead investigator Scott G. Kitchen.

A paper on the study was published yesterday in the journal *PLoS Pathogens*.

Source: UCLA



## Current treatment options for the restoration of articular cartilage.

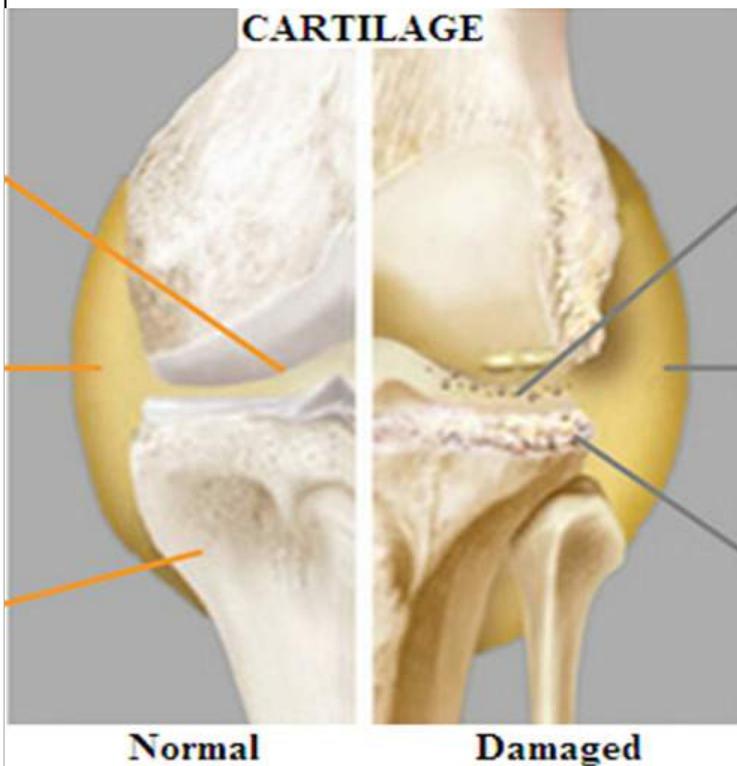
As most older people with severe Haemophilia will testify, cartilage and bleeding is a bad combination resulting in deterioration of joints over time. So what do we know and what have we learned over the last few decades about cartilage and what can be done to repair damage.

these seem to lack the mechanical durability. There is some research and development that is looking at artificial tissue matrices and processes that can stimulate growth but to date; there has not been a clinical technique that has shown any long-term promise. Ultimately, the goal will be to take precursor cells from an easily accessible source in the

body like the edge of the pelvis, mix them with growth factors that have been derived genetically in the lab, and provide an artificial matrix that in combination can produce restoration of cartilage at minimal cost and patient issues.

There are also transplant systems have shown encouraging results but there are still problems. Graft matching and contouring to the recipient surface is difficult. Donor sites can be a limiting factor. Furthermore, the fibrous tissue interface between the donor and recipient site may contribute to breakdown in the long run. There is also another biological repair process that has shown encouraging results but it must be remembered that this is not normal cartilage.

The technique is expensive and is technically difficult to perform. There are no randomized prospective studies that compare the natural history of the repair tissue to that of other forms of repair tissue. Long-term functional outcome is still a significant question mark. In addition, it has not been shown that implantation can prevent degenerative changes. In the future, we probably will see delivery systems using stimulating growth factors, cartilage cells, and synthetically derived matrices. When placed in combination and with the right mechanical stimuli, we may ultimately achieve true restoration of articular cartilage.



While articular cartilage does appear to have some regenerative capabilities, it appears to lose this capacity over a period of time, making restoration of surfaces more and more difficult. To date, no technique has been completely successful in achieving exactly normal regenerative cartilage. Arthroscopic procedures to salvage and clean up tears etc. provide temporary relief of symptoms. This probably works by removing degradative enzymes that contribute to synovitis and also to the further breakdown of the cartilage. Bone marrow stimulation produces only a fibrous type of cartilage and therefore does not offer a long-term cure. There are grafting procedures that are used to attempt a patch / repair but

# RIDE FOR A CURE—HFQ Wheelathon 2012



Hi, my name is Hugo Mitchell. I am in grade 4 at Eagle Junction State School and I would like to find a cure for Haemophilia.

For Haemophilia Awareness Week in October 2012 I will be cycling around the Nundah Velodrome, trying to do as many laps as I can over a one hour period.

I was hoping you will consider supporting me by either:

- sponsoring me an amount of money per lap  
Or
- riding with me and asking your friends/family to sponsor you.

All money raised will go to the Haemophilia Foundation Queensland ([www.hfq.org.au](http://www.hfq.org.au)) to support kids with inherited bleeding disorders.

Here are the details:

**RIDE DATE**            Sunday 7 October, 2012

**LOCATION**             Nundah Velodrome (Criterium Circuit) Hedley Ave, Nundah

Hi Everyone

Hugo is challenging all HFQ members to take part in this event. If you live close to Brisbane the venue will be as above. If you live in a regional area contact Liz to make arrangements for your area.

The wheelathon is open to all two wheel cycles, wheel chairs and motorised scooters. Liz will have available sponsorship packages for people to use—if you would like one either ring Liz on 0419706056 or email [info@hfq.org.au](mailto:info@hfq.org.au) and Liz can explain it all to you.

We have the Nundah track open to us from 0930 until 12noon with the laps starting at 10am and finishing at 12am. There will be red cupcakes and drinks available to purchase after the event.

This is not a racing event but rather an endurance event. It is not an event to see who can go the fastest but rather to gain sponsorship for how many laps you can achieve.

Join Hugo and Liz (yes she will be riding her bike) and Erl the president (on his motorised scooter) for a great fund raising event for HFQ.







# Latest News

## **Outreach clinic dates for the remainder of 2012**

Townsville	August	Monday 6th 2012
Cairns	August	Tuesday 7th 2012
Gold Coast	September	Tuesday 4th 2012
Gold Coast	September	Tuesday 18th 2012
Toowoomba	September	Friday 28th 2012
Nambour	October	Friday 26th 2012

**Contact the nursing staff at RCH and RBWH if you have questions**

## Regional Luncheons

Every year HFQ organises and sponsors luncheons in regional areas. The following dates are the regional luncheons for the remainder of 2012.

Cairns	Sunday 19th August 2012 (Craig Bardsley and Adam Lish from Brisbane will be attending)
Gold Coast	Sunday 30th September 2012 (Erl the president and his wife June will be attending)
Toowoomba	Sunday 14th October 2012 (Erl the president and his wife June and Craig Bardsley will be attending)
Sunshine Coast	Sunday 11th November 2012 (The Weatherall family will be attending)

Information and booking forms will be made available to all who attend outreach clinics. If you wish to attend you can also call Liz on 0419706056 or email at [info@hfq.org.au](mailto:info@hfq.org.au).

# Latest News continued

## 2012 HFQ AGM NOTICE

VAGALIS CAFÉ, 30 RACECOURSE RD, HAMILTON 4007

SEPTEMBER 9TH 2012 @ 2PM—4PM

ALL HFQ MEMBERS ARE WELCOME TO ATTEND

PLEASE RSVP TO LIZ 0419706056 OR INFO@HFQ.ORG.AU

TEA COFFEE AND LIGHT REFRESHMENTS WILL BE SERVED

**Haemophilia Foundation Queensland is on**

**Facebook.**



**Become a fan—Like Us!**

## Ladies Luncheons



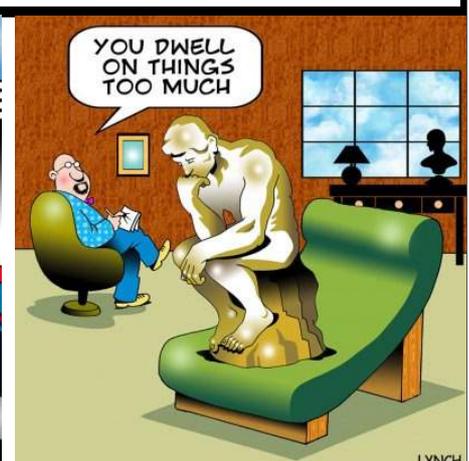
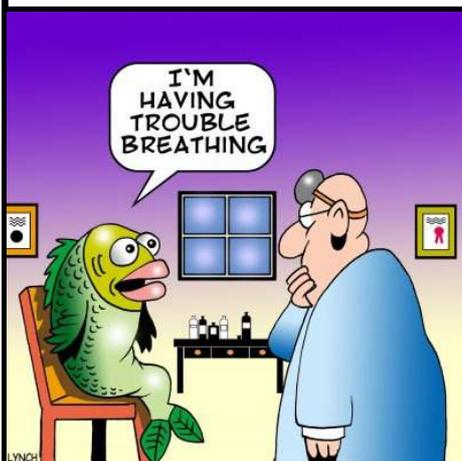
Mums & mums to be, wives & partners or anyone who is affected by an inherited bleeding disorder are invited to attend Ladies Luncheons. This is a bi-monthly event where ladies can get together for support and chatting.

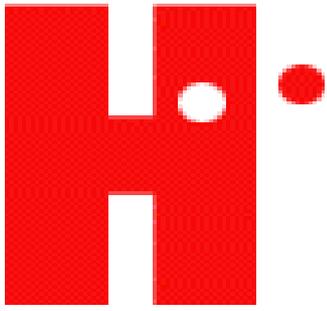
The next function is planned August—please email [info@hfq.org.au](mailto:info@hfq.org.au) or ring Liz on 0419706056 if you would like more information or to book your spot.

If you would like to arrange ladies luncheons in any regional areas give Liz a call or email to discuss.

Great website to visit for boys and families (and older guys who like a laugh)

<http://www.youngbloods.org.uk/Interactive/Cartoon+for+Kids>





# HFQ 2012 Youth Camp

## Emu Gully Adventure



If you are between 8 and 16 years of age and have an inherited bleeding disorder you are cordially invited to attend the 2012 Youth Camp at Emu Gully on the weekend of the 25th of August.

The programme is full of fun activities from Swinging logs to Commando Cable Crossing to Rock Climbing and a High Adventure Night Walk. Check out the website [www.emugully.com.au](http://www.emugully.com.au)

Liz will be sending out information to families at the end of June for this camp. If you want to let Liz know you are interested and to ensure you get the information please email her on [info@hfq.org.au](mailto:info@hfq.org.au) or phone 0419 706056. Numbers are limited so let Liz know as soon as you can to secure you a place.

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