



The 'H' Factor

Issue 36

Spring 2013

The President's Press

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This is my last report as President of HFQ as I am stepping down at the AGM on the 15th of September. Thank-you to everyone for their support of me in the role for the past 12 months. Special thanks to Liz for her boundless energy and patience

It has been a busy couple of months. Liz has been overseeing the upgrade of the HFQ website which is now live. The new site presents a more professional image of our organisation, and is an easy one to navigate around. This website will have ongoing updates of events and

news so make sure you check it on a regular basis, and visit our shop for great HFQ goodies. www.hfq.org.au

Youth Camp at Emu Gully was a great success again this year. Haemophilia took a back seat as the ten boys got stuck into the activities on offer. The purpose of these camps is to build self-confidence, reinforcing the notion that our boys are young men living with haemophilia rather than being defined and limited by their condition. The camp's philosophy is based on the ANZAC tradition of mateship and comradery, and the message is delivered in an age appropriate manner by the camp councillors who are very experienced with coaching and leading young men. Aimed at boys from eight years of age, these camps are a regular feature on the HFQ activities calendar. I would personally highly recommend these camps - this was our son's second year attending and he had a ball. As always, many thanks to Craig and his team of youth mentors who add an enormous amount of value to the experience.

The WFH 2014 World Congress in Melbourne is getting closer (May 2014), and the board of HFQ would like to encourage as many individuals as possible to attend. HFQ have committed a sizeable amount of funds to assist as many people from the HFQ community to attend as possible. At the last board meeting it was confirmed that up to \$600 per person (one person per family) could be applied for to assist with the cost of an economy air fare to Melbourne. Applicants must cover their own costs of Congress registration and accommodation. Interested persons should email their expression of interest to the manager at info@hfq.org.au. A ballot will be held if there are more expressions of interest than the allocation will cover.

Haemophilia Foundation Queensland

HFQ Manager

PO Box 451

Spring Hill

Phone: 0419 706056

Email: info@hfq.org.au

Facebook:

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

We are on The Web
www.hfq.org.au

President's Press contd.

The HFQ Christmas party venue is still to be decided however families will be notified either by email or mail of the details. Regional lunches are also in the process of being planned for Cairns, Toowoomba, Nambour, Mackay, Rockhampton and the Gold Coast. If you would like information on any of these events, make sure you email the manager to ensure you are updated. The HFQ website will also carry this information.

You will notice in the body of this newsletter a good-bye from Liz. Liz has been our manager for 3 ½ years and will be leaving us in November. Liz had decided to pursue her love of exercise and fitness and is going to be working as a personal trainer specialising in people who are recovering from illness or accidents. I can't thank Liz enough for her commitment, hard work and support. Liz has provided valuable direction for our organisation, and has been instrumental in driving our agenda and achieving outcomes that have made a real difference to our community. I would also like to recognise and thank Liz's daughter, Alicia, for her ongoing assistance and support. We wish both Liz and Alicia all the best in the future.

Regards

Howard Mitchell



2013 - Incoming HFQ President - David Stephenson

Aspects of all our futures are tied together in blood and it's HFQ that works to represent all those with bleeding disorders in Queensland to guarantee we maintain engagement with government and service providers ensuring community needs are maintained and any issues addressed. For me as new

president of HFQ it's about ensuring the good work of advocacy, health promotion and support for those affected and touched by bleeding disorders and associated

issues continues. This year's board has an extensive mix of demographic including medical which makes for excellent outcomes with balance.

I would like to thank Howard Mitchell our outgoing president for his excellent guidance at the helm of HFQ and luckily he is continuing as Vice President as is Sarah Hartley as secretary and Peter David as treasurer. Of course there must be a special mention for our manager Liz who's passionate drive has been invaluable - thanks so much Liz from everyone in our community!

When I look back at the last family camp where people were deeply touched by others stories, and with youth where I saw personal growth as an outcome of our mentoring program and with the OBE project that continues to support ageing as well as the varied targeted health promotion events.... it shows the value of HFQ as an effective organisation.

My background brings many years of experience from several state foundations as well the national body (HFA) including personal experience with bleeding disorders.

It's clear to me that as government goal posts change from time to time we need to be active in ensuring the bleeding community is maintained as a priority group. I look forward to catching up with you all at one of our next events.

Lastly I want to thank the new board for all the good work they are going to put in this year!

Regards David Stephenson HFQ.....Advocacy, Health promotion, Support

ABOUT HFQ

The Haemophilia Foundation of Queensland (HFQ) provides advocacy, education and support for people in Queensland affected by inherited bleeding disorders. The Foundation employs a fulltime 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)

HFQ Management Committee

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

LADIES

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

<http://mygirlsblood.org>

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
Moana Harlen—Psychologist	3646-7937
Mona Chong – Psychologist	3646-7937

ROYAL CHILDRENS HOSPITAL

Dr Simon Brown-Haematologist	3636-9030
Joanna McCosker—Nurse	3636-9030
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
AND TOWNSVILLE HOSPITALS:**

Book through Joanna at RCH and Beryl at RBWH

HFA Report by David Stephenson

Queensland HFA representative FACTORED IN: Update



Queensland delegates to the national body HFA were recently elected by the HFQ board. The role of state Delegates is to represent state issues as well as facilitate a communications conduit both into and out of the state. Sarah Hartley and David Stephenson have been elected. I welcome Sarah to the role and I am sure her contribution will see significant benefit as we work together. Leaving the role is Leanne Stephenson who has given a great deal and who's ability to sum up complex issues into down to earth, easy to understand speak will be missed, thank you Leanne.



WFH World Congress in Melbourne is the largest international meeting dedicated to Haemophilia, drawing

experts from around the world on topics that affect you and your family. People from 120 countries will be attending . You have the opportunity to get the latest leading edge information and the ability to ask questions on topics with international experts in their field. 11-15 May 2014

13-19 October 2013 - **Haemophilia Awareness Week** is an opportunity for Haemophilia foundations and other organisations, as well as individuals and families, to take part in a campaign and activities to raise awareness about Haemophilia and related inherited bleeding disorders throughout Australia. We encourage all of our supporters to participate. Last year over \$19000 was raised by people. HFA is calling on people to support this by taking part in Red Cake Day - all you have to do is bake some delicious red cakes or cupcakes, decorate them and share them with friends, work colleagues and others for a gold coin donation. Monies raised that are sent to HFA go to a range of programs and services run around the country, for more information go to:

<http://www.haemophilia.org.au/eventsandawards/cid/2/parent/1/pid/2/t/eventsandawards/title/haemophilia-awareness-week>

Youth Project 'Beyond Prophylaxis' is an ongoing HFA project that you will have read about in previous publications, the next stage of this is Leadership and Mentoring training workshops for young people across the country, this is about having fun while gaining skills with friends - an online youth community that is growing in popularity, have a look today:

<http://www.factoredin.org.au/>

CLOTTING FACTOR TREATMENT PRODUCTS:

New clotting factor products are in development and we are soon to see products coming to market. Some of these will include longer acting clotting factors. We are yet to see the impact these products will have on the market, what they will cost, and what uptake would be like if these products were available. Some people have already been involved in clinical trials in Australia and we are looking forward to registration and availability of these products. HFA treatment product policy is to increase options for treatment and advocate to the NBA and all jurisdictions for a supply of a range of products that provide different treatment options for patients & allow clinical choice and support prescribing and management experience to clinicians.

** If you have any feedback please call Liz at HFQ**

HEP C - THE SILENT KILLER:

Pain, fatigue, mobility problems, bleeding and viral infections all adds up to an overload with health conditions which creates a significant barrier to managing health issues like HEP C. We are now seeing more people with significant liver issues resulting from HEP C infection. The unfortunate feature of HEP C is that you can feel ok but clinically there can be major problems bubbling away. So don't wait until it's too late, make an appointment today for a liver check with your doctor.

Regards ... Dave and Sarah

HFQ Advocacy, Health promotion, Support

Physiotherapy Update



Hi my name is Mick Hockey.

I started in the adults haemophilia physio position with the Queensland Haemophilia Treatment Centre in July, replacing Emma Paterson who has moved to Perth to finish her Masters in Musculoskeletal and Sports Physiotherapy. I graduated from UQ in 2006 and have since worked in multiple hospitals in Queensland. I also worked for two years in a private practice physio clinic in Mareeba, North Queensland. My current workload is made up of 0.5 Haemophilia and 0.5 Orthopaedic inpatients. My particular interests in physiotherapy lie in the musculoskeletal field, although in recent years I have been focussing on the areas of acute post-surgical care, critical care and clinical education of university students.

It is my role not only to assist with assessment and rehabilitation post bleeds but to promote a healthy and active lifestyle. I am available to prescribe individualised exercise programs for patients who wish to improve strength, endurance, mobility, flexibility and cardiovascular fitness. In keeping with principles of promoting proactive health care, HFQ have purchased five pedometers for use by haemophilia patients through the Queensland Haemophilia Centre. Whether you walk a little or a lot (or think you do!) the use of a pedometer provides an objective measure so you know just how much incidental exercise you get throughout the day while walking. This information not only serves as a motivator to walk more, but aides in the prescription of what other exercise, and how much of it you should be doing. If you're interested in using a pedometer or help with the prescription of an exercise program, please contact me. Ph: 36468135, email michael_hockey@health.qld.gov.au



Hepatitis C Update—Dr John Rowell

Hepatitis C has affected a large number of persons with Haemophilia prior to the introduction of screening of blood products for production of concentrates and heat treatment of concentrates. Many have been infected for 20-30 years with possibility of developing fibrosis and cirrhosis of the liver (sever scarring) and possibly a chance of developing liver cancer.

There is major progress in the therapy of Hepatitis C. A new test called a Fibroscan is now available both as a private test (cost approx. \$270) or available through the Liver clinic at the Royal Brisbane and Women's Hospital that more reliably assesses the level of fibrosis in the liver and allows better decision making regarding the need for antiviral treatment in the short term. I would encourage all those with on-going hepatitis C to have an initial Fibroscan to allow discussion of possible treatment. With discussion, a plan can also be developed for people from rural and regional areas.

Recently two drugs, Telaprevir and Boceprevir, have been added to the PBS (Pharmaceutical Benefits Scheme) and can be used in conjunction with Ribavirin and pegylated Interferon for treatment of specific genotype 1 Hepatitis C patients—either as initial treatments or following previous relapse or failure of previous treatment. These treatments showed improved response rates from 30-40% in those with no previous response, to 70-80% in those who relapsed after treatment with Ribavirin and PEG-Interferon. Unfortunately both drugs have significant side effects which require dose supervision—including rash, anaemia, dry skin, fatigue and distortion of sense of taste (dysgeusia). Treating teams will ensure there is close follow up so that side effects are monitored, managed and minimised wherever possible.

There are many new drugs in the research pipeline and undergoing clinical trials with the eventual aim of being used in a shortened course of treatment possibly without Interferon. New drugs in trial will hopefully be submitted to the Federal Drug Administration in the USA in 2013-14 and if successful may allow approval in Australia following that (although there was a 2-year delay for Telaprevir and Boceprevir).

With new drugs becoming available it is important to be assessed with a FibroScan and blood tests and then closely monitored. Continuing liaison with either the Haemophilia Centre or Liver Clinic is important to monitor progress or development of any complications and keep up-to-date with availability of new therapies. I would encourage you to make contact with the Haemophilia Centre if you have any further questions or want to follow up with assessment regarding Hepatitis C.



Monkeys Achieve Drug-Free Control of HIV

a promising strategy

edited by David Stephenson

Monkeys Achieve Drug-Free Control of HIV – a promising strategy

Adding both an arthritis drug and a chemotherapy drug to a highly intensified antiretroviral regimen appears to have led to a drug-free control of HIV among macaque monkeys. Publishing their findings in the journal *Retrovirology*, a group of Italian and American researchers added the gold salt auranofin and the chemosensitizing agent buthionine sulfoximine (BSO) to a five-drug antiretroviral regimen given to macaques infected with simian immunodeficiency virus (SIV). In a previous study, the researchers had found that the addition of auranofin succeeded in reducing both the viral reservoir and the post-therapy viral load set point.

Of the seven monkeys in the trial, all received the five-drug ARV cocktail. Two of them also received auranofin, three of them received auranofin and BSO, and two received no additional therapies.

After the researchers stopped the therapy of the three monkeys taking auranofin and BSO, their viral loads initially rebounded. But with time the animals experienced a significant drop of viral RNA and DNA in peripheral blood cells—an indicator of a diminished viral reservoir—as compared with levels seen before the monkeys began ARV treatment. The monkeys ultimately achieved enough control of their infections to prevent the development of AIDS. The researchers found that the presence of CD8 cells as well as an enhanced level of cellular immune response among the monkeys played a key role in this apparently successful therapy.

The researchers wrote, “The level of post-therapy viral set point reduction achieved in this study is the largest reported so far in chronically SIVmac251-infected macaques and may represent a promising strategy to improve over the current ‘ART for life’ plight.”

The investigators plan to start a human clinical trial of this therapy in early 2014.

Good bye from Liz

As many of you will already know I am going to be leaving HFQ as the Manager in November. Over the past 6 months I completed my certificates III and IV in Personal Training and will be taking up a role with Jetts Fitness in Fortitude Valley as a Specialised Personal Trainer. I will be working with people who are recovering from major illness's and injuries helping them back to being fit and healthy through exercise. My qualifications as a registered nurse and my 75% completed Sports Psychology degree are going to come in very handy. I have loved working with HFQ as your manager over the last 3 1/2 years and have been very proud of how HFQ has grown and developed during this time. We have become a strong foundation with strong goals and I just know the new manager is going to love working with the HFQ board members and community implementing the 2013-14 strategic plan. We have grown as a community and have in place some very exciting and unique programmes including the youth mentor programme and the wellness strategy for men as they age, both programmes I am proud to say I was part of. I would like to wish all from HFQ all the very best and if we meet up again I can assure you it will probably be on the working end of a set of weights.

Love Liz



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Social Work News

Qld Haemophilia Centre



1. PATIENT TRAVEL SUBSIDY SCHEME On 1 January 2013, the Patient Travel Subsidy Scheme (PTSS) mileage subsidy rate increased from 15 cents to 30 cents per kilometre and the accommodation subsidy rate from \$30 to \$60 per person per night when staying in motel accommodation. The subsidy for private accommodation remains unchanged at \$10 per person per night. The PTSS provides assistance to patients, and in some cases their carers, to enable them to access specialist medical services that are not available locally. If you live over 50 kms away from the RBWH or RCH you are eligible for patient travel subsidy if you need to attend certain clinic appointments or be admitted to hospital in Brisbane. Ask your local GP for the appropriate travel forms or give us a call to discuss the process.

2. NEW TEAM MEMBER We are pleased to welcome Dr Moana Harlen to the team at the Queensland Haemophilia Centre. Moana is working as the Senior Haemophilia Psychologist at the RCH Centre but many of you will get to meet Moana as she will provide cover for both hospitals during leave etc.. Look out for the introduction Moana has written about herself for this newsletter.

3. CONFIRMING APPOINTMENTS Please check to see if any appointment letter you receive mentions the need to confirm your acceptance of appointments made for you. Failing to confirm, where necessary, will mean that someone else will be given the appointment slot. In addition your hospital chart will not be available if you do

attend and you may not get another appointment for a significant period of time.

4. CONCERNS AND COMPLIMENTS Most hospitals have feedback forms so you can give feedback about your experience within the hospital system. Ask a staff member if you can't locate them.

5. CHANGE OF CONTACT DETAILS Moving homes is a busy and exciting time and there are many issues to think about. Please don't forget to let us know if you are changing addresses or phone numbers or if your GP details have changed. There are a number of important reasons why Qld Haemophilia Centre and hospital staff might need to contact you including confirmation of surgery dates and management of bleeding episodes.

6. BUILDING RESILIENCE WORKSHOPS. In conjunction with the HFQ, Mona and I have been able to develop a workshop around building resilience to deal with life's issues. It covers topics including Dealing with Stress, Healthy Ageing, Resilience Building, Optimising Mental Health and Relaxation. We were able to present the first workshop in Brisbane on Friday 2nd August. It was funded by a grant from Hepatitis Queensland for World Hepatitis Day. Staff from Hepatitis Qld attended and provided an excellent update about the services they offer. In addition they were able to answer a lot of questions about living with the conditions. A heartfelt thanks to Liz for all the hard work she did to put together the application and the assistance she offered in planning the day. A total of nine people attended the Brisbane session. We hope to be able to conduct more sessions in a variety of areas across the State. Seven people attended a forum in Cairns where some of the presentations were repeated. Thank you to everyone who came along to the sessions and participated so openly. Thanks also to Hepatitis Queensland for the funding and to Liz for organising the day so efficiently. Thanks also to the HFQ Board for supporting and facilitating these types of projects in the community.

Social Work News Cont'd.

7. ADVANCED HEALTH DIRECTIVE An Advance Health Directive is a formal way of giving instructions for your future health care, and comes into effect only if you are unable to make your own decisions. An Advance Health Directive allows you to plan what medical treatment or health care you would like in the event that you cannot make decisions for yourself. It also enables you to appoint an attorney for health and personal matters if you want. You can download the form from the Justice Website or you can buy one from a newsagency. Part of the Advance Health Directive form needs to be completed by a doctor, so get them to explain your options, any unfamiliar terms, and ask them to provide more information if you need it. Before completing the form, first take time to carefully reflect on the decisions you have to make. Remember, you are putting in place a plan that will determine your future health care. Consider what is important to you. Discuss these matters with your family or close friends. Go to www.justice.qld.gov.au and type in Advanced Health Directive to read more about the issue. *This information was taken from the Queensland Department of Justice website.*

8. GUARDIANSHIP and POWER OF ATTORNEY The Queensland Government website www.justice.qld.gov.au also provides information about Power of Attorney and Guardianship. A section about making health care decisions for others lists a number of questions to help you understand treatments which are being proposed.

The questions are useful in any health care setting and include:

What does the treatment **involve**?

What are the **benefits** of treatment?

What are the **risks** of treatment?

What are the **consequences** of not having treatment?

Is there an **alternative** treatment available?

More information can be found by going to the website and typing "health care decisions" in the search box.

Please feel free to call me (Monday to Thursday) or Mona (Friday) on (07) 3646 8769 if you have any questions about the information in this article or any other haemophilia related issue.

Maureen Spilsbury – Advanced Social Worker – Haemophilia

Phone (07) 3646 8769 (Monday to Thursday)

Mona Chong – Advanced Psychologist – Haemophilia

Phone (07) 3646 8769 (Friday only)



Psychologist News by Dr Moana Harlen



a primary school teacher and then trained to be a clinical psychologist. I have worked with adults, children and families in a wide range of clinical, community and educational settings assessing and treating depression, anxiety, drug and alcohol misuse and other mental health issues. I also have extensive experience working with families involved in child protection to improve long term outcomes for children. When I started in June I pretty much hit the skies flying with the HTC team and met children and their families in Mackay and Rockhampton. I am very excited to be a member of the QHC team and I am looking forward to meeting and working with the children and their families and adults of the Queensland Haemophilia community.

The Family Factor

The HTC team at the RCH are currently working with colleagues at UQ to develop a parenting program to support families with children who have haemophilia. This has the potential to be a very useful program and we would really appreciate help from parents of children with severe haemophilia to participate in evaluating the effectiveness of the program. Please contact Joanna or Moana if you would like further information about how to be involved.

Hi my name is Moana and like my predecessor Sarah, I come from the Land of the Long White Cloud (many years ago), and have come to love the gorgeous blue skies of sunny Queensland. I have always been passionate about improving outcomes for children and started my career as

Dr Moana Harlen - Senior Psychologist - Haemophilia

RCH, Herston Phone 07 3646 7937 (Monday to Friday)



AccuVein

 by Beryl Zeissink

I was recently invited to attend a meeting of the OBE group. One of the interesting topics we discussed was the "nifty" little gadget called the AccuVein that both the RBWH and RCH have on loan from one of the pharmaceutical companies.

We all know that some of us have better veins than others....and those with the not easiest veins to find, have a bit more trouble. It was "illuminating" to look at everyone's veins, and we even found some "new" ones, so rotating vein choice won't be as hard now!!

Both HTC's, have this device and for those learning venous access for the first time it has proved to be a most useful tool.

For the novelty of it or for more serious vein finders if you want to have a look at your veins, the next time you are at the hospital, just ask your haemophilia nurse.



Greenspot Repeat Prescriptions

Royal Brisbane & Women's Hospital - Pharmacy Department.

Some of you may have noticed that there is now an answering machine on the RBWH pharmacy "Greenspot" number.

For those that would prefer to use an email address to request script collects, please use this email address

Email: RBWH-Pharmacy@health.qld.gov.au

Please provide your name, date of birth, address, telephone number (that they can contact you on), your medication required & the date you would like to collect your factor.

News from RCH

A big thank you for everybody's patience and all the thank you's and kind words we have received over the last few months.. It has been and continues to be an exceptionally busy year, however some amazing achievements by some of our boys and families make the "crazy" so worthwhile.. I am so proud of all "my boys" and their families for sticking with it and getting some amazing results... You know who you are... Joanna

Welcome to BRuCe <http://brucecalc.net/>

BRuCe is a calculator for children with haemophilia and their families. It provides information about how changes in patterns of physical activity can influence the risk of bleeds. The risk of bleeds is expressed in terms of expected number of bleeds in a year.

You can use BRuCe to estimate the expected risk of bleeds associated with a particular pattern of physical activity. For example, you could use BRuCe to estimate the effect on risk of bleeds of playing two hours of soccer each week.

BRuCe has been produced by researchers at the George Institute for Global Health and Neuroscience Research Australia with funding from AHCD, the Australian Haemophilia Centre Directors' Organisation.

How to use BRuCe

To use BRuCe, click on the BRuCe – bleeds risk calculator tab. Enter data in the **YELLOW** cells. You will need to enter five numbers:

- The number of bleeds you experienced in the **last year**.
- The amount of time (average number of hours per week) you spent doing moderate-risk activities **last year**. Moderate-risk activities are activities in which significant collisions might occur. Examples of moderate-risk activities are running games and soccer. If you need help doing this, click on the Help me enter data button.
- The amount of time (average number of hours per week) you spent doing high-risk activities **last year**. High-risk activities are activities in which significant collisions might occur. Examples of high-risk activities are skateboard riding and rugby.
- The amount of time (average number of hours per week) you expect to participate in moderate-risk activities over the **next year**.
- The amount of time (average number of hours per week) you expect to participate in high-risk activities over the **next year**.

Don't worry if you can't give exact numbers – just enter your best estimates.

BRuCe will use the numbers you entered to estimate the expected number of bleeds that will occur in the next year. So you can determine how a change in patterns of physical activity will effect risk of bleeds.

Note that BRuCe only provides estimates of the expected number of bleeds. You can think of these estimates as a "best guess" of the number of bleeds that will be experienced in the next year. The actual number of bleeds cannot be predicted exactly. Nonetheless, the expected number of bleeds is the best way to quantify the risk associated with a change in patterns of physical activity.

REMEMBER FACTOR REPLACEMENT WILL ALWAYS BE YOUR BEST PROTECTION

GIVE FACTOR BEFORE SPORTS PARTICIPATION

IF YOU HAVE SUSTAINED A SPORTING INJURY PLEASE USE P.R.I.C.E* AND CONTACT YOUR HAEMOHLIA TREATMENT CENTRE FOR FURTHER ADVICE AND FOLLOW UP

ALWAYS REMEMBER YOUR HEAMOPHLIA TREATMENT CENTRE IS THERE TO GIVE YOU ADVICE ON ANY SPORTING ACTIVITY OR SPORTING INJURY.

News from RCH contd.

Below is a list of all the regional case managers that families can access for everyday items like getting general pharmacy scripts for saline, numbing cream etc... The Haemophilia team no longer has the capacity to continue to manage these items due to the increasingly busy nature of the health system. Factor is and always will be ordered only by the Haemophilia Team.

Paediatric Oncology Regional Case Managers – Queensland					
Location	Regional Case Manager	Contact Number Fax Number	Email	Working Days/Hours	Alternative Contact if RCM Unavailable
Bundaberg	Margaret Appo	(07) 4150 2303 F: (07) 4150 2309	Bundaberg-paediatric-oncology-team@health.qld.gov.au	Wednesdays	Deborah Spry (NUM) / Annie McKay (Clinical Facilitator), (07) 4150 2301
Cairns	Denise Petersen	(07) 4226 6657 (07) 4226 6657 F: (07) 4226 6748	CBH_Paediatric_Oncology@health.qld.gov.au	Mon/Wed 0800 - 1630	Caroline Witter, NUM Paediatric Unit (07) 4226 8396 or Team Leader (07) 4226 6510
Gold Coast	Michelle Noyes Tues, Thurs and Fri Nicolette Thornton Monday - Thursday Lynne Jones	(07) 55197489 0402 274 697 F: (07) 5519 8266	michelle_noyes@health.qld.gov.au Nicolette_thornton@health.qld.gov.au	0800-1630 Mon-Fri	Nicolette Thornton, Nurse Practitioner Paediatric Oncology/Haematology Palliative Care (07) 55197489 (Mon – Thurs), Anna Creevey, NUM Paediatric Unit (07) 55197736
Hervey Bay	Lynne Jones	(07) 4325 6545 (07) 4325 6840 F:(07) 4325 6786	LynneM_Jones@health.qld.gov.au Chemo Requests: Oncology_HBH@health.qld.gov.au	0700 - 1530 Monday 0700 - 1100 Tuesday	Di Johnson (NUM Paediatrics) (07) 4235 6666/0407126 142 Chemo Requests: Adult Day Oncology Fiona Fuller/Cheryl Betley (07) 4325 6563
Logan		(07) 3299 9119 F: (07) 3299 8035	Logan-Beaudesert_Paediatric_Oncology_Team	Mondays Thursdays 0800 - 1630	Marian Rigney, NUM Paediatric Unit (07) 3299 8681
Mackay	Karen Caris	(07) 4885 7286 F: (07) 4885 6929	MKY-Paediatric-Oncology-Team@health.qld.gov.au	Mon-Thu 0800 – 1630	Helen Alvers, NUM Paediatric Unit, (07) 4885 6903 or Team Leader (07) 4885 6900
Nambour	Nicole Henson	(07) 5470 5837 F: (07) 5470 5433	SC-Paediatric-Oncology-Team@health.qld.gov.au	Tue/Thu 0800 - 1630	Paulene Rogers NUM Paediatric Unit (07) 5470 6793
Rockhampton	Lori Nancarrow	(07) 4932 5004 F: (07) 4920 6452	Rockhampton_Paediatric_Oncology_Team@health.qld.gov.au	Thursdays and every second Wednesday	Sally Hillman, ANUM Paediatric Unit (07) 4920 6449.
Toowoomba	Elizabeth Ratcliffe	(07) 4616 6414 (07) 4616 6412 F: (07) 4616 6936	Toowoomba_Paediatric_Oncology@health.qld.gov.au	Tuesday to Friday	Andrea Barber, NUM Adult Day Oncology (07) 4614 5843
Townsville	Karen Beckett	0427 628 127 F: (07) 4433 2941	Karen_J_Beckett@health.qld.gov.au	Alt Mondays, Thursdays, Fridays	Sue Skimmer, NUM Paediatric Unit (07) 4433 2348



Queensland Government

RCM Contact List v20 08072013
Created by State Educator for QPHON QPHON@health.qld.gov.au

Version 20

News from RCH contd.

Pharmacy Department, Royal Children's Hospital

Does your child have a repeat prescription?

Pharmaceutical benefits - PBO/PBS1 AI4800011

Repeat authorisation

Valid until the supply of the medicine or until the next script is obtained

Prescriber no. 2495 Gun

Patient's Medication no. 95427 1 EXP: 30/09/2017

Patient's name and address

MRN Postcode RPBS

Authority no. Enrolment no.

Original prescriber (print or inscription item, strength, quantity, directions and contraindications if applicable)

Trimethoprim - Sulphamethoxazole (Septrin) 40mg-200mg/5mL Mixture 1.0 x 1

SHAKE WELL BEFORE USE and Give FIVE (5) mL by mouth twice a day on Monday, Tuesday and Wednesday of each week as directed by your doctor.

Original prescriber details

Date 06/05/2013

PBS approval no. HQ272F No. 1

No. of items already dispensed (including repeat scripts) if supplied in bulk 1

Priced items only \$

Name and PIC approval number of pharmacist dispensing this supply

Valid to 06/05/2014

Name and PBS approval number of pharmacist issuing the authorisation

Royal Children's Hospital Pharmacy Department Herston Road, Herston, 4029

Prescription no. this supply HQ272F 06/05/2013

Date this authorisation prepared

I declare that I have obtained electronic prescriptions for the information relating to my endorsement in a Pharmaceutical Benefits Scheme (PBS) and to determine payments due to suppliers in respect of this information and also the need to record details of an order or payment (prescription) for use in a repeat script in a payment of benefit under PBS or PBS1. With your consent, the PBS approval number in this information may be used for future prescriptions. The collection of this information is authorised by the National Health Act 1952. This information may be disclosed to PBS Suppliers, the Department of Health and Ageing, Department of Veterans Affairs, Canberra, the Department of Finance, the Department of Health and Ageing, the Department of Health Services or an authorised officer of the Department of Health Services.

Prescriber name: 2795969

Clinical unit: RCH

Date: 6 1 5 13

Item	Quantity	Qty disp	Supply Qty	Approval number if required
(a)	2	5	4	
	1	5	4	(3416T)
7/12	1	1	4	
2nd 4/12	20	20	4	(non-PBS)
3rd 1/12	1	0	4	(9441X)
				(non-PBS)
				(non-PBS)

Patent or pharmacist copy

- If you have a yellow sheet attached to your script – this is a repeat.
- This repeat allows the prescription to be dispensed again.
- You can leave your child's repeats at RCH Pharmacy or take them with you. Ask us about our easy RCH repeat service for scripts kept on file with us.
- **Some prescriptions need special approvals from the Government. It is difficult for your child's doctor to request another approval if there are still repeats left on the previous prescription.**
- If you think your child may have repeats on file at RCH Pharmacy – please ask us.
- If a repeat script is lost, it may not be able to be replaced.
- Please ask our friendly staff if you have any questions.

Prepared by PBS Officer at Royal Children's Hospital Pharmacy Department July 2013.

News from RCH contd.

Queensland Health

Important information

Removal of Secondary Safety Net

From 1 July 2013, the Secondary Safety Net (SSN) will no longer be available for pharmaceuticals dispensed in Queensland public hospital pharmacies.

The SSN financially assists patients requiring a large number of medications at the same time by capping the number of prescriptions they pay for to four.

Patients will have to make a co-payment for all their prescription items. For example, if you have five prescription items dispensed, you will need to pay a co-payment for each of the five prescriptions—the amount to be paid is no longer capped at the cost of four prescriptions. This change brings Queensland in line with the rest of Australia.

Financial assistance

If you are unable to pay for your prescriptions at the time of collection, we can provide you with an invoice with details on how to pay at a later date.

Commonwealth Safety Net

The SSN change does not affect the Pharmaceutical Benefits Scheme (PBS) Safety Net Scheme. Access to the PBS Safety Net Scheme will continue to be available to all Queenslanders. For information on accessing the PBS Safety Net Scheme visit:

www.humanservices.gov.au/customer/services/medicare/pbs-safety-net
or call 1800 020 613 (free call).

Further information and assistance

If you have any concerns about the changes you can seek further information at :

RCH Pharmacy, Level 1, Foundation Building
Tel: 3636 5022



Queensland
Government

News from RCH contd.

Children's Health Queensland Hospital and Health Service

Frequently Asked Questions

Removal of the Secondary Safety Net

What is the Secondary Safety Net (SSN)?

The SSN is also known as the 'four item rule'. It was a financial cap put in place by Queensland Health that limited the number of medications that had to be paid to four (4) items at any one visit.

Why is the SSN being removed?

The Queensland government is bringing its hospitals into line with community pharmacies and hospitals in all the other states by removing the four item rule. **The four item rule is being removed at all Queensland Hospitals.**

What will happen now?

After 1 July 2013, you will be required to pay for all medications issued to your child. Your invoice will **no longer be capped at four items**. You will receive Safety Net stickers for all the items you pay for. If you regularly get more than four (4) items, you will reach the PBS Safety Net a lot faster than when the SSN was in effect. The PBS Safety Net protects patients and their families requiring a large amount of medication.

How do I reach the PBS Safety Net?

The PBS Safety Net is reached by accumulating stickers to go on your blue **Prescription Record Form (PRF)**. These can be collected for all family members on the same PRF. They can be from community pharmacies, private and public hospitals. For more information on the PBS Safety Net please ask our staff at the pharmacy window. The leaflet entitled 'Pharmaceutical Benefits Scheme' also has information on reaching the Safety Net.

What if I can't afford to pay for my child's medication?

Until the PBS Safety Net is reached, the removal of the SSN may cause financial burden for some families. Pharmacy's invoicing procedures will remain the same. It is preferred that invoices are paid when medications are collected, however parents/carers also have the option of paying invoices by credit card over the phone. Please note; each invoice must be paid in full; partial payments for one invoice cannot be processed.

What about medications that are not covered by the PBS?

Many patients at the Royal Children's Hospital receive medications that are not covered by the PBS, or are not available at other hospitals or at community pharmacies. The cost of these medications will not change, but as stated above, payment will not be capped at four (4) items. If your child has a Health Care Card, the maximum co-payment you will pay for each medication will be \$5.90. If your child does not have a concession card, the maximum co-payment you will pay for each medication will be \$36.10. Nutritional products are on a different schedule.

2013 Youth Camp Update



The HFQ Youth Camp was held this year again at Emu Gully. This year our four wonderful youth mentors, Jamie Rogers, Adam Lish, Ian Zaro and Trace McKellar were the leaders under the supervision of Craig Bardsley and Alicia Fistonich. The entire weekend was the boys (with a few parent helpers) and was as usual a fantastic success. Thank you so much to our youth mentors—guys you make us all very proud. Below are some highlights and some of the feedback from some of the boys.

By Adam Lish
HFQ Board Member & Youth Mentor

Recently HFQ conducted their annual youth camp, held at Emu Gully adventure camp. This was the third year in a row we have run it and I am proud to say we had a tremendous turn out of boys who attended and achieved extremely positive result from the weekend.

This camp is designed to bring boys with Haemophilia out of their comfort zone and interact with others in their position to get through some of the most challenging activities Emu Gully has to offer. As a participant myself I can say that the character, teamwork and ability of all the boys was amazing. Our Emu Gully instructors Mitch and Al were very impressed with our efforts and can't wait to put us through our paces next year.

I'd like to put out to all the boys who attended the weekend and are reading this, thank you for coming out for the weekend and I hope it was well worth it. HFQ looks forward to running the event next year and we hope to once again do it bigger than the year before.



Sons comments

- Best thing about camp is making new friends
- The best activity was the army truck ride – really cool and lots of fun

Mums Comments

The benefit in my eyes is about giving kids independence. For boys who are experiencing difficulties with moving on to self-treatment in particular, camp offers a safe environment where they can experience life away from mum and dad and be supported by older kids who have already transitioned to the next phase. It's great for the boys' self-confidence and loads of fun too.



I thought the camp was excellent. Really worth the drive down (from Gladstone). They were a very nice bunch of boys. Good the see the older ones taking care of the younger ones. Thanks very much for organising it.

These are Jacob's words about camp

"Camp was interesting and fun. I really liked the food. My favourite activity was crawling through the tunnels. I liked seeing other boys doing their treatment and I will definately be going again next year"

Gene Therapy Research - Empty decoys divert antibodies from neutralizing gene therapy in cell, animal studies

Edited by David Stephenson

Gene therapy researchers have produced a bioengineered decoy that fools the immune system and prevents it from mistakenly defeating the benefits delivered by a corrective gene. The decoy was effective in animal studies, and if the approach succeeds in humans, it offers a potential new treatment for genetic diseases such as hemophilia, while advancing the broader field of gene therapy.

"This decoy strategy could be individualized to patients and could greatly expand the population of patients who may benefit from gene therapy," said study leader Katherine A. High, M.D., director of the Center for Cellular and Molecular Therapeutics (CCMT) at The Children's Hospital of Philadelphia. "Right now, 30 to 60 percent of adult patients develop antibodies that block the ability of an intravenously infused vector to reach the target cells in the liver. This approach holds the promise of overcoming this roadblock—pre-existing antibodies—and allowing successful intravenous gene therapy in virtually all adult patients."

High and co-corresponding author Federico Mingozzi, Ph.D., formerly of Children's Hospital, published the team's study today in *Science Translational Medicine*.

High, a Howard Hughes Medical Institute Investigator, has led pioneering investigations of gene therapy at Children's Hospital for the inherited bleeding disorder hemophilia and other diseases.

Previously, in clinical trials, High used adeno-associated virus (AAV) as a vector—a delivery vehicle—to ferry a corrective DNA sequence to patients with a mutation causing hemophilia B, the second most common form of the disease. The delivered gene enables the patient to produce a needed blood-clotting factor.

AAV does not cause human disease, but because we are routinely exposed to this virus, 30 to 60 percent of people develop antibodies that neutralize AAV if it enters the circulation. To extend the potential benefits of gene therapy to a broader population, researchers have long sought ways to better manage this immune response. The decoy strategy could solve this challenge for any disease in which vectors must be delivered through the circulation.

The current study by High and colleagues relies on a capsid, the protein shell surrounding a virus. Following in vitro studies in human serum, the researchers injected empty AAV capsids along with gene therapy vectors into a mouse model. The anti-AAV neutralizing antibodies bound to the capsid decoys, allowing the DNA-carrying vectors to evade the antibodies and enter the targeted cells in the liver.

The study team next engineered the capsids to disable their ability to enter target cells. This prevented the capsids from triggering a second immune response, from T cells, that also could eliminate the corrective genes. The gene therapy was safe and effective in rhesus macaque monkeys, which produced higher levels of clotting factor, with no adverse effects.

"Our results, which held up over a range of doses, suggest that in clinical studies, it will be feasible to adjust the ratio of empty capsids to gene vector doses, depending on an individual's pre-existing level of neutralizing antibodies," said High. "That means we could personalize gene therapy to make it more efficient for each patient."

"This work should make it possible to bring effective gene therapy to most adults with severe hemophilia B," High continued. "Each patient would receive a personalized final formulation that contains just the right amount of empty capsid to neutralize any pre-existing antibody, and allow the gene-expressing vector to reach the liver."

Source: [Children's Hospital of Philadelphia](https://www.childrenshospital.org)

<https://www.sciencecodex.com/empty-decoys-divert-antibodies-from-neutralizing-gene-therapy-in-cell-animal-studies-115923>

Dave's Updates from the Journals

Dave Stephenson the HFQ president spends a good deal of his personal time searching articles in journals for The H Factor. We are now going to dedicate a page to updates from the Journals which are all summarised by Dave. Dave gives the reference each time after the article if you would like to read further about the topic.

Is haemophilia B less severe than haemophilia A?

A number of observations suggest that severe factor IX deficiency (<1%) may be less clinically severe than the corresponding factor VIII deficiency: (i) Less factor consumption. There is evidence that patients with haemophilia B (HB) consume yearly less FIX for replacement therapy than patients with haemophilia (HA). Patient registries and data from various sources indicate that regular prophylaxis is implemented less frequently in HB. (ii) Less severe gene mutations. At variance with HA, missense gene mutations are prevalent in severe HB, supporting the view that some FIX may be produced in these patients, albeit not measurable in patient plasma by means of the relatively insensitive available assays. (iii) Less severe clinical symptoms. In the frame of a process meant to develop a score to express the varied clinical severity of both haemophilias in different patients, those with severe HB were less clinically severe, and hence had lower scores, than those with HA. (iv) Less need for orthopaedic surgery. Patients with severe HB needed joint arthroplasty (an indirect index of arthropathy severity) less frequently than those with HA, and this difference was maintained when various confounders were accounted for. In conclusion, these and other data give a hint that HB may be less clinically severe than HA. However, these data are not conclusive, because there are also fewer data in favour of a similar degree of severity of HA and HB. Source <http://onlinelibrary.wiley.com>

What should men living with severe haemophilia need to know? The perspectives of Canadian haemophilia health care providers

Haemophilia is a complex disease to manage. Home-based management of haemophilia has placed greater responsibility for disease management on individuals with haemophilia, heightening the individual's need for knowledge, particularly among individuals with severe haemophilia. The aim of this study was to identify and understand the knowledge needs and gaps of Canadian men with severe haemophilia from the perspectives of health care providers. A qualitative approach was undertaken. Data were collected using semi-structured focus groups and interviews with health care providers from Haemophilia Treatment Centres (HTCs) across Canada; data were analysed using thematic analysis. Three focus groups and two interviews were conducted; 13 individuals participated in this study. Health care providers identified the following areas of knowledge required by men with severe haemophilia: disease pathology, causes and consequences of bleeds, bleed prevention, recognition, treatment, how and when to access support, activity selection and risk reduction, benefits of exercise, genetic inheritance patterns, impact on career selection, travel and ageing. Knowledge gaps and challenges to knowledge provision were highlighted. In addition, providers emphasized the influences of timing, rapport and context on readiness to receive and assimilate information and recommended tailoring education to the individual and creating a developmental curriculum and knowledge assessment tool. Provision and uptake of disease knowledge is essential to patient self-management. To effectively receive, retain and assimilate information, individuals with severe haemophilia require the right information, from the right source, at the right time. Education should be tailored to the needs of the individual, provided throughout the lifespan. Source <http://onlinelibrary.wiley.com>

Osteoporosis in Men with Hemophilia -

Despite the commercials on TV, osteoporosis—a disease characterized by weak, brittle bones—doesn't just occur in older women. When Joe Nozemack, a publisher in Portland, Oregon, fell in the bathroom, he sustained a hairline fracture in his left hip. A bone scan showed that he had osteoporosis. He was 33. "I was not too surprised," says Nozemack, now 41. Difficult-to-treat childhood bleeds from his severe hemophilia A and inhibitor led to target joints in his elbows and knees. Consequently, Nozemack wasn't very active. "One of the things that generates the bone density is activity," he says.

There may be a connection between hemophilia in men and earlier onset of osteoporosis. Further, having the added diagnoses of HIV and hepatitis C may also contribute to loss of bone density. Until there are more clinical trials on men with hemophilia, the exact causes of their osteoporosis remain uncertain. Without standards of care, there is no clear consensus on screening and treatment. Talk to your Haemophilia Treatment Center on your next review and if you haven't had a review in some time you should make an appointment today. Source = <http://www.hemaware.org/story/osteoporosis-men-hemophilia>



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