

# The 'H' Factor

Issue 37

Summer 2013

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## A New Year Approaches and World Congress comes to Aus.

### Erl tells you why you should attend the World Congress.

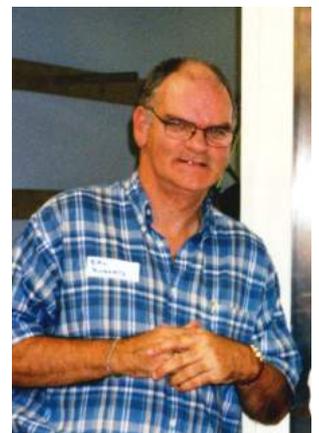
I had heard about the World Fed and what they were doing from the literature that came to HFQ and the work I had done with HFA over the years. I was always interested to go to an international conference to be able to talk to people from other countries, you know, and what an eye opener that was!



The reason why people, if they ever get the opportunity, should go to international conference, is because we are in such an isolated, fortunate bubble, in Australia. You can meet so many different people from around the world. It's terrible that so many people from developing countries still have no treatment. They have to live like we did in the early days when we didn't have clotting factor and the older guys in Queensland like me know what it's like.

I remember meeting people at Congress who really struggle because they have little or no treatment back at home. It's a massive eye opener to meet these people & talk to them. Some people can treat while at Congress but then they go home and there is little treatment for them. It's sad. I will always recall a guy I met who had just one leg and then he had to have his second leg amputated after a massive bleed that turned to gangrene. Imagine it, this is haemophilia, we would not imagine this sort of thing happening in Australia. We also have a responsibility to try and change this. That's an important part of the Congress.

You have plenty of opportunity over a five day conference to talk to people and mix with people - you have meals, social functions and breaks . Make contacts. Apart from that you've got international speakers covering all the topics



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<https://www.facebook.com/HFQLD>



## President's Press

Hi everyone,

Although we are nearly at the end of another year with Xmas around the corner, its really the start of a new cycle for HFQ with our new manager Graham. Liz who you all know has handed over the keys to Graham after introducing him to the world of bleeding disorders and what that means to support all those touched by bleeding. Please join me in thanking Liz for her fine efforts that has framed HFQ in a very proactive, output focused community needs driven picture, drop her a thank you. We all wish her well for the future!

HFQ delegates ( Sarah our secretary and myself ) along with Graham met up with other state delegates for the HFA AGM. This is always an opportune venue to come together bringing ideas and experiences to the one table, working like this is key to achieving national and local goals and ensuring services that we all take for granted like product, choice, medical / social issues, National Disability Scheme advocacy, viral etc etc remain significant. I notice in some other parts of the world governments are questioning costs – HFQ / HFA maintains a voice representing your balanced needs in measured, cost effective services across community.

The National Blood Authority attended and presented a picture of what they do and it was interesting to note that , unlike previous years, the clotting factor usage has stabilised but is still a significant cost at around \$165 million dollars a year – you all realise we are living in the lucky country! There was also discussion about the upcoming tender which may mean

product change for some. The question was asked about risks in relation to inhibitors which does seem to be a common concern for many community members, however there is currently no evidence to indicate there is any concern. I was reassured NBA take safety and efficacy as a priority over cost. It's way too early to know what, if anything will happen in relation to tenders, stay tuned.



So as the year draws to a close we can be proud of HFQ achievements, these have been: Life enhancement seminar, Newsletter, GP training day, Youth mentor training, Youth Camp, Family camp, Newborn lunches, Ladies luncheon, OBE's meetings and Regional lunches – Cairns, Townsville, Mackay, Gold coast with the addition of Toowoomba, Sunshine coast & Rockhampton, as well as working with HFA.

So thanks everyone for supporting each other through HFQ, together we can and make a difference.

*Dave*

**David Stephenson** ( President)

HFQ.....Advocacy, Health promotion, Support

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**Disclaimer:** All articles, advice and information included herein are written by various individuals who volunteer their input. While the 'H' Factor magazine puts every effort into providing honest and accurate information and where possible, reference to research articles are made to validate content, it cannot be held liable for any errors or inaccuracies in published articles. The views expressed in this newsletter are not necessarily the opinions of the Editor, their associates or supporters. Publication of contributions will be at the discretion of the Editor. Any articles containing racist, sexist, homophobic or defamatory remarks will not be published. Other original contributions and letters are welcomed and encouraged. Articles in the 'H' Factor cannot be reproduced without permission.

## ABOUT HFQ

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

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

- ◆ **Medic Alert bracelets (50% discount)**
- ◆ **Electric Shavers (up to \$75 off)**
- ◆ **Supportive footwear (75% off)**

### HFQ Management Committee

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

### HFQ Delegates to HFA

Mrs Sarah Hartley      Mr David Stephenson

### About The H' Factor

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

**Graham Norton**  
HFQ Manager & The 'H' Factor editor

## Queensland Haemophilia Centre Contact Details

### ROYAL BRISBANE AND WOMEN'S HOSPITAL

Dr John Rowell — Haematologist	3646-8067
Beryl Zeissink — Nurse	3646-5727
After Hours — Page Haematologist	3646-8111
Michael Hockey — Physiotherapist	3646-8135
Maureen Spilsbury — Snr social worker (Mon-Thur)	
Mona Chong— 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 — Psychologist	3646-7937
After Hours—Banksia Ward	3636-7472

## HAEMOPHILIA CLINICS

### RBWH

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

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

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

### RCH

Phone Joanna about appointments

Banksia Outpatients — Dr Simon Brown — Thursdays at 2.30pm

### OUTREACH CLINICS

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

Book through Joanna at RCH and Beryl at RBWH

### LADIES

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

# Beating the holiday blues!

'Tis the season to be jolly... really? The festive season can bring about a myriad of emotions. If you have lost a loved one or something important in this year, it would be difficult to celebrate Christmas joyously. If you are blessed with having loved ones, the increase in demand; shopping, entertaining, planning, budgeting etc - within a looming deadline can result in stress and lead to distressing feelings of frustration, anxiety and even anger. Often it is because we fail to prepare, over-commit, and / or overextend ourselves.

With some practical strategies, you can navigate this festive period more successfully.



can leave you feeling resentful and overwhelmed.

**8. Stick to healthy habits.** Have a healthy snack before holiday parties so that you don't go overboard on sweets, cheese or drinks. Continue to get plenty of sleep and physical activity.

**9. Take a breather.** Make some time for yourself. Spending just 15 minutes alone, without distractions, may refresh you enough to handle everything you need to do.

**Seek professional help if you need it.** Despite your best efforts, you may find yourself feeling persistently sad or anxious, plagued by physical complaints, unable to sleep, irritable and hopeless, and unable to face routine chores. If these feelings last for a while, talk to your doctor or a mental health professional.

In emergencies please call Lifeline 13-11-14

Dr Desdemona (Mona) Chong,  
Advanced Clinical Psychologist  
RBWH

P: 36468769 Work Day; Fridays

**1. Acknowledge your feelings.** If someone close to you has recently died or you can't be with loved ones, realise that it's normal to feel sadness and grief. You can't force yourself to be happy just because it's the holiday season.

**2. Reach out.** If you feel lonely or isolated, seek out community, religious or other social events.

**3. Be realistic.** The holidays don't have to be perfect or just like last year. As families change and grow, traditions and rituals often change as well. Choose a few to hold on to, and be open to creating new ones.

**4. Set aside differences.** Try to accept family members and friends as they are, even if they don't live up to all of your expectations.

**5. Stick to a budget.** Before you go gift and food shopping, decide how much money you can afford to spend. Then stick to your budget.

**6. Plan ahead.** Set aside specific days for shopping, baking, visiting friends and other activities. Keep things simple.

**7. Learn to say no.** By failing to say "no", we say "yes" to more than we can comfortably handle. It

Information for this article was taken from the following websites

<http://www.mayoclinic.com/health/stress/MH00030>

<http://www.stressaffect.com/coping-with-holiday-stress.html>

## Research Help Wanted

In 2014 the Haemophilia World Congress comes to Melbourne and we are encouraging people to attend. There will be many opportunities to learn how healthy we are and what we can do to improve our wellbeing. One presentation has asked us for help and in turn I hoped you may be able to help us also. It's an on-line survey that asks people with bleeding disorders to anonymously report how well they are. It closes at Christmas so the results can be analysed and presented at congress.

If you have 10 minutes to spare over the holidays, please give something to HFQ this Christmas

Continued on next page →

# Hydrotherapy and Haemophilia

Hydrotherapy refers to the use of movement through water for therapeutic purposes. The use of water based exercise dates back many centuries and continues to be one of the most effective therapy options for many musculoskeletal ailments.

Hydrotherapy takes advantage of the physical properties of water and how these affect the body.

Some such properties are buoyancy, hydrostatic pressure, temperature and turbulence or resistance. Buoyancy is one of the most beneficial physical properties of hydrotherapy. Exercising in water allows the practice of movements such as walking, without 100% body weight loading the joints of the legs. When standing in water up to the height of the naval, the load through your feet is approximately 50% of standing on land. That load is decreased to around 10% when the water level is at neck height. This is beneficial in rehabilitation post joint or muscle bleed or surgery. It is also a very effective way of exercising, and thus strengthening and improving the range of motion of arthritic joints.

Hydrostatic pressure refers to the compression effect that water immersion provides. It is thought that this sensory input assists with the activation of muscles and in decreasing pain associated with the movement of sore muscles and joints. A range of temperatures are used to different effect depending on the aim of the therapy. Many sports people use ice baths after a competition to assist with a speedy recovery and though many people don't like the sensation of getting into cold water it is actually a very effective way of managing pain and inflammation. More typically though, in hydrotherapy

a warmer water temperature is used. Often Japanese Onsen's are of a temperature of 40 degrees or more, aiming to improve peripheral circulation and decreased blood pressure.

Most modern dedicated hydrotherapy facilities tend to use a pool that is heated to 30-34 degrees

celcius. This is a good temperature to help loosen joints and muscles whilst not causing the patient to overheat when performing exercises.

The final positive physical property of water to discuss is turbulence or resistance. The movement of the body through water is resisted by the water both in front of the movement, and also by the turbulence behind the movement. This effect can be

increased by using a device such as a hand paddle when exercising the arms. The resistance can be gradually increased as strength and stability is improved. Both the core muscles around the abdomen and back, and the peripheral muscles on the arms and legs can be exercised very effectively in this way.

Many people who participate in hydrotherapy for rehabilitation or general health and well-being attest to its effectiveness in improving strength, stability and flexibility. This translates into improved function in day to day physical activities, and ultimately an improved quality of life.

The Royal Brisbane and Women's Hospital has a world class dedicated hydrotherapy pool, one of only a handful in the southern hemisphere. Michael, the Queensland Haemophilia Centre Physiotherapist regularly uses it in the rehabilitation of patients with bleeding disorders.

*Michael is looking at starting a dedicated hydrotherapy class for people with bleeding disorders in the new year. This would be for patients looking to recover from a specific injury, or just hoping to improve strength, flexibility, core stability and quality of life! If you are interested in participating in such a class please get in contact with Michael directly on 3646-8135 or through HFQ.*

*From previous page*

...your time! It only takes ten minutes to complete the survey at <https://es.surveymonkey.com/s/hemophiliawellbeingenglish>. If they don't have online access they can call me and I will do it over the phone on their behalf.

If we get enough people completing this anonymous survey, Prof Remor has said he will separate out the Australian data so we can know something about our own collective perceptions on wellbeing. This will help HFQ plan activities for the new year and to ask for help and funding on the issues they identify.

## RCH PsychoSocial News

Hi all,

I thought that it might be worthwhile providing a refresher about my role as the psychologist at the RCH Haemophilia Treatment centre and what this entails.

My role is to help the Haemophilia Team provide comprehensive care for the families of children with haemophilia/bleeding disorders and their families through the provision of psychosocial support.

This can involve:

- Advocacy on behalf of the child / parent / family with government and non-government agencies, schools etc.
- Social support such as when haemophilia is impacting on the family or when other stressors maybe impacting on the treatment of haemophilia.
- Individual (child, adolescent and adult), couples, family counselling

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## RBWH Social Work / Psychology News

SOCIAL WORK NEWS – Qld Haemophilia Centre  
RBWH

1. Have you read the most up to date information regarding **HEPATITIS C**? What is the latest news on the topic of interferon-free treatment? What are the response rates with Bocprevir and Telaprevir? Do you know what a Fibroscan measures? For the answers to these questions and many more go to the Hepatitis Australia website at [www.hepatitisaustralia.com](http://www.hepatitisaustralia.com) or the Hepatitis Queensland website at [www.hepqld.asn.au](http://www.hepqld.asn.au) The HFQ and HFA newsletters and websites are also a good way to stay up to date with the latest information.

It's very important that this issue doesn't get forgotten in the busyness of life and staying informed about the latest developments can help you make the best decisions regarding your future health care. Don't forget to come along to regular haemophilia clinics at the RBWH to discuss your own particular situation.

2. Did you know that you can ask to see a Social Worker at **CENTRELINK** if you require more information about a decision that is made regarding

payments? They can also offer support and information regarding government and community support services. You can make an appointment at your local service centre or call **132 850** to speak to a Centrelink Social Worker.

3. Undercover **CARPARKING** for visitors to the RBWH operates 24 hours a day, 7 days a week. *Metro Carpark* is on Butterfield Street and is the closest carpark to the main RBWH buildings. They can be contacted on (07) 3252 4333. Ask Mona or Maureen about a 5 day (consecutive days) visitors pass which costs \$75. *Wilson Carpark* is on the corner of Herston Road and Gilchrist Avenue. The hospital is connected to this carpark via a walkway on Level 6 in the Ned Hanlon Building or on the ground level along Bowen Bridge Road.

4. Abraham Lincoln said .....**"A GOAL properly set is halfway reached"** and Vincent van Gogh said **"Our goals can only be reached through a vehicle of a plan, in which we must fervently believe, and upon which we must vigorously act. There is no other route to success."** If you would like to know more about how to identify, develop, plan and achieve your goals contact us for a chat.

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## Erl's Congress Encouragement *cont from page 1*

relevant to haemophilia. You have the opportunity to talk to these people either after their talk or at some social event later on over a cup of tea. I mean if you've got problems with whatever it is, your joints, your liver, or hepC or any viruses; you have this opportunity to talk to people who are experts. What is the latest? I'm desperate to know! They are there to talk to. Massive opportunity.

Congress is a very positive experience. I mean, even with the sad stories you hear from other countries; and people should not be scared of the medical nature of the congress. In Australia we are fairly well informed, we get a lot of information; we know the technical terms. Information turns up in our newsletters, we go to clinic regularly, it won't be a problem at all. Yes, there are some highly technical, medical meetings that happen, but they are all usually within the medical professional stream. These are not meetings you have to go to, but the ones that are aimed at the whole group are held as concurrent overlapping sessions, so never feel afraid that you're going to get lost in the technical detail because a lot is delivered in a fashion you'll be able to understand and as I said, afterwards you'll be able to meet with these people, and talk to them, sort things out that you don't understand, things which are confusing you and get it in layman's terms.

You definitely should make a big effort to go to Melbourne because this time the world is coming to us. It's a huge opportunity for everybody in Australia to go to an international conference when it is pretty much just down the road, you really should go. To have those speakers on hand and not go when other

conference attendees are travelling across the globe is madness! It's not really that far at all!

To get the most out of the conference think about your accommodation and mobility. You can get reasonably priced accommodation 500 or 600 metres from the conference centre but it's a big area in itself; a physical space you've got to deal with, so remember to bring all your mobility aids and pace yourself. You need to get your conference kit early. And you need to look at your program seriously and carefully. Set aside somewhere to look through it carefully and pick out what you want to go to. And then you have got to work out for yourself which ones you can actually make it to. You might have to prioritise because with the concurrent programs you may not be able to attend everything you want to, so also talk to other people down there. What are they doing? Who are they listening to? Always bowl up to people and have a chat with them, find out what they're doing.

They will have places set aside to rest up, plenty of chairs around and some mobility aids you can borrow. There will be a treatment room if you need it, but they expect you to bring your clotting factor with you. The overseas guys appreciate being able to use the treatment room. During the talks there will be breaks, or times between sessions or at meal times where you have a chance to go through and look at the posters and at the exhibition. You can talk to exhibitors about treatment and care and all sorts of things. It's worthwhile talking to them and you get all kinds of literature you'll want to cart home to read. So; somewhere along the line make sure you do spend time checking those extra things out.

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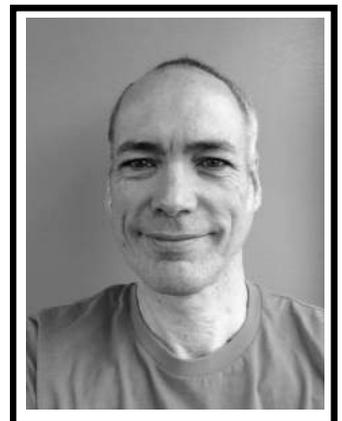
## Introducing Graham

Who is this new man replacing Liz, I hear you ask? According to an acquaintance of mine, I am of an age where I should know better but do things anyway; which seems strangely appropriate for this role.

Having spent my formative years in New Zealand, famed for its sheep and exporting anyone with an IQ over 100, I am still confused and unsure of what I would like to be when I grow up. I started working life drawing charts for the navy and progressed to working with people as a mediator and then health promotion in NSW.

When this began to pall I moved to Queensland to offer the limited pearls of wisdom I had gained managing a state health promotion team for Healthy Communities. Now I've taken on Liz's old job so I can do real work helping the community and moving HFQ forward to embrace the increasingly complex needs of our membership.

Please call me at the office on (07) 3338 5645 or email [info@hfq.org.au](mailto:info@hfq.org.au) if you'd like to say hello or have things you like to discuss about the organisation.



# Ability & Mobility, not Disability with Segway



Disability, it takes many forms and for those that cannot safely use wheelchairs or scooters it presents a significant quality of life issue in getting around, something that the majority of people simply take for granted. So it was with much anticipation that Segway mobility arrived on the scene in Qld. It's introduction, although not really focused on disability or mobility issues, for me has jumped my quality of life to a new level.



Before Segway, I was looking at early retirement as walking any distance was an issue, but now it is no longer a problem. Whether it be at work in the office or enjoying the best of Brisbane at South Bank in the great Qld

climate, Segway has provided a safe and intuitively easy method of transport. They can travel up to 30km on a single charge, can traverse uneven ground, reach speeds of 20km/hr all on a small footprint.

Transporting the Segway at 54.5kg is much like an electric wheelchair so you would need a station wagon with ramps or a boot lift. It has been designed with impressive safety features and is extremely safe to use. It's not waterproof but is fine in all but major downpours. I must thank the current government for its proactive approach in changing the law to make it legal to use on foot and bike paths, as well as 'Segway Qld' for their support. I can now remain as an effective working member of the Qld community with a healthy engaged lifestyle.

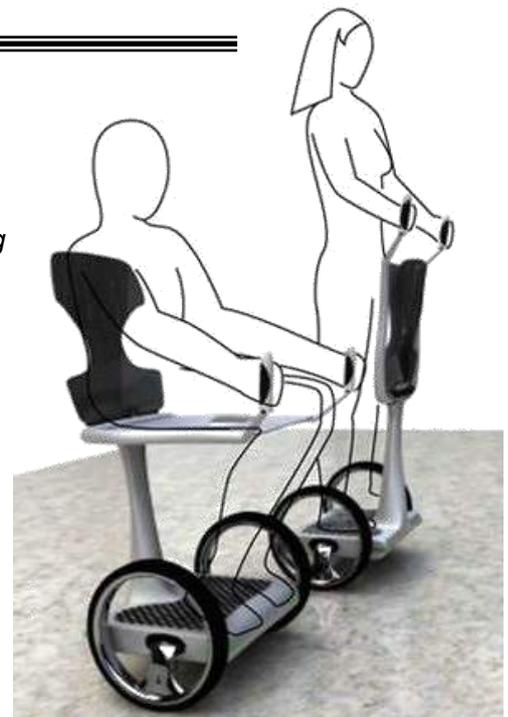
The only problem is my wife wants one.

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## Editors Comment:

People with all sorts of disabilities (MS, Parkinson's, knee injuries, etc.) are writing about the Segway saying it has changed their lives, restoring some normalcy, but there is still some way to go before legislators and the community view it as more than a snazzy personal mobility device and start to see it as a legal "disability assistance" device.

While Dave, like others, loves the Segway; it doesn't fit wheelchair ramps when fitted with some tyres and there are other minor issues that will need to be addressed over time. But designers are already working on modified units. For example, one prototype I would gladly break my leg if it meant that I got to ride it is the EAZ Disabled Mobility Device. It is designed to be used in both an upright and sitting position. This makes it perfect for people who would normally require a wheelchair or a walker. Okay, maybe that's a little bit of an overstatement to say I'd break my leg, but this innovative wheelchair/Segway from designer Grayson Stopp is still incredibly cool and innovative.



# Getting the help you need

## — Now and when the NDIS rolls out

Currently anyone with a bleeding disorder can access government welfare and assistance through the Queensland Haemophilia Centre. Adults through the Royal Brisbane and Women's Hospital, and children through the Royal Children's Hospital. The physiotherapist is able to provide individual assessments and exercise programs to enhance or maintain physical function. This includes improving mobility, strength, flexibility and endurance.

They can also provide referrals to services that assist with daily living and mobility aids. These include orthotics, assistive devices for daily living tasks and mobility aids such as wheeled walkers or wheel chairs. In some cases assistance can be provided with applying for funding to subsidise these products.

The Physiotherapist and Social worker can also work together to assist those who are seeking suitable employment, whether it be for the first time or to return to the work force. The social worker can also help you connect with Centrelink who provide



support for people needing assistance because of disability or age.

In the future the National Disability Insurance Scheme will fund individualised support for people with disability that should give more choice and control to a person's support needs.

It was started by the previous labour government and was legislated with bi-partisan support, but it may yet have changes made to it by the present government. It will focus on early intervention, recognising that timely support can minimise the impact of a disability. It will provide assistance at the right time, rather than only once people reach crisis.

The National Disability Insurance Scheme (NDIS) began being rolled out from July 2013. It is now called DisabilityCare Australia. Roll out of the full

scheme in Queensland will commence progressively from July 2016 and by July 2019, all eligible Queensland residents will be covered.

If you are eligible, DisabilityCare Australia will work with you to:

- develop an individual plan to help you achieve your goals
- consider the supports needed to strengthen family and informal caring arrangements, and
- connect you to mainstream services and community supports.

Eligibility is based on having a significant permanent disability and:

- needing assistive equipment or home modifications to join in activities or do things, or
- you usually need support from other people to join in activities or do things at home or in the community.

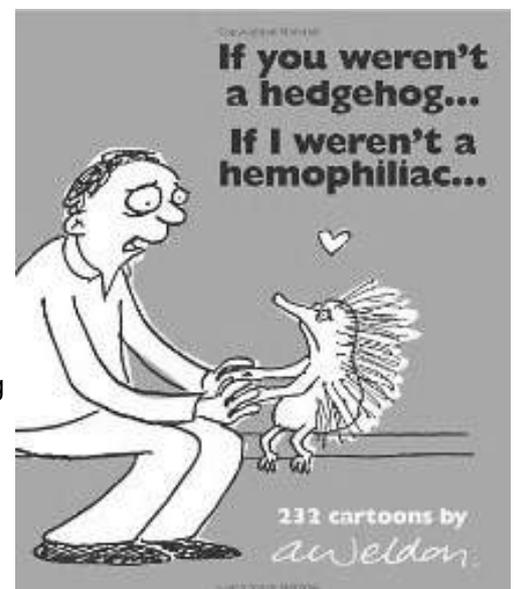
Disabilities may be attributed to intellectual, cognitive, neurological, sensory, or physical impairments, or a psychiatric condition.

You will also need to be aged under 65 when you first become a participant with DisabilityCare Australia.

DisabilityCare Australia should give every Australian the certainty of knowing that if they or a loved one has a permanent and significant disability, they will get the support they need.

Through DisabilityCare Australia, thousands of Australians start to receive individual support, more choice, and greater control over the support they receive. People with disability will be better supported to live their life and achieve their goals.

Once it is rolled out around the country, DisabilityCare Australia will support around half a million Australians living with a permanent and significant disability.



# MyABDR update

Suzanne O'Callaghan, Haemophilia Foundation Australia



With its first release due in February 2014, the MyABDR project is moving ahead at a rapid pace.

MyABDR will be an exciting new online tool to help you record home treatments and bleeds, stocktake and update contact details using a secure app for smartphones and/or a computer web site. It will

link directly to the Australian Bleeding Disorders Registry (ABDR), the system used by Haemophilia Centres for clinical care of their patients. For people who prefer a paper-based recording system, this is also being developed alongside as an alternative.

The collaboration between HFA, the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) on behalf of Australian governments has given the project real energy and a wide range of expertise to call on.

## Focus group testing

People with bleeding disorders were involved early in the development phase. The MyABDR community survey in mid 2013 was followed by a focus group workshop in October. Seven individuals with diverse treatment experiences from around Australia met with the HFA and NBA MyABDR project team in Melbourne. Their job was to do intensive alpha testing – initial product testing of the first prototype - and give feedback on how it would work with their normal treatment and recording routines. There were lively discussions and suggestions and the consensus was that the prototype was looking good.

HFA Council delegates and haemophilia health professionals have also given feedback and suggestions at previews at their annual meetings.

## Community testing

The NBA technical team is currently reworking MyABDR in preparation for the next step in late December 2013 – beta testing of the revised prototype to fine tune the detailed design and iron out bugs. As well as another workshop, a larger community focus group will be involved in beta testing on their smartphones and computers at home.

## MyABDR features

Features in the first release version of MyABDR will include:

- Default settings for recording treatments based on last details entered for each treatment type
- A body image with a pop-up list to identify the location of the bleed
- Detailed notes field
- An easy to use inventory section to manage the stock you have at home
- Family logins to switch between multiple family members
- Able to update height and weight, contact and delivery address details
- Screen displaying treatment plan
- Reports of treatment and bleed histories – these can be printed from the computer web site version.

Other features have been staged for the next versions of MyABDR. Some rely on current projects - for example, standardising barcodes to include barcode scanning in MyABDR.

If you are interested in home testing, please contact Suzanne at HFA on [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au) or phone 1800 807 173.

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## In Memory of Luciano Capocchi

We are deeply saddened to report the death of Lou, on Thursday, November 14 Lou Capocchi, veteran volunteer, passed away in Cairns. With his passing Haemophilia Foundation Queensland lost one of our long standing north Queensland supporters.

Lou was an inspirational member of HFQ, and we are extremely proud to have had his help across the years. He was first in line to help when HFQ needed support in north Queensland and was the teller of many stories with which he shared his experiences and inspired others.

He will be deeply missed by the board of HFQ and those members who knew him. Our deepest condolences are extended to Faye and her family.



# Tattoos and Bleeding Disorders

## How to enjoy body art without compromising your health

It seems everyone has tattoos. Teens, dads, mums, young, old... they are as commonplace as pierced ears. It makes sense that people with haemophilia will have tattoos as well. Some of our members do. As do their moms, probably!

Tattoos not only make a statement, but also tell a story. In 2012, 20% of Americans had a tattoo. People with bleeding disorders are included in this number—demonstrating that they can also enjoy body art, with proper precautions.

Some tattoos are sentimental. It might be a blue tongue lizard or a gecko skittering up your arm like the ones you used to chase as a kid. Some are symbolic. Tim Andrews the director of a haemophilia camp in the USA, designed his own tattoos and shared it with friends from camp, who have “blood brothers” incorporated in the design. “It’s a way to personalize yourself,” says Andrews. “a way to give a message or a cue to society.”

## Tattoo Precautions

But before you book your tattoo appointment, talk to your haemophilia treatment centre (HTC) staff. Chances are they have experience with patients who’ve gotten body art. The best advice is to infuse first! Andrews infused his regular factor dose the day he got his tattoo and the following day. “I had no complications because I treated properly,” he says.

Tattooing can be painful and/or traumatic, even for people with bleeding disorders who deal with routine needle pokes and pain. “The one on my chest was painful,” Andrews says.

If you still want to go ahead, choose an experienced tattooist whose premises are registered with the council. Make sure the tattoo parlour you choose looks clean, safe and professional. Check that the tattooist uses new, sterile equipment for each client, or thoroughly sterilises their equipment with an autoclave before use. If a parlour looks dodgy, trust your judgement and keep away.

After tattooing your body, the operator should clean your skin with an anti-bacterial disinfectant, using pre-dispensed cleaning solution and single-use wipes, apply antiseptic cream from a single-use container to the treated area of skin and cover the site with a sterile dressing. Aftercare for a new tattoo involves washing with antibacterial soap and applying ointment, then finishing with lotion.

Failure to do this has the potential for the tattoo to cause problems. Unsterilized needles could spread HIV, HCV and bacteria. Your body can form

granulomas, small bumps around particles of pigment, or raised scar tissue. Some people develop allergic reactions to the inks or pigments. Even temporary tattoos from so-called black henna can cause problems. While traditional henna, a brown dye made from a tropical plant, is typically safe for skin tattooing, black henna is not. It contains an ingredient used in black hair dye that is not approved for skin use. Skin reactions reported included redness, blisters, weeping lesions, sun sensitivity and scarring.

## Your Art Gallery

Tattoo remorse is real! In 2011, more than 100,000 tattoos were removed by surgeons in the USA. Such procedures can call for months of treatments that can cause bleeding, redness and soreness, and take weeks to heal.

Where you have your tattoo can also have future ramifications. If you want to go into many professional occupations you may want to keep tattoos in places that you can conceal! Nearly 40 percent of people have had tattoos removed because of a new job or career. Other reasons included embarrassment, problems with clothing and feeling that tattoos degraded body image.

The best overall advice: Avoid making a hasty decision when choosing to get a tattoo. “Wait until you’re sure you know what you want,” Andrews says. If you want a tattoo, take your time to think about it and wait until you’re at least 21, because what looks “cool” today might turn cold later.

Edited from an article originally published in: <http://www.hemaware.org/story/tattoos-and-bleeding-disorders>



7-9 March 2014.  
Get ready to let loose,  
have fun and enjoy!

**HFQ's 2014  
Weekend Camp**  
for the community is  
being held at Noosa  
North Shore Retreat,  
Sunshine Coast  
**LIMITED PLACES**



Yippee!!

TIME FOR FRIENDS...

I hope we're going to  
the 2014 HFQ  
Community Camp

Meet up with everyone  
Say Hi to old friends and  
meet new friends.  
Activities for kids and  
adults, which will include  
Health and wellbeing  
sessions presented  
by the team from RCH and  
RBWH. Social Times, Fun  
Times. Surprises and  
Support.



Fun for all  
the family

Book Now!

Safe family  
friendly  
atmosphere.

Looking forward to  
seeing you there!

Contact Graham at  
HFQ to register  
your interest for  
this years camp.

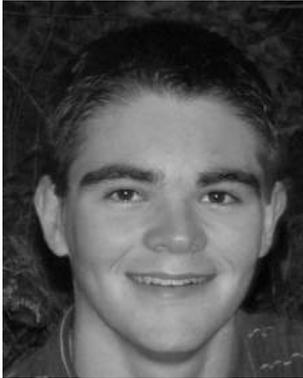


Haemophilia Foundation Queensland

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Mobile: 0419 706 056



# Living Life Full Throttle



While the Australian heroes of Motorsport retire around us, HFQ is pleased to offer a hot tip for a bike rider worth following. He's not Australian but he is living life to the full and living with haemophilia. Austin Shaw-O'Leary is a 17 year old Canadian living his dreams and aiming for the big time.

Last year Austin competed in the final round of the Spanish Moto2 Championship in Valencia Spain and this year Austin he turned Pro, winning the Pro Superbike Championship & Pro Sportbike Championship in Atlantic Canada and finishing 4th overall in the in the Canadian National Championship. Next year he wants to continue to grow his race craft and work to compete overseas, possibly in the AMA Pro Racing Series in the United States or in British Supersport in the UK. Austin is a sportsman on land air and water as he is also keen skiing, boating, and he wants to learn to fly!

Austin is also making sure he takes time to visit other people with bleeding disorders and is an example of life lived to the full. If you want to follow Austin or have other dreams always check it out with your HTC Clinical staff so you know how to maximise the fun and minimise the bruising! Austin is a young man with a future in need of support (fans and funding) if you want to follow or support him, check out his website at [www.AustinShaw-O'Leary.com](http://www.AustinShaw-O'Leary.com)




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## Australia's New eHealth Record System

When you're regularly treated by different healthcare professionals, it can be challenging to keep track of all your health information.

The Australian Government's personally controlled electronic health (eHealth) record system will help you take control of all your health information and help your doctors to provide you with the care you need.

### Why choose an eHealth record?

Depending on the level of severity, haemophilia may have little impact on your life or it may be a complex condition to manage. Having an eHealth record means you, and healthcare organisations you authorise can quickly access information regarding your health.

**Clear information** – A summary of your most important health information will, over time, mean your healthcare professionals have an understanding of your health status.

**Less stressful** – Better connected health records will mean you will not have to remember every medication or health-related incident, or unnecessarily repeat tests.

**Safer** – The healthcare organisations you authorise will be able to access your key information, such your haemophilia type as well as details of previous adverse reactions to medications or allergies. Even when you

are travelling, local healthcare professionals are able to access your records to provide the appropriate care you need.

**Better self-management** – You can keep your own notes in your eHealth record to better track your progress, response to treatments and medication through to diarising any bleeding episodes.

**Share the load** – If you wish, you can nominate a trusted person, like a carer or family member, to view or manage your eHealth record.

**Emergency help** – Healthcare organisations can temporarily access your eHealth record in an emergency to ensure you get the best care.

### What will my eHealth record look like?

Information already available for you to have in your eHealth record includes Medicare data such as details of medications and medical checks for which a Medicare or pharmaceutical benefit was claimed.

Your eHealth record can also hold your details about the location and custodian of your advance care directive, if you have one.

Your doctors, nurses and other healthcare specialists will also be able to add clinical information to your eHealth record as their organisations connect and

*Continued on P 16*

## HFQ Functions for You!

If Haemophilia Foundation Queensland is to be a successful organisation it has to provide what people with bleeding disorders in Queensland need and support the work done by haemophilia treatment centre staff. We do this through social functions, individual support as well as financial support and advocacy where we can. Each year we want to enable meetings of members in their local areas and state wide where there is a need.

Recently we had a Christmas function in Brisbane and several regional end of year functions are also planned. In the new year we have our community camp scheduled for March. If you and / or your family would benefit from coming to this camp, please talk to Graham or the haemophilia treatment centre staff about how we can help make this happen.

We have also booked a camp for our young men in August. This was highly successful last time and if you are interested, or have a son who might be interested in attending, please contact Graham for more information.

## RCH PsychoSocial News

Family support program – The Family Factor utilises a holistic approach to family support. This means that issues and challenges specific to a family that may have the potential to negatively influence child developmental outcomes are identified and then goals are set and treatment provided to address such issues.

I provide the above services in different settings and modes of delivery. As I am a member of the multidisciplinary Haemophilia Team you will see me at the RCH at clinic reviews, or in the inpatient or outpatient wards. For appointments I often see parents in my office which is based on Level 4, Joyce Tweddell building at the RBWH and occasionally I home visit families. Hopefully in the near future we will be able to use skype to communicate with regional families but in the meantime the phone is a reliable way to keep in touch, along with emails. So feel free to give me a call or send me an email, or have a chat if I see you at the RCH.

### The Family Factor

Currently we involved in a collaborative research project with Dr Paul Harnett from UQ aimed at assessing the effectiveness of the Family Factor as mentioned above. I'd like to send out a big thank you to those parents who have volunteered to participate and hope they are finding it helpful. I am

*I would gladly welcome ideas about any particular things you are interested in reading more about*

learning a lot from the parents about the intricacies of daily life of families of boys with haemophilia. It's not too late for any parent interested in participating to get involved; just give me or Joanna a call.

To help me keep this section relevant to the families of the children with haemophilia I would gladly welcome ideas about any particular things you are interested in reading more about or perhaps you might like to share a little parenting gem yourself.

Just to get things started here is a little snippet from The Family Factor program concerning practical everyday things that parents can do to help children feel good about themselves whilst at the same time passing on important family values.

**Praise them** when they do something that you like, and you want them to do it more often. It's a very simple way to pass on the values you want to instil in your child. So if family values include the importance of taking care of others then tell them how well they did sharing a toy with their sibling or something along those lines. If giving things a try is a family value, then tell them what a great job they did when they let mum or dad access their port or veins when they were a bit worried. **Be specific**, so instead of just saying "good job champ" or "you're awesome" follow it up with what behaviour they just did.

## H Date Claimer



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

Fun activities from Swinging logs to Commando Cable Crossing to Rock Climbing and a High Adventure Night Walk. For info check out their website [www.emugully.com.au](http://www.emugully.com.au)



Lock in the weekend & talk to Graham if you'd like to come along. NB: All boys attending are permitted to bring along one parent.

**HFQ 2014 Youth Camp**  
**22 August 4 Emu Gully Adventure**

*Continued from page 10*

# Bully in the next bedroom - are we in denial about sibling aggression?

By William Kremer BBC World Service

Siblings routinely pick on one another, but when does bickering become bullying - and what can parents do about it? Society often regards the scrapping and squabbling, the play fighting and not-so-playful fighting as a normal part of growing up.

A new study in the journal *Pediatrics* questioned 3,600 children & almost a third said they had been the victim of some sort of sibling aggression in the past 12 months. In comparison, research suggests that up to a quarter of children are victims of schoolyard aggression every year.

A more familiar label for "sibling aggression", the bad stuff that goes on between brothers and sisters is bullying. This is defined by experts as intentional acts of aggression, repeated over a period of time, where an individual or group is in a position of power over someone.

So sibling relationships would seem the perfect breeding ground for bullying, since children live together for a long period of time and there is usually an intellectual and physical power imbalance.

When you add a child or children with bleeding disorders into the family mix, you can get an imbalance in parental focus and sibling relationships can become even more emotionally intense than usual - the siblings without a bleeding disorder are natural competitors for family resources and parents' attention and can feel left out.

A paper published in the *Journal of Interpersonal Violence* questioned adult siblings about how they had treated each other during childhood. Most reported they had been bullied, with around a third saying it had gone on for several years.

Despite the aggression, victims and perpetrators gave high ratings for closeness, both before and after the

incidents they described and almost all the respondents - 85% - said such behaviour should be expected; but the sibling aggression study showed that children who reported recent sibling aggression were more likely to be suffering from mental distress. Another project found that half the children who suffered from sibling bullying also suffered bullying at school.

The researchers said that if you only have sibling bullying or school bullying you are about 2.7 times more likely to experience unhappiness or have behaviour problems, but if you have both then it's 14 times more likely.

While sibling fights are normal, parents need to be aware of a pattern developing over time. Parents should consider what might be causing the problems and are advised to talk to their children about what's happening.

There is one known predictor - it's when siblings perceive there to be a wide disparity between how they are treated and how their brothers and sisters are treated. The research says that play fighting is valuable; since it teaches children what the limits of acceptable behaviour. If they are worried, they could speak to a health professional.

If physical aggression happens, it is often done covertly and parents should keep an eye open to what their children are up to. Often bullying is emotional or mental and parents should be loving but firm, with clear rules of behaviour as well as affirming their love for all their children. It should be clear to parents when children go too far because they haven't learned the limits - and when they do it on purpose but parents have to guard against being preoccupied with their own or their individual children's issues that they fail to intervene.

From: <http://www.bbc.co.uk/news/magazine-24639063>

## eHealth Records

*Continued from page 14*

participate in the eHealth record system. This includes the creation of a shared health summary that can be written by a healthcare professional such as your GP. A shared health summary is an overview of your health, allergies, details of medications you are taking and immunisations you have had – key information that doctors and nurses need to know about when treating you and making decisions about your health care.

### How do I register for an eHealth Record?

You do not need a computer or computer skills to have an eHealth record. People seeking health care in Australia can register in a number of ways:

- In person at the Haemophilia Community Camp on 7-9 March 2014
- In person by visiting your nearest Medicare Local (see [www.medicarelocals.gov.au](http://www.medicarelocals.gov.au) or a Department of Human Services centre that offers Medicare services (<http://humanservices.findnearest.com.au/>)
- Online – visit [www.ehealth.gov.au](http://www.ehealth.gov.au)
- Over the phone – call 1800 723 471 (select option 1)

# Hopes for New Haemophilia Treatment

*It's still relatively early days for Gene therapy but scientists continue to investigate and experiment looking to achieve a safe and effective treatment. This article gives you a glimpse of just one small corner of this work but adds to our overall knowledge ... enjoy.*

*Regards ... David Stephenson*

Last month (Nov 2013) scientists said they had treated haemophilia in dogs by fixing a flawed gene, marking a step forward towards treating the condition in humans, too.

Haemophilia A, the most widespread form of the inherited bleeding disease, occurs in around one in 10,000 men. It occurs through a malfunctioning gene which causes a deficiency in a blood-clotting protein called Factor VIII. There is currently no cure. Uncontrolled bleeding is treated by coagulant injection, although some patients' immune system can react to this.

A team led by David Wilcox at the Medical College of Wisconsin in Milwaukee used a virus as a microscopic Trojan Horse in tests on dogs. They tucked a functioning version of a factor VIII gene into a harmless virus. The virus was then used to "infect" three dogs with haemophilia A, delivering the good gene into stem cells that make platelets, tiny cell fragments that clot the blood.

Two of the dogs that produced the highest levels of Factor VIII after the therapy had no episodes of severe bleeding throughout the two-and-a-half-year

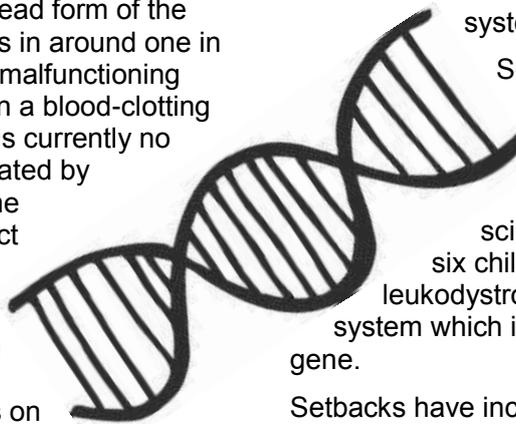
duration of the study. None of the three dogs required drugs to suppress their immune systems after being given the new gene, according to the study, appearing in the journal Nature Communications.

Gene therapy is based on the idea that inherited diseases may be combated by slotting in functioning genes to replace defective ones. It burst on the medical scene in the late 1990s and is one of the most alluring areas of biotechnology, offering the theoretical promise of blocking or reversing inherited disease. But this new frontier has also been hit by occasional setbacks, notably an unexpected or uncontrollable response from the immune system.

So far, successes have been few, limited to single-gene disorders — as opposed to complex multi-gene disorders that account for the commonest diseases. In July, scientists in Italy said they had treated six children with metachromatic leukodystrophy, a disease of the nervous system which is caused by mutations in the ARSA gene.

Setbacks have included the death of an 18-year-old U.S. volunteer, Jesse Gelsinger, in 1999, and the development of cancer among two French children treated for "bubble baby" syndrome, a chronic lack of immune defences.

Source - <http://www.chinapost.com.tw/health/eye-health/2013/11/21/394116/Gene-tests.htm>



## RBWH Social Work and Psychology News *continued from page 10*

And finally don't forget.....

**5. PATIENT TRAVEL SUBSIDY SCHEME** Don't forget that people who live over **50 kms** away from the RBWH or RCH are eligible for patient travel subsidy if they need to attend certain clinic appointments or be admitted to hospital in Brisbane. Call your local hospital for the appropriate travel forms and then your GP will need to sign the referring doctor paperwork. Give Mona or I a call to discuss the process. It's wise to begin setting the paperwork in place as soon as you know your hospital appointment dates.

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 newsletter or any other haemophilia related issue. Give us a call if you are up at the RBWH and drop in for a chat in our office if we are free.

**Maureen Spilsbury – Advanced Social Worker – Qld Haemophilia Centre**  
**Phone (07) 3646 8769 (Monday to Thursday)**  
**Mona Chong – Advanced Psychologist - Qld Haemophilia Centre**  
**Phone (07) 3646 8769 (Friday only)**

# Aging With Haemophilia - Managing aging issues

Better treatments and comprehensive care provided through the haemophilia treatment centers (HTCs) mean people with haemophilia are now reaching their golden years. While living longer is something to celebrate, it also means facing aging-associated health conditions, such as cancer and kidney disease.

A review of previous studies, conducted by the University of Washington School of Medicine identified five co-morbidities that aging patients with haemophilia and their providers need to address—cancer, cardiovascular disease, joint disease, liver disease and renal disease. These can all be managed by talking to your clinician at the HTC or appropriate specialist.

## Cancer

Cancer is a common cause of death for people with haemophilia. The authors attributed this to overlooked symptoms, such as blood in the urine or stools, and delayed treatment because of bleeding complications.

Patients who are co-infected with HIV are more prone to non-Hodgkin lymphoma, basal cell cancer and Kaposi sarcoma. But the rates have been cut in half in the past decade with the use of HIV treatments.

The most common cancer in patients with haemophilia and hepatitis C virus is a liver cancer called hepatocellular carcinoma.

## Cardiovascular Disease

When it comes to heart health, previous studies of the protective effect of haemophilia have been contradictory. The authors note that older people with haemophilia can be sedentary and overweight, and have other risk factors for cardiovascular disease. Heart-healthy lifestyle changes apply to the bleeding disorders community, too—quitting smoking, starting exercise, eating a low-cholesterol diet and taking medications, if necessary. In cases in which standard heart function tests, such as walking on a treadmill or riding an exercise bike, are too difficult because of advanced joint arthritis, your physiotherapist may recommend substituting water exercise or other solutions.

## Joint Disease

Although prophylaxis is common in younger patients with severe haemophilia, it is less common in older men. Because primary prophylaxis is the only known approach to prevent or limit joint disease, older people with haemophilia often suffer from advanced arthropathy. Managing their advanced joint disease, takes a multipronged approach that should

include pain medications; RICE (rest, ice, compression, elevation), splints, casts and physical therapy; and daily exercise. Less invasive procedures, such as synovectomy, may decrease bleeding frequency and pain in target joints but cannot reverse bone and cartilage damage. Joint replacements can be successful in the right patient. Exercise and maintaining a healthy weight were also recommended.

## Liver Disease

A major cause of death and disability in people with haemophilia is chronic liver disease from hepatitis C infection. People co-infected with HIV tend to experience more rapid development of cirrhosis and liver failure.

Currently, the most successful treatment regimen for hepatitis C is a combination of pegylated interferon-alpha and ribavirin. Unfortunately, this regimen fails to clear the virus in up to 50% of patients and can be difficult to tolerate, but new treatments are starting to come on stream and to manage liver disease you should talk to your HTC clinician or liver specialist to determine the extent of disease and to manage any progression.

## Renal Disease

The most surprising finding was from a previous survey which found a 50-fold increased risk of dying from kidney disease by adult patients with haemophilia. The main contributing risk factors were the presence of inhibitors or HIV infection, high blood pressure and kidney bleeding.

Although this list of possible issues related to aging may look daunting, the secret to staying healthy as you get older is being proactive. Scheduling routine screenings, doctor visits and exams will help you stay on top of your health concerns.

Edited from an article by Sarah Aldridge that appeared in HemAware <http://www.hemaware.org/story/getting-older-hemophilia>

## HFQ World Congress Sponsorship Application Form.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Telephone: \_\_\_\_\_ Mobile: \_\_\_\_\_

Email: \_\_\_\_\_

**Eligibility:** you are not required to provide personal health information, however to determine your eligibility HFQ may need to confirm that you satisfy one of the categories below - please tick relevant box and list a contact person at your haemophilia treatment centre for confirmation.

- Haemophilia                       Von Willebrand Disorder                       Other bleeding disorder  
 Carrier                               Carer     Partner  
 Relative                               Other

Contact person at Haemophilia Treatment Centre for confirmation: \_\_\_\_\_

### Your Proposed Congress Budget

Item	Explanation / Details Where, how many nights etc	Cost \$
Congress registration Note: WFH (provides discount savings on registration)		
Accommodation		
Flights		
Other expenses (please specify)		
Total expected costs		
<b>Less your personal Contribution</b>		
<b>Total Funding Requested</b>		

Please describe how you will benefit from attending the congress and why you want to attend (*add other page if required*).

Signed: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Please Return to HFQ by COB 17 January 2014.  
Email: [info@hfq.org.au](mailto:info@hfq.org.au)

Phone: (07) 3338 5645  
Post: PO Box 122, Fortitude Valley, QLD 4006

# HFQ Sponsorship

## Application to HFQ Congress Education Fund.

The WFH 2014 World Congress is to be held in Melbourne on 11-15 May 2014. This is the first time we have had the international haemophilia congress in Australia. It is a great opportunity for Australians to participate in the largest international meeting for the global bleeding disorders community and to network with people from around the world.

HFQ has limited funding available to assist Queensland Members and Affiliates to attend congress. If you are seeking funding please complete the expression of interest form on the back and return it to HFQ by Friday 17 January 2014. For information on the costs for congress please visit [www.wfh2014congress.org](http://www.wfh2014congress.org)

## Who can apply?

Funding will only be available to a person living with a bleeding disorder or who is affected by a bleeding disorder in some way, such as carer, partner or relative. Please indicate on the form if you are a couple or where you plan to share costs.

## How much funding is available?

HFQ would like to offer financial support to as many Queenslanders as possible to attend the congress. Full funding is not available and in most cases only a contribution to your costs will be made by HFQ, such as your registration fees and / or part of your other expenses. Total funding per person will not be more than

\$1000.00 so that we can support as many people as possible.

Please prepare a budget to determine the amount of funds you require and provide as much information as you can in your expression of interest. Please note that although demand is expected to be high, some additional funds may be available under exceptional circumstances so if you will benefit from attending Congress and need more than \$1000 please talk to us. With the high level of interest, it is likely that not everyone who applies will get the funding requested but we will do our best to meet your request.

Applications will be considered by HFQ according to selection criteria agreed to by the board. Payments may not be as much as requested and successful applicants will be expected to register for the congress and make their own travel arrangements, accommodation and other bookings etc. Funds will need to be repaid to HFQ if the recipient does not attend the congress (unless there are special circumstances).



**WFH 2014  
WORLD CONGRESS**  
THE LARGEST INTERNATIONAL MEETING  
FOR THE **GLOBAL BLEEDING DISORDERS  
COMMUNITY** MELBOURNE, AUSTRALIA • MAY 11-15

[WWW.WFH2014CONGRESS.ORG](http://WWW.WFH2014CONGRESS.ORG)