

# Life Challenges

Haemophilia Awareness Week  
11-17 October 2009

During Haemophilia Awareness Week, Haemophilia Foundation Australia and Haemophilia Foundations around the country work together to raise awareness to the general community, community organisations and governments about inherited bleeding disorders. The theme this year is "Life Challenges".

There are many ways you can help us promote Haemophilia Awareness Week:

- set up a stand in your workplace, school, hospital or library
- hand out promotional items in your local area
- assist your local Haemophilia Foundation during the week
- organise a casual clothes day at your workplace or school
- organise a luncheon, sausage sizzle or morning/afternoon tea.

Promotional items are available for schools, work places, hospitals and community centres. To place an order for items (free of charge), download an order form from our website [www.haemophilia.org.au](http://www.haemophilia.org.au) (click on the logo on our homepage to be directed or under *Events and Awards*). Note that stock is limited.

We are always keen to hear from people of all ages who are willing to share their personal stories during Haemophilia Awareness Week in our media campaign. Even though you may not think your story is of particular interest to others, personal stories such as yours may be the best way for us to raise awareness.

Contact Natashia on 1800 807 173 or [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au) if you are interested. 

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Suzanne O'Callaghan is Policy Officer, Haemophilia Foundation Australia

# KEEPING UP-TO-DATE WITH HFA

Suzanne O'Callaghan

News these days crosses our path in many ways – on TV, in print media, such as newspapers and magazines, on the internet, via email or SMS. We might rely on habit to keep up-to-date – watch a regular news item on TV or check a particular news web site at various times during the day – or find it helpful to be reminded with a news update via email or on our mobile.

To cater for the different ways our members prefer to receive their news updates, HFA offers several different ways of keeping up-to-date – and they are all free:

**National Haemophilia:**

magazine-style journal which is published four times a year in print and electronically. It contains news items and longer in-depth articles. To join the mailing list, contact HFA with your details and specify whether you want the print or electronic version – email hfaust@haemophilia.org.au or phone 1800 807 173.

**H.Link:**

newsletter produced twice a year to keep HFA supporters up-to-date with the latest news and information about HFA activities. You can join the print or electronic mailing list by contacting HFA with your details – email hfaust@haemophilia.org.au or phone 1800 807 173.

**Youth News:**

newsletter produced four times a year by the HFA Youth Committee. It has articles and games for young people, and focuses on personal stories, events, sports, education and fun. Join the print or electronic mailing list by contacting HFA with your details – email hfaust@haemophilia.org.au or phone 1800 807 173.

**HFA E-News:**

email news bulletin which is sent out via email about 12 times a year. E-news items include updates on HFA events, links to the latest electronic editions of HFA newsletters, *National Haemophilia* and new publications, and other important news items relevant to Australians with bleeding disorders. To join the HFA E-News mailing list, go to the HFA web site (www.haemophilia.org.au), click on the SIGN UP FOR NEWSLETTER BUTTON and fill in your details.

**HFA web site news RSS feed:**

the feed will give updates on new items on the HFA web site News page. This page has news items with the latest on HFA activities and information HFA would like to draw to the attention of the Australian bleeding disorders community. To set up a feed, use your internet browser's RSS web feed instructions – in Internet Explorer 7, these can be found under Tools in the menu.

**HFA Facebook page:**

if you use Facebook to network with your social group, you may like to join HFA's Facebook page as a fan. The page highlights HFA events and new resources, has photos and discussion boards. 



# NOTES FROM THE PRESIDENT

Gavin Finkelstein

As we prepare the Haemophilia Foundation Australia (HFA) annual reports to meet our governance responsibilities I have been thinking about the achievements of the bleeding disorders community in Australia, and reflecting on our history.

**It was thirty years ago this year, in 1979, that the Haemophilia Societies of Victoria, New South Wales and South Australia came together to form the Australian Federation of Haemophilia Societies.** The next few years from that time was perhaps the most devastating and challenging period for the bleeding disorders community in Australia and worldwide.

Our peer leaders and treaters in the past have given us much to be grateful for, as it was through their advocacy that we now have haemophilia centres for specialized treatment and a range of clotting factor products to use for our treatment. Comprehensive care is now considered a best practice standard for delivering haemophilia care. However, unless we understand our history, where care and treatment has come from, and what it might take to ensure we maintain the highest standards for care and treatment, we could fall behind.

Those new to the bleeding disorders community may not know of our history. In 1983 HIV was identified in the United States in people who had been treated for their haemophilia with human blood products. Soon after it was found that members of the haemophilia community in Australia had acquired HIV too. By

1984 consumers from the bleeding disorders community were represented on government committees set up to address the impact of HIV/AIDS. In 1985 the federal government allocated funding for the Australian Federation of Haemophilia (AFH) to provide support and education. AFH was soon publishing a monthly newsletter to keep the community informed about blood safety, and financial support for people with medically acquired HIV. Lobbying started in earnest for improved haemophilia services/support in all states/territories.

In 1986 AFH was incorporated as Haemophilia Foundation of Australia and over the next three years ACT, WA, Tasmania, Hunter Valley and the Queensland patient support groups joined HFA. In 1988, the Medical Advisory Panel and the Nurses Group met for the first time and the HFA resource development program started. In 1993 HFA was renamed Haemophilia Foundation Australia and adopted the red dot H logo representing haemophilia in Australia.

Since the time of the HIV epidemic, the volunteer leaders at HFA have fought hard for support and for safer treatment products. Further issues arose, including the wide impact of hepatitis C and continual blood product shortages, until we finally saw the first recombinant clotting factor product registered for use in Australia in 1994. Patient and clinician advocacy to governments led to increased supplies of this imported product and it was given to eligible children who were treated with prophylaxis for the first time in 1995.

It is important for us to remember this history and the hard work of so many volunteers who have helped improve the situation in Australia for the bleeding disorders community. A lot has happened and many families have been deeply affected. It is clear that it would not have been possible to bring about what has been achieved without volunteers who were willing to fight for what they believed in and to create a better future for the next generations.

Our state/territory Foundations and HFA were not always here – they grew out of the need for peer support and for advocacy to address gaps in services, and the need for adequate supplies of treatment products. We should remember we need to be ready for any new challenges that might arise. We have only had limited treatment product choice for all, regardless of age and blood borne viral status, since 2004. We need to remain informed about best practice and we need to make sure our Foundations are strong and viable.

I urge you at this time of reporting and community accountability to take the time to go to your local Foundation annual general meeting and take an interest in what is happening at your Foundation and at HFA. And carrying on the spirit of the last 30 years, to be prepared to speak up and help, if need be. **H**

# IT'S NOT TOO LATE TO REGISTER FOR THE CONFERENCE IN BRISBANE

Sharon Caris

It is not too late to register for the 15th Australian & New Zealand Haemophilia Conference at The Sebel in Brisbane, 8-10 October 2009.

A team of health professionals and members of the bleeding disorders community in Australia and New Zealand have each volunteered their time to bring together the program which we hope will interest people with bleeding disorders, their families and people who provide care and treatment and services to our community.

We thought the theme "Life Challenges" would capture a range of experiences and interests. The commitment of so many stakeholders in our community to a better understanding of the challenges for people with bleeding disorders and

their carers is quite possibly one of the greatest strengths of our community!

For people who have not been to a conference before it might help to know that most of the sessions have relevance to people with haemophilia, von Willebrand disorder and other related bleeding disorders in some way. Although some sessions will be quite specialised, most include a clinical or treatment focus as well as the personal experiences of people with bleeding disorders and their families.

We have included topics which are of current interest and concern to those who receive services and those who provide services and care, including government officials who plan some of the health services used by members of our community.

If you want to understand more about how others receive their care and treatment in Australia and around the world, and what is considered best practice in the treatment and care of bleeding disorders, the conference is a good way to find out more.

Many people tell us they really enjoy conferences because they meet others who share similar experiences and concerns for the first time – for example, they might meet others with haemophilia or von Willebrand disorder, or be around the same age (young or old!), with similar health issues, or they may be parents with young children or teenagers who are relieved to meet others with children of the same age.

A large graphic of the number '15' with 'TH' in a smaller font to its upper right, all enclosed within a circular border. The background features several overlapping circles of varying sizes, creating a sense of depth and movement.

## Australian & New Zealand

### HAEMOPHILIA CONFERENCE

*Life Challenges*

A stylized logo consisting of the letter 'H' with a dot above it, enclosed within a circular border.

**Brisbane, 8-10 October 2009** [www.haemophilia.org.au](http://www.haemophilia.org.au)

For people who have not been to a conference before it might help to know that most of the sessions have relevance to people with haemophilia, von Willebrand disorder and other related bleeding disorders in some way.

For others just being reminded that they are part of a community which seeks excellence and the best outcomes for people living with bleeding disorders is a reason for attending the conference!

There is already a list of excellent speakers from around Australia, New Zealand, Canada, United Kingdom and USA.

The conference really does offer something for everyone and a chance to socialise at the various social functions – the Exhibition Opening and Welcome on the Thursday evening, the Gala Dinner on the Friday night at Hillstone and the Mens' and Womens' Breakfasts on the Saturday morning.

We will also have a Remembrance Service at Hillstone before the Gala Dinner on the Friday night. This is a time to think of friends and family, and the people we have cared for in our community who have died. The service is non-religious and everyone is welcome.

For current program information and updates visit [www.haemophilia.org.au](http://www.haemophilia.org.au).

You have missed the early bird cut off date for registrations but it is still not too late to register and the cost is reasonable. You can register on line at [www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences) or hardcopy forms can be downloaded and you can fax or post them to HFA. A copy of the program is enclosed with this edition of *National Haemophilia*. **H**

Ally Loran is Administration Officer, Haemophilia Foundation Australia

## STAFF CHANGES

*Ally Loran*

I'd like to introduce myself – I am Ally and I have been with Haemophilia Foundation Australia since 20 July ....what a hive of activity!

I am originally from England, (many moons ago) then Perth, Western Australia. Our family (husband, and three teenage daughters!) moved to Melbourne in 1993 due to my husband's work.

Upon realizing we were not going home (Perth) anytime soon, my volunteering in a local nursing home changed my career direction into healthcare. To be sure of my change in commitment I worked in several areas - home care respite work, allied health assistant, occupational therapy department, secretary and finally at the Alfred in the position of Administration Manager, Allergy, Immunology and Respiratory medicine. From there I traveled into the world of Private Practice – Practice Managing for a Plastic and Reconstructive Surgeon. The call to actually feel in some small way I could make a difference to the lives of others has brought me back to the not-for-profit-world.

I am married to Kevin (for 34years) we have three daughters, three sons-in-law and five grandsons. This combined with my interest in running, baseball and of course the West Coast Eagles is pretty much who I am!

I look forward to working with each and every one of you, and thank you for the kind and warm welcome I have received. **H**



# WELLBEING WEEKEND

*Suzanne O'Callaghan*

How do you find time to catch up with the latest on health issues, learn some techniques for managing or improving your health and take stock of how things are for you at the moment in a busy world when you already have more than enough health issues to take care of?

The idea of a "Wellbeing Weekend" came from consultation with community members during the HFA hepatitis C needs assessment. Their suggestion was to put together an educational weekend with a focus on wellbeing that covered hepatitis C, relaxation, exercise, managing joint issues, telling others and mental and emotional wellbeing. They thought the weekend should also include enjoyable indoor and outdoor activities and time to talk and mix informally in a comfortable environment.

## Putting it together

It seemed like a promising concept, so HFA sought and received funding from a philanthropic Trust to pilot the "Wellbeing Weekend". The next step was to plan a suitable program. To help with this, HFA set up a Development Group for the Weekend, with a range of expertise: people with bleeding disorders and hepatitis C, partners, Haemophilia Foundation representatives, health professionals and community educators.

HFA also talked with some members with bleeding disorders and hepatitis C about the types of activities and topics they would find helpful in a Wellbeing Weekend and how the weekend should work. They were keen that the weekend should be in a rural retreat with bush walks nearby, and that there should be some guided meditation, some work on how to advocate for yourself, creative

activities, complementary therapies and the opportunity for a massage – and that partners/support people should be invited.

How best to invite people to attend? The Weekend was advertised in the local Haemophilia Foundation newsletter and on the HFA web site and Facebook site. The Haemophilia Centre also took an active role and contacted individual patients to draw their attention to the Weekend and see if they were interested.

## A Weekend away

HFA was able to book a venue for the Weekend that was already well-known for being comfortable and accessible, with good food and set in a quiet mountain location surrounded by bushland. Eleven men with bleeding disorders and six partners/support people took part in the Weekend. Ages ranged from people in their 20s to those in their 60s.

As the Co-ordinator of the Weekend, I was very impressed by the creative ideas of the Development Group and the facilitators for making sure there was a holistic approach to wellbeing for the Weekend:

- Starting the Weekend with fun getting to know you activities on Friday night, followed by guided meditation on Saturday morning
- Show bags with the program, liver-friendly recipes, DVD demonstrating t'ai chi and yoga movements for people with bleeding disorders, herbal teas and a chocolate sample (for its health benefits, of course!)
- Information resource table
- Venue proprietor cooked some of the liver-friendly recipes for participants to try

- Samples of low-fat cheese and dip and non-alcoholic wine provided for tasting
- Each participant offered a half-hour massage by a professional masseur to help with relaxation

Each session was conducted by a facilitator with expertise in the area and most had experience of working with people with bleeding disorders. All took considerable trouble to make sure they tailored their session specifically for the group. A Haemophilia Counsellor was present for the entire weekend and the local Haemophilia Social Worker followed up participants afterwards if they had anything they wanted to discuss further. The privacy of the group was very important to all who came and throughout the weekend we discussed how to make sure this was respected – which meant that everyone felt safe to discuss issues openly.

The focus was on practical activities - trying things out - and group discussion relating to people's own experiences. Participants were enthusiastic about contributing to the sessions and talking with each other in the breaks. Some had not been involved with Haemophilia Foundation activities for many years and commented on how important it was to meet others with similar problems and chat about how to continue working, exercising and living a full life. It was also an opportunity to learn some new skills – how to self-massage away tension! – and find out useful information, such as where to find t'ai chi classes close by for people with arthritis or understanding how hepatitis C affects the liver.

The creative and team-building activities were loads of fun – many hidden talents unfolded! – and gave us all time for a laugh, but were also very relaxed so that people could be very involved or take a more low key approach if they preferred. Unfortunately the weather was a bit problematic, so walks in the bush needed to be snatched when the rain stopped – but the venue was very cosy, so made for good chats around the log fire.

### **Where to next?**

At the end of the Weekend participants evaluated the weekend and gave suggestions. Comments included:

*Came away with a better perspective and the information/techniques to make a difference to my health.*

*Good to share experiences with the only people who can truly empathise with our complex lives.*

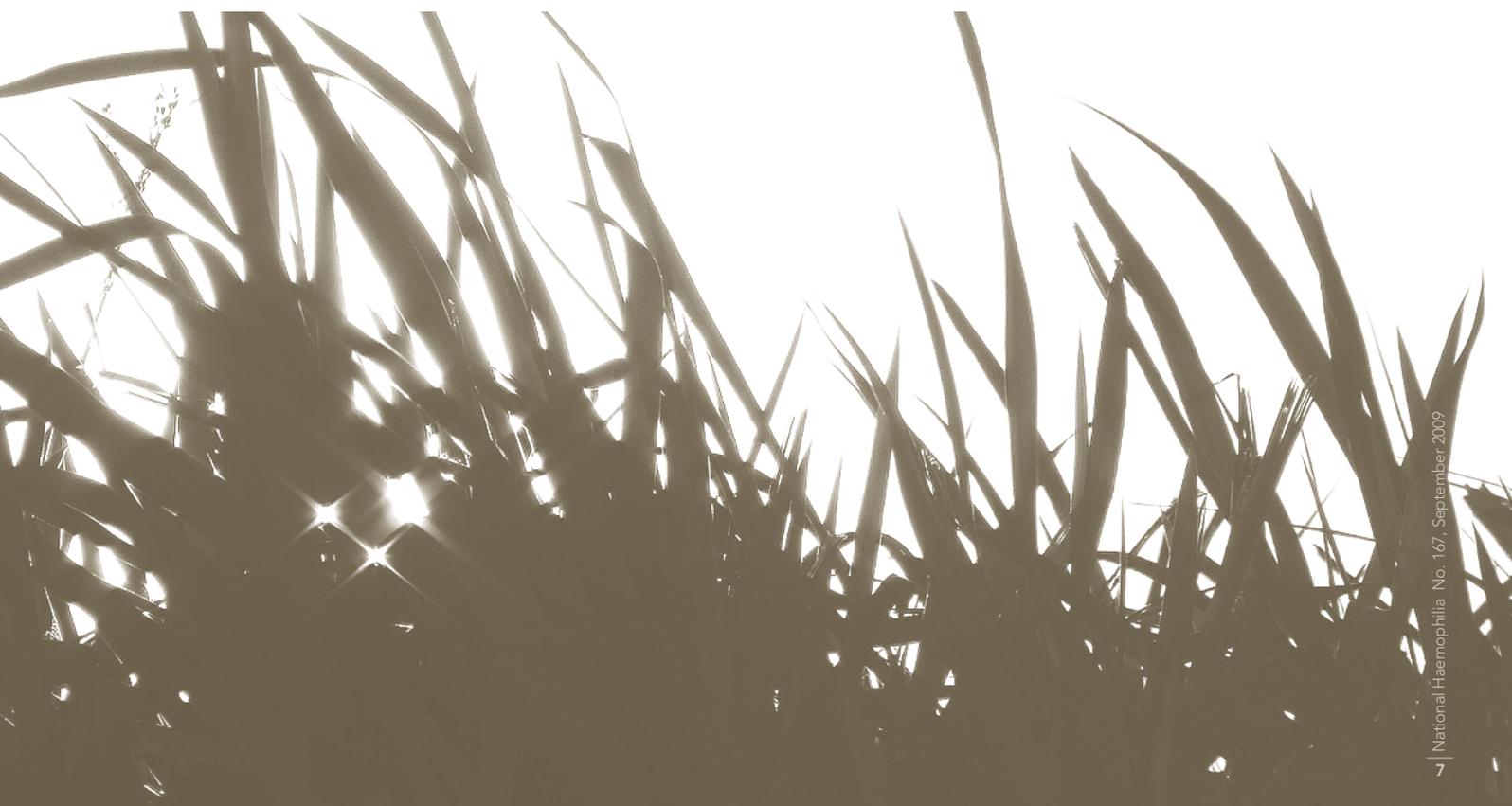
*Definitely to be able to speak openly with others in similar situations has been wonderful. Learning from each other, drawing strength from each other is invaluable.*

*Helped to 'normalise' the various issues of HIV/hep C/haemophilia and helped to progress thinking on some long standing issues.*

From the pilot Weekend HFA is developing a toolkit on how to hold a Wellbeing Weekend for state/territory Haemophilia Foundations and other interested organisations. It includes guidance on planning the weekend, a revised program and curriculum, checklists and sample resources. For more information, contact Suzanne O'Callaghan at HFA – [socallaghan@haemophilia.org.au](mailto:socallaghan@haemophilia.org.au) phone 03 9885 7800.

Thanks to all those who made the Weekend possible: the members of the Development Group, the people who gave input on topics and activities, the Haemophilia Centre and Haemophilia Foundation involved, the facilitators, the staff at HFA for their support and the people who attended and gave so much to the Weekend itself. **H**

Their suggestion was to put together an educational weekend with a focus on wellbeing that covered hepatitis C, relaxation, exercise, managing joint issues, telling others and mental and emotional wellbeing.



In HFA's hepatitis C needs assessment, many people with bleeding disorders and hepatitis C talked about how the fatigue caused by hepatitis C affected their everyday lives. This article looks at why illness involving inflammation, such as liver disease, can make us feel tired.

# HOW INFLAMMATORY DISEASE CAUSES FATIGUE

New research in *The Journal of Neuroscience* may indicate how certain diseases make people feel tired and listless.

Although the brain is usually isolated from the immune system, the study suggests that certain behavioural changes suffered by those with chronic inflammatory diseases are caused by the infiltration of immune cells into the brain. The findings suggest possible new treatment avenues to improve peoples' quality of life.

Chronic inflammatory diseases like rheumatoid arthritis, inflammatory bowel disease, psoriasis and liver disease cause "sickness behaviours", including fatigue, malaise and loss of social interest. The researchers found that in mice with inflamed livers, white blood cells called monocytes infiltrated the brain. These findings support previous research demonstrating the presence of immune cells in the brain following organ inflammation, challenging the long-held belief that the blood-brain barrier prevents immune cells from accessing the brain.

"Using an experimental model of liver inflammation, our group has demonstrated for the first time the existence of a novel communication pathway between the inflamed liver and the brain," said the study's senior author, Professor Mark Swain of the University of Calgary.

Swain and his colleagues found that liver inflammation triggered brain cells called microglia to produce CCL2, a chemical that attracts monocytes. When the researchers blocked CCL2 signalling, monocytes did not enter the brain despite ongoing inflammation in the liver.

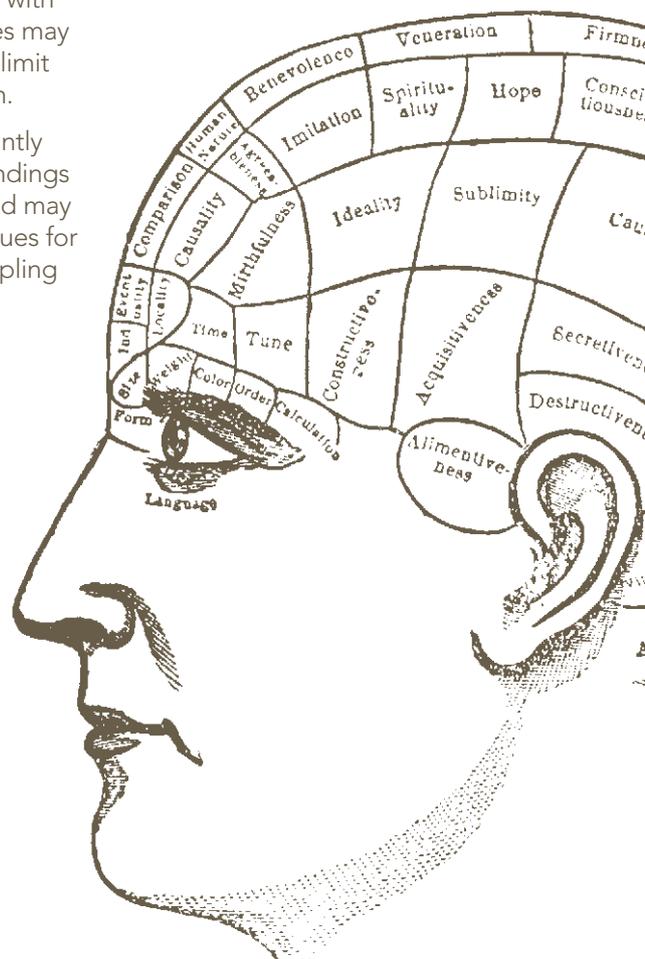
In the mice with inflamed livers, preventing the entry of monocytes into the brain reduced sickness behaviours; mice showed more mobility and social interaction. The findings suggest that people with chronic inflammatory diseases may benefit from treatments that limit monocyte access to the brain.

"Sickness behaviour significantly impacts quality of life. Our findings further our understanding and may generate potential new avenues for treatment of these often crippling symptoms," Swain said.

"The brain is the master coordinator of many of our bodies' defence responses, so it must be able to sense injury and inflammation in distant body organs. This study starts to explain the peripheral communication signals that activate the brain," said Nancy Rothwell, of the University of Manchester, an expert on brain inflammation, who is unaffiliated with the study. **H**

Original article adapted from materials provided by Society for Neuroscience via EurekAlert! Abridged here from [www.sciencedaily.com](http://www.sciencedaily.com) (28 Feb 2009).

The brain is the master coordinator of many of our bodies' defence responses, so it must be able to sense injury and inflammation in distant body organs.



# HFA / THAI TWINNING

Sharon Caris

HFA has been working with the National Hemophilia Foundation of Thailand and the Thai Patient's Club since 2006 in a twinning relationship sponsored and supported by World Federation of Hemophilia (WFH).

WFH now has 44 haemophilia organisation twinning relationships in 53 countries around the world.

Twinning can be a positive two-way experience that motivates staff and volunteers, attracts youth involvement, and enables both sides to learn from each other. The links made between developed and developing countries enable each country to share knowledge in areas including patient education, outreach, fundraising, and ways of operating a successful haemophilia organisation.

HFA's first visit to Thailand in November 2006 marked the start of a special relationship between the haemophilia communities in both countries. At that time Gavin Finkelstein (President) and Sharon Caris (Executive Director) represented Haemophilia Foundation Australia at meetings with clinical and patient leaders and health administrators in Bangkok to discuss opportunities for the work that could be done between the two countries.

In April 2007 Gavin Finkelstein, Sharon Caris, Paul Bonner (HFSA and representing HFA Youth Committee) and Rob Christie (WFH) participated in a workshop in Bangkok attended

by 50 members of the Thai Patient's Club and health professionals working with haemophilia patients at Ramathibodi Hospital. Workshop sessions focussed on developing networking and outreach skills. An outcome of the workshop was the identification of several peer leaders who could work in their local regions around Thailand to strengthen local relationships and connections between patients and their families and health professionals and increase access to care and treatment.

In September 2008 Mr Nawin Pajakgo and Mr Narong Yamnuak (fathers of boys with haemophilia) came to Australia for a series of meetings and activities with representatives of the Australian bleeding disorders community. They attended the Annual General meeting of Haemophilia Foundation Queensland (HFQ) in Brisbane and later visited the HFA office in Melbourne to meet people with bleeding disorders and HFA staff to discuss policies and procedures. They also made presentations about haemophilia services and care in Thailand to Haemophilia Foundation Victoria (HFV) representatives and health professionals from the Henry Ekert Haemophilia Centre. After leaving Melbourne they travelled to Adelaide to meet with Royal Adelaide Hospital Haemophilia Centre staff and later attended the Haemophilia Foundation South

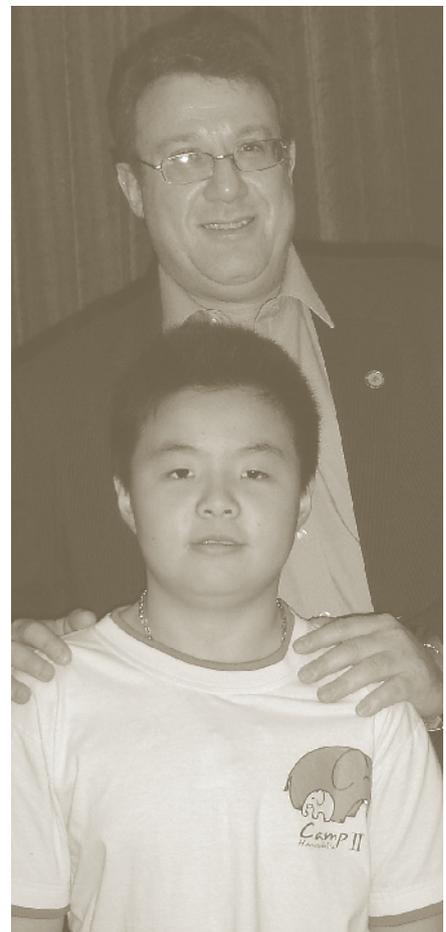
Australia Family Camp and HFA Youth Camp at Wirrina Cove.

Everyone who met the Thai visitors, learned much about the achievements and ongoing needs of the bleeding disorders community in Thailand and benefited from the friendship and sharing of ideas.

We are pleased that two Thai Patient's Club representatives (mothers of boys with haemophilia) will attend the 15th Australian and New Zealand Haemophilia Conference in Brisbane in October 2009. A second Thai-Australia workshop in Bangkok and an outreach visit to a regional area of Thailand is planned for early 2010. **H**



L - R Narong Yamnuak, Nawin Pajakgo from Thai Patient's Club



Gavin Finkelstein President, Haemophilia Foundation Australia with a member of Thai Patient's Club

With the development of more successful treatments for hepatitis C, antiviral treatment has become a more viable option for some people with bleeding disorders and hepatitis C. What factors suggest that treatment is more likely to be successful? This article explains the importance of hepatitis C genotype (strain of the virus) and rapid or early reduction in viral load in treatment success.

# RAPID OR EARLY RESPONSE: PART OF A NEW CUSTOMISED APPROACH TO HEP C TREATMENT

Mary Sawyer

Treatment for hep C has come a long way over the last 20 years. Treatment can lead to a complete cure and it can reduce your chance of long-term complications such as liver failure and liver cancer, improve your quality of life and prevent you from spreading hep C.

Since 2004, standard treatment for hep C has consisted of weekly injections of pegylated interferon with twice-daily oral doses of ribavirin for six or 12 months. This treatment gives a cure rate of 50-80%, but it has its problems - it's time-consuming and can have unpleasant side effects.

The latest development is the move to response-guided treatment which can be tailored to the individual person to maximise the chance of a cure while minimising the side effects.

## How do you know if you have been cured of hepatitis C?

You are cured of hep C when there is no more virus in your blood.

Your doctor will be able to tell you that you are cured if you have a sustained viral response (SVR) to treatment which means that no hep C virus can be detected in your blood six months after you finish treatment.

Research has shown that an SVR to treatment is a good indication that you have cleared the virus for good.

## How can you tell how successful your treatment is going to be?

Not everyone has the same results from antiviral treatment for hep C. For example, women do better than men, younger people do better than older people, people with a normal body weight do better than those who are overweight or obese, and people with less liver damage have a better chance of successful treatment. Your iron levels and your alcohol consumption can also affect how well you will go on the treatment.

Two of the most important factors that will predict whether you will have an SVR are the strain of hep C virus (genotype) you have and the amount of virus in your blood (viral load) before you start treatment.

## How can your genotype affect your treatment success?

There are six known strains of hep C virus, known as genotypes 1 - 6. Each of these can be further divided into subtypes, such as genotype 1a, 1b, 2a, etc. Some genotypes are easier to treat than others. Your doctor can do a genotype test to determine your viral genotype and help decide the dose of treatment, how long you should stay on it and how likely you are to reach an SVR.

In Australia about half the people with hep C (54%) have genotype 1, about a third (37%) have genotype 3, and genotype 2 accounts for approximately 5%.

If you have genotype 1 or 4 you are generally given 12 months of treatment and have about a 50%

chance of a cure. If you have genotypes 2 or 3 you are generally given six months of treatment and have a 70-80% chance of a cure.

## How can your viral load affect your treatment success?

Hep C viral load is the amount of hep C virus in your blood. The results of the viral load test, known as an "HCV RNA quantitative test", are given as the number of International Units of virus in each millilitre of blood (IU/mL). Most people with chronic hep C have between 50,000 and five million IU of hep C virus in each millilitre of their blood. When the test cannot detect any virus in your blood, the level is "undetectable".

- A high viral load is considered to be above 400,000 IU/mL
- A low viral load is considered to be below 400,000 IU/mL
- Changes in viral load are sometimes expressed in terms of logs: a 1-log change means a 10-fold increase or decrease; a 2-log change is a 100-fold increase or decrease.

Viral load cannot tell you how serious your infection is or how much damage the infection has caused your liver. Its main purpose is to predict how well you will do on antiviral therapy and to monitor how well you are doing once you start. The lower your viral load when you start treatment the better your chance of an SVR.

# With viral load testing and genotyping, your doctor can tailor both your treatment dose and your treatment duration to avoid the downsides of treatment and give you a better chance of an SVR.

## Viral load monitoring during treatment

An early decrease in viral load while you are on treatment indicates that it is working. Research shows that people who respond early and rapidly also have a better chance of being cured.

- **Rapid viral response (RVR):** a viral load of less than 50 IU/mL four weeks into treatment. If you have an RVR your chance of cure is better than 85% and your doctor may recommend that you shorten your treatment.
- **Complete early viral response (cEVR):** a viral load of less than 50 IU/mL 12 weeks into treatment. If you have a complete EVR you have a good chance of being cured.
- **Partial early viral response (pEVR):** a drop in viral load of at least 2-log (e.g. from 600,000 IU/mL down to 6,000 IU/mL) at 12 weeks of treatment, but still detectable virus in your blood. In people with genotype 1 the chance of viral clearance is low and treatment is generally stopped.

If the virus in your blood is still detectable at week 24, you have a poor chance of having an SVR: it's very unlikely (only a 1-2% chance) that you will clear the virus and therefore treatment is generally stopped.

- **Non-response (non-EVR):** no significant drop in viral load in the first 12 weeks of treatment.

## Summary: Response-guided treatment recommendations

Having a treatment schedule designed around how you respond to treatment is possible because the diagnostic tests are now available for genotyping and accurately measuring viral load. The main diagnostic test to measure as accurately as possible the levels of virus in your blood is the supersensitive polymerase chain reaction (PCR) TaqMan HCV test.

## Give yourself the best chance

There are effective treatments for chronic hep C. Getting the correct treatment at the correct time gives you a chance of clearing the virus from your bloodstream.

Recent research and advances in sensitive diagnostic tests have allowed doctors to make changes to the standard treatment to get you the best results: not all people with hep C should be treated the same. With viral load testing and genotyping, your doctor can tailor both your treatment dose and your treatment duration to avoid the downsides of treatment and give you a better chance of an SVR.

*For more information on hepatitis C treatment, talk to the medical specialist who treats your hepatitis C or contact the national hepatitis C infoline 1300 HEP ABC (1300 437 222). *

**Figure 1. Treatment modifications table**

	Genotype 1 or 4	Genotype 2 or 3
<b>Standard treatment</b>		
Dose of ribavirin (can change depending on body weight)	1000 – 1200 mg/day	800 mg/day
Duration of treatment	48 weeks	24 weeks
Response (cure) rate	50%	80%
<b>Treatment modifications</b>		
RVR at 4 weeks and low viral load before treatment	Your doctor may consider reducing treatment to 24 weeks	Your doctor may consider reducing treatment to 16 weeks
No EVR at 12 weeks	Your doctor may consider stopping treatment depending on how well you are coping with side effects	

# RICE AND FACTOR..... A REALLY SMART (AND AGE OLD) RECIPE!

Catherine Piggott

Minor and recurrent joint bleeds are the trademark of haemophilia A and B, and the compound effect of damage caused during each episode commonly leads to the alteration of joint function, deformity and pain.

Recognition of a bleed and prompt attention to treatment is necessary to prevent and minimise these long term complications.

You know all about your clotting factor - how much you may need, and how often - and the nurses and doctors at haemophilia centres can help or review your treatment requirements. But having your clotting factor is not all you can or should do for effective treatment. There is other basic SMART stuff that everyone should be reminded of.

## Rest/Immobilise

### Ice

### Compress

### Elevate

**Rest** the joint in a position of comfort - it may need a temporary splint or brace for full immobilisation. Reduce your activity.

For the elbow or wrist you could use a sling.

During a period of major swelling of either the knee or the ankle, when the muscles may be weaker and joint instability may also be a problem, the use of crutches could be recommended for walking and "relative rest" of the joints.

**ICE** – first check your skin sensation that you can feel and tolerate direct application of the cold temperature, and check throughout the time that there are no redder spots or pressure

areas etc - incorrect application can burn the skin!

Remember that swelling often encircles a whole joint, or a large thigh area, so a small gel ice pack will not be a smart choice!

A swollen joint (no matter what the underlying reason) is always painful and has reduced movement.

Try this:

- Ankles, hands, wrists and elbows can all be immersed in a bucket of cold water
- Knees and thighs – get an old towel and fold it into four, wet it, squeeze it, put it in a plastic bag (so it doesn't stick to everything else!), freeze it, remove from the bag, and put it around your knee, thigh, or elbow
- Do cold application for 10 to 15 minutes, perhaps gently moving the joint while the pack is on, and do it 3 times a day while it is still swollen. Smarter, because if you sense a bleed and you are out somewhere, you can always grab an old towel to use!

**Compression** – to stop excessive swelling, and control swelling after you do the ice packs, the pressure may also slow the bleeding.

A smart choice would be an elasticised circular pull-on bandage such as "Tubigrip". These are available in many sizes - smaller for elbows, medium for ankles, bigger for knees and huge (if necessary) for swollen muscly thighs!

- A double layer worn in the day, but not at night as you have the limb at rest and elevated.

Smart people would have a length of each size in the glove box of the car

for instant help at any time! Ask the physiotherapist at your clinic for some next time you are there.

**Elevation** - this lowers the pressure of blood in the veins, and limits its escape into tissues, thus limits bruising and allows swelling to reduce.

- Place the affected limb on a pillow as you rest, up on a chair or the bed for lower limbs, or high on the table for elbows and wrists. Gently move the limb occasionally so stiffness doesn't set in and to keep the muscle pump action going.

## So Remember:

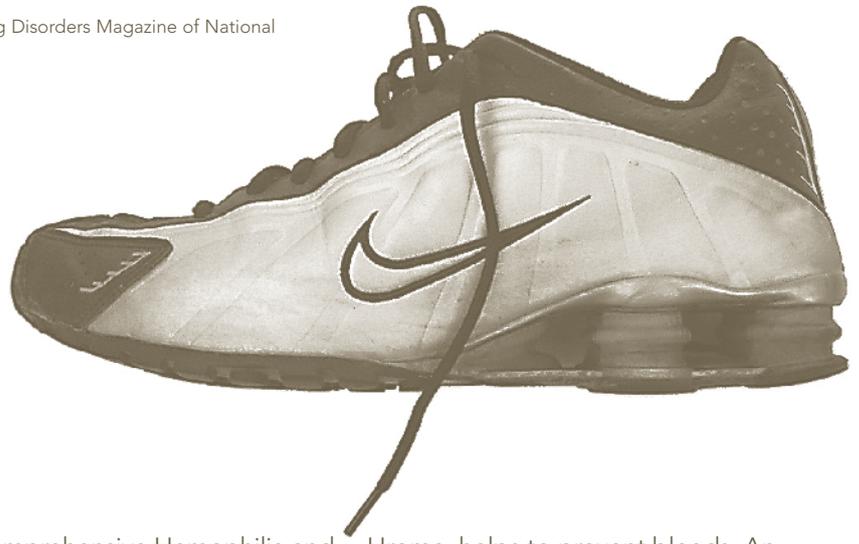
Clotting factor alone is not the only treatment. Also remember that the doctors and nurses at your haemophilia centre are there to help manage the condition, the physiotherapist will be very helpful in advising on a range of paced exercises for mobility and strengthening as you improve, and you can have a great impact on the outcome.

Quick and effective use of these age old hints should improve your own management of a bleed - recovery can be optimised, pain reduced, and restoration of function hastened.

**Smarter thinking puts RICE into your Factor recipe. H**

# FOCUS ON FOOTWEAR

Matt McMillen



Whether you are running a 10K race or simply walking the links at your local golf course, it is important to wear a good pair of shoes or inserts. After all, every step you take puts a little more wear and tear on your ankles. That can quickly add up to a lot of pain and discomfort, especially if you have a bleeding disorder. Wearing proper footwear, however, can reduce the risk of ankle bleeds and arthritic pain, and that means you can stay active and on your feet.

“Being active and healthy is harder to do with bad feet”, says Ruth Mulvany, RPT, of the Department of Physical Therapy at the University of Tennessee in Memphis. Mulvany was awarded a National Hemophilia Foundation Physical Therapy Excellence Fellowship for her study of rocker-bottom shoes and their effect on the comfort and gait of people with hemophilic ankle arthropathy, a painful degenerative condition caused by recurring bleeds. “Studies have shown that 6,000 to 10,000 steps a day are recommended for good health” she says. “But when your feet hurt, taking even one step is discouraging”.

John McNeil, who has severe hemophilia A, takes footwear seriously. That’s why he wears high top sneakers, which provide both ankle support and stability whenever he is on the basketball court.

“I have arthritic ankles” says McNeil, 28, of Charlottesville, Virginia. “If I do something active in the wrong shoes, it hurts the next day.”

That kind of pain and discomfort can begin a vicious cycle, says Nicole Hroma, PT, the senior physiotherapist

at the Comprehensive Hemophilia and Thrombophilia Program of Children’s Memorial Hospital in Chicago.

“If you hurt your ankle and get a bleed, then you will rest it so that it doesn’t bear weight.” Hroma says. “But when you do that your muscles tighten. That can cause you to lose range of motion and make you more susceptible to future bleeds. ”

To find the right footwear, Mulvany recommends shopping at a shoe store rather than online. While the internet may be convenient, you need to try on a shoe before you buy it. Look for shoes with good cushioning arch support and plenty of wiggle room for your toes, says Mulvany.

“People with bleeding disorders who have foot and ankle problems do better with sturdy, laced-up, high top shoes that support the arch and the ankle,” Mulvany says. “Those who have limited ankle motion often report that they do best if the shoe has a bit of a heel, like a cowboy boot would have. This puts the foot in a position that supports their limited motion.”

When McNeil needs shoe advice he turns to his physical therapist.

This is a good idea for anyone with a bleeding disorder. Consult with your physical therapist, podiatrist or orthopedist before buying your next pair of shoes. Such experts can identify problems and provide recommendations while steering you away from styles that could do your feet more harm than good.

Custom-made inserts for people with bleeding disorders keep the foot in place and properly aligned. That, says

Hroma, helps to prevent bleeds. An added advantage is that they fit inside most dress shoes, which often lack support. For a study that gathered data from 1999 to 2006, Hroma and her colleagues recruited 60 children who were patients at the Children’s Memorial Hospital’s HTC. Half of the children wore inserts, while the other half did not. Hroma and her colleagues presented the study at the World Federation of Hemophilia Congress in Istanbul, Turkey in June 2008.

“We had clear results – the kids wearing the inserts averaged about seven bleeds in seven years.” Hroma says. “The other kids averaged 30 bleeds.”

“Sometimes, inexpensive, commercially available shoe inserts can make a huge difference in comfort and function.” Mulvany says. Again, check with your physical therapist or podiatrist to learn what is right for you.

Don’t wait to determine what fits your needs best. If you have problems with your feet or ankles, early and aggressive intervention is essential so that you don’t lose your stride.

“You need to take care of your feet and ankles early,” Hroma says. **H**

## Note from the editor

It is recommended that people with bleeding disorders discuss footwear issues with their physiotherapist. A referral to a podiatrist or other specialist may be necessary. Some state/territory Haemophilia Foundations offer subsidies for footwear.

# WOULD YOU LIKE TO PARTICIPATE IN 2009 GLOBAL FEAST?

Natashia Coco

Global Feast is a fundraising opportunity for Australians to raise funds which will be used for people with bleeding disorders around the world who need our help.

Without proper treatment for their bleeding disorder, most children with severe haemophilia will die when they are very young. An estimated 400,000 people worldwide are living with haemophilia. **75% of people with bleeding disorders throughout the world are undiagnosed and untreated, particularly in countries where health care is not well resourced.** WFH is striving to close this gap. Australia is one of the fortunate countries where people with bleeding disorders receive high quality care and treatment. We can all make a difference by working with World Federation of Hemophilia (WFH).

Invite your family, friends and work colleagues to a meal and ask them to bring a donation instead of flowers, wine or a gift. If a dinner isn't your "cup of tea", any type of festive event will do - a pancake breakfast, pizza party, backyard barbeque, afternoon tea or picnic lunch. Do it at home, or meet in the park! Be creative and have fun! We can help you run your own Global Feast event at any time during the year!

All money collected for Global Feast will be donated directly to WFH. WFH will use these funds to provide safe and effective blood treatment products free of charge to people in urgent need. WFH works in more than 50 developing countries providing programs, services, educating families and training doctors and nurses in some of the poorest regions of the world.

For more information and promotional items, contact Natashia at HFA on 1800 807 173 or [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au)



Joan and friends celebrating Global Feast

## Joan from Victoria shares her Global Feast experience

"I need to tell you all how I feel about the wonderful opportunity the haemophilia community has in Australia each year. It is called Global Feast.

When I first read about Global Feast in the newsletter a couple of years ago, there was a story about a young boy who has haemophilia in Zimbabwe, and what it has always been like for him in a country with few resources – it's nothing like the same treatment that is available for our guys in Australia. My husband, who is now in his 70's, has received wonderful treatment from hospitals here all his life.

My tears flowed at the thought of how different it is for this boy I read about, and for so many others like him. I realized that here was an opportunity to help, even in a small way, and I decided to hold a Global Feast!

I'm not a gourmet cook, but I do like a challenge, and I certainly enjoy sitting down to dinner with friends, so I set a date, enlisted my husband's help, and the encouragement of other friends and relatives".

We figured through that if we gave people a 3 course meal, they would feel inclined to be generous. We figured that the maximum number of people we could seat in reasonable comfort was 16, so we invited 21, thinking that some would not be able to come, and if it happened that they could all come, then 5 of us (probably family) could sit on the lounge chairs with plates on our knees.

Having decided on a date, and sent out the invitations, I set about planning the menu. I

thought about the main course first – buffet style seemed easier than trying to keep in mind any different dietary needs and preferences. Two prospective guests are vegetarian. I decided on one pasta dish which has a small amount of meat. I just would hold back the meat for a vegetarian portion of it. I also did two types of roast meat which I served sliced on a platter. There was also a vegetarian frittata, as well as a tossed salad and bread.

For the entrée we had a selection of finger foods, and for dessert a choice of chocolate tart and hot fruit crumble.

On the night – a cold night in August – so good eating weather, 18 people were able to come, and were seated in reasonable comfort.

Compliments and exclamations flowed, about the food, and the amount of work I had put in. But as I kept saying, it really wasn't a huge amount of work – yes, a bit of planning and organizing, and yes, a bit of work, but spread over a few days, but really, how could I not do it, when I thought about those kids in Africa and other countries that could do with a bit of help!

Bottom line - \$200 was donated on the night! And last year, what else could we do, but repeat the success – that time \$300 came in.

I'm looking forward to this year's dinner, but what would be even better would be to read in the newsletter later in the year, that more than the usual handful of people took part in this great opportunity to help." **H**

# HFA WEB SITE UPDATE

Suzanne O'Callaghan

## What's new with the HFA web site?

Since the launch of the new HFA web site in early April 2009, we have added some new functionality and have been watching to see how it is received.

### Online videos

An exciting step has been to add a video module. This means you can watch short videos on the HFA web site – a bit like YouTube, so that you can click on the Play button and have the video play on your screen. As with YouTube, the size of the video needs to be under 10 minutes so that it is small enough to play on most people's internet browsers.

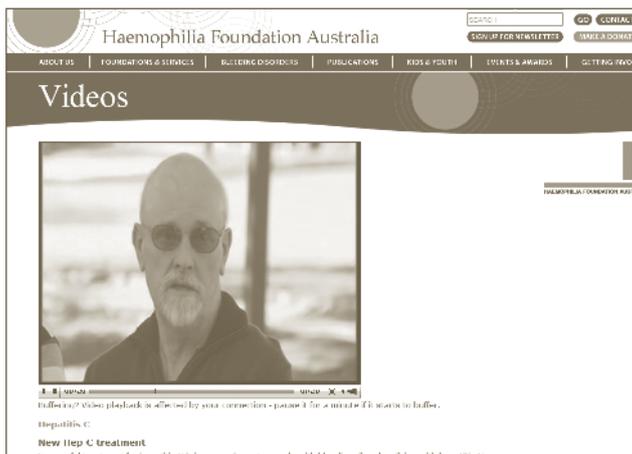
So when Seven Network gave HFA permission to put a short news clip they made about hepatitis C treatment for people with bleeding disorders on our web site, we were able to add the news clip to our video page and alert web site users with a news item. This has proven to be a very popular page, with 70 downloads in its first 9 days on the web site.

We only have permission to show the Seven news clip until 31 August, but the success of the news clip video has led us to consider what other short videos we have that can be converted and added to the HFA web site. Stay tuned for more information!

## HFA publications

Another step has been to revise our publications page format to make sure it is easy to know what each publication is and how to download it and so that it comes up quickly in search engines like Google.

Our new revised publications pages list each publication with a short blurb, a thumbnail of the cover and clear download instructions. The blurb is not only helpful for web site users, it also helps search engines to locate relevant information when people are searching on keywords. Take a look at the Publications page and let us know what you think! 



# CALENDAR

## WFH Global Forum 2009

Montreal, Canada 24-25  
September 2009

email [mbrooker@wfh.org](mailto:mbrooker@wfh.org)  
[www.wfh.org](http://www.wfh.org)



**15<sup>TH</sup> Australian & New Zealand  
HAEMOPHILIA CONFERENCE**  
*Life Challenges*  
Brisbane, 8-10 October 2009 [www.haemophilia.org.au](http://www.haemophilia.org.au)

## 15th Australian & New Zealand Haemophilia Conference

Brisbane 8-11 October 2009

ph 03 9885 7800  
fax 03 9885 1800  
email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
[www.haemophilia.org.au](http://www.haemophilia.org.au)

## Haemophilia Awareness Week

11-17 October 2009

ph 03 9885 7800  
fax 03 9885 1800  
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**Hemophilia  
World Congress 2010**  
Buenos Aires • ARGENTINA  
Saturday, July 10 - Wednesday, July 14

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