

# National Haemophilia

Haemophilia Foundation Australia

[www.haemophilia.org.au](http://www.haemophilia.org.au)

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## RED RUN CLASSIC

Red Run Classic see page 11



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# The 14th Australian and New Zealand Haemophilia Conference

The 14th Australian and New Zealand Haemophilia Conference will be held in Canberra later this year. Enclosed in this edition of National Haemophilia is an updated conference registration brochure which details the conference program to date, and the registration form so that you can register. The conference runs over two days and will cover topics such as:

- prophylaxis
- helping families manage bleeding disorders better inhibitor treatment
- understanding von Willebrand Disorder
- better health and fitness
- fitness in children
- youth matters
- complications of ageing
- issues for carers
- impact of Hepatitis C
- dealing with depression
- managing pain
- women with bleeding difficulties
- care of mothers who are carriers and care of the new born
- genetic counselling
- ethics
- ensuring safe and adequate supplies of treatment products

Remember that some Haemophilia Foundations offer subsidies to assist people to attend the conference. We encourage you to explore options so that you can join with other people from around Australia and New Zealand who are also affected by inherited bleeding disorders to learn more and share your experiences.

# 14<sup>th</sup>

## Australian & New Zealand Haemophilia Conference Canberra 4-7 October 2007

bleeding disorders - achieving success to last a lifetime  
[www.haemophilia.org.au](http://www.haemophilia.org.au)



# PARENTS EMPOWERING PARENTS (PEP)

Earlybird  
registrations close  
31 July 2007.

For more information visit  
[www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences) or contact HFA on  
1800 807 173.

HFA values the support of:

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The internationally regarded Parents Empowering Parents (PEP) training program will be offered in conjunction with the 14th Australian and New Zealand Haemophilia Conference.

PEP teaches parents who have children with a bleeding disorder how to be better parents and how to manage their child's bleeding disorder more effectively. Parents will learn new parenting skills to enable them to deal better with the daily challenges of raising a child with a bleeding disorder. The program best suits parents of pre-school and primary school aged children with haemophilia.

The training program will run in two parts – the first is a train the trainer program for nurses, social workers and psychologists to learn how to teach the PEP Program to parents of children with haemophilia. The first part will be run before the Canberra conference on the Monday-Wednesday (1-3 October) by US trainers Edward Kuebler from the University of Texas Gulf States Treatment Center and Danna Merritt from the Hemophilia Hemostasis Thrombosis Center, Children's Hospital of Michigan, Detroit.

The second training program will be run for parents on the Sunday and Monday after the conference (7-8 October).

We are pleased to offer the opportunity to parents who come to the Canberra conference to stay on in Canberra after the conference to attend the PEP training for parents on the Sunday and Monday. It will be held at The Brassey in Canberra. The hotel room rate of AUD\$113 includes breakfast. You may wish to stay at The Brassey for the conference as well as the PEP

training at this rate, however you will need to make this clear on the registration form.

The training for parents will only be offered if there is sufficient interest. The course will be offered free of charge, however parents requiring accommodation will need to cover the cost of their accommodation on the Saturday and Sunday nights (AUD\$113 per room per night). Costs have been kept low to make the training accessible to families, however some further financial assistance may be available from State/Territory haemophilia foundation or HFA.

Even if you are unable to attend the training in Canberra you may later have the opportunity to do the training in your State in the future, because haemophilia nurses and social workers will plan to run the programs in their States after completing the training.

**For more information about PEP go to [www.pepprogram.org](http://www.pepprogram.org).**

Talk to your haemophilia social worker or nurse to discuss the benefits of this program. If you would like to attend the PEP workshop you must contact Sharon Caris, at HFA  
[scaris@haemophilia.org.au](mailto:scaris@haemophilia.org.au) before 31 July 2007. H

# BUILDING THE HFA NATIONAL HEPATITIS C STRATEGY

Suzanne O'Callaghan

What does it mean to have a bleeding disorder and hepatitis C in Australia? What is HFA's role in this? Developing a national hepatitis C strategy is a current priority for HFA. Through this, HFA aims to understand the needs of people with bleeding disorders and respond to those needs.

HFA is building its national hepatitis C strategy in stages. Stage one was an initial consultation to identify the major issues and resulted in the information booklet *Hepatitis C: information for people with bleeding disorders – no. 1*. This booklet is being given out nationally through Haemophilia Centres and is also available on the HFA web site.

## HEPATITIS C NEEDS ASSESSMENT

Stage two is the consultation for the Hepatitis C Needs Assessment. The bulk of this stage has been completed with a great deal of goodwill and support from State/Territory Haemophilia Foundations, Haemophilia Centre staff and Hepatitis C Councils.

Over February and March 2007 focus groups of people with bleeding disorders and their families/partners were held in several States and Territories. These were carried out in collaboration with the local Haemophilia Social Worker/Counsellor and Haemophilia Foundation. The groups met with the HFA Policy Officer and the Haemophilia Social Worker/Counsellor and talked about the impact of hepatitis C on all parts of their life. Some common themes in the discussions were:

- Hepatitis C is an added layer of difficulty on top of haemophilia which already makes life difficult enough.

- Many people experience fatigue, depression, other mood disorders and nausea.
- For some it can have a huge impact on their financial situation.
- People with bleeding disorders and hepatitis C feel they have to be proactive to get the information they want and referrals to hepatitis clinics.
- Treatment is worthwhile, even if unsuccessful, but side effects are very difficult. Pre-planning is crucial.
- Most have not experienced much discrimination, especially recently. However, they are very careful about whom they tell they have hepatitis C or haemophilia.

I also met or had a teleconference with the Haemophilia Foundation Committee, staff at the Haemophilia Centres and the local Hepatitis C Councils in most States/Territories. In general the issues they raised were similar to the focus groups but all of them were concerned about whether people were having their hepatitis C monitored, particularly young men who might not be aware of the need to keep an eye on their hepatitis C and their liver health.

The Hepatitis C Councils have been very positive. They are keen to share resources with HFA and to provide support and advocacy services to people with bleeding disorders, although they understand that some people with bleeding disorders may prefer to use haemophilia-specific services. Their rural workers stay up-to-date with hepatitis services in rural and remote areas and would welcome queries on what services are available.

## NEEDS ASSESSMENT REPORT

I am writing up this consultation into a report with quotes and stories from the focus groups to make it as readable as possible. The report will also include a summary of the 2003 HFA Hepatitis C Survey results. We are aiming to have the final report ready for members and other interested people to read and comment on by October 2007.

## EVALUATION

Stage three of the consultation will evaluate the impact of the work HFA has undertaken on hepatitis C by that point and check that we have covered the issues across all States and Territories. It is planned for October-November 2007. The evaluation could include focus groups in some States where focus groups have not yet occurred.

## WEB SITE AND PRINTED INFORMATION

HFA's work on a national hepatitis C strategy has mobilised a lot of energy into the area. The HFA Hepatitis C Advisory Group, which includes experts in bleeding disorders and hepatitis C, helped to develop the HFA information booklet on hepatitis C. Feedback has been good, with one Haemophilia Centre reporting that the information had prompted some people to come in for a liver health review. HFA approached Hepatitis C Councils to link to some of their relevant Internet resources via the HFA web site and they were happy to support this. Hepatitis Australia (formerly Australian Hepatitis Council) has invited HFA to adapt their *My Rights* booklet on discrimination and *Your Choice To Tell* booklet on disclosure for people with bleeding disorders. The Australia/New Zealand Haemophilia

Social Workers' and Counsellors' Group is helping HFA to redraft these booklets.

#### EDUCATION

The 14th Australian and New Zealand Haemophilia Conference in October will be an opportunity to provide up-to-date education on hepatitis C for haemophilia health professionals as well as people with bleeding disorders. Two sessions on hepatitis C have been scheduled to cover the major issues.


In June 2007 Hepatitis Australia hosted the National Hepatitis C Health Promotion Conference which brought together workers from all over Australia to think about how to promote health to their particular communities. Sharon Caris featured on a panel of experts discussing how to involve diverse communities and spoke about the range of perspectives people with bleeding disorders may have. One conference session was devoted to people with bleeding disorders. We had the good fortune to have several haemophilia social workers and counsellors and foundation staff in the room as well as some experienced Hepatitis C Council workers. Leonie Mudge from NSW, Maureen Spilsbury from Queensland and I gave the presentations then held a workshop on involving people with bleeding disorders in managing their hepatitis C.

#### HEPATITIS C THINK TANK

In March 2007 hepatitis C medical and nursing specialists and other health and community workers met with key government and health decision-makers to develop a strategy for managing hepatitis C treatment in Australia. HFA was able to make two recommendations to be put before the Australian

Government Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH):

- The hepatitis C treatment package should also include support from hepatitis nurses and help with psychological and social issues.
- The Pharmaceutical Benefits Scheme criteria for government-subsidised hepatitis C treatment should no longer include that you have never had interferon treatment before.

If you have any questions about the HFA national hepatitis C strategy or needs assessment, feel free to contact me at the HFA office. 

In general the issues they raised were similar to the focus groups but all of them were concerned about whether people were having their hepatitis C monitored, particularly young men who might not be aware of the need to keep an eye on their hepatitis C and their liver health.

People with bleeding disorders who have hepatitis C often say that fatigue is a symptom that affects their life greatly. This can be a complex mix of many things, including the impact of the virus on the body and sleep disturbances. If you are having problems with tiredness or sleeping, talk to your doctor or your haemophilia social worker/counsellor and you could also ask for a referral to an occupational therapist.

The following article is abridged from "ABC Health Updates" and was published in "The Hep C Review", December 2006, Edition 55, the journal of the Hepatitis C Council of NSW. Although it talks about fatigue from the perspective of the general community, it also includes some insights that may be useful to people with hepatitis C.

Tiredness seems to be one of the most commonly reported hepatitis C symptoms. It is also often seen as a modern condition within the general community. Should we all be getting more sleep? Or are the causes more complex than that?

# TIRED ALL THE TIME?



Pooped, shattered, knackered, bugged. Being fatigued is an everyday experience that for most of us is the trigger to put on your PJs and get a good night's sleep. But what about when you just can't seem to get going in the morning? When you run out of puff half way through the day? When you're zonked all the time?

A recent survey by Sydney's Woolcock Institute of Medical Research found that 11.7% of a random selection of the NSW population suffers from chronic daytime sleepiness. Dr Nat Marshall, the study's lead researcher, adds that 32% of people surveyed have insomnia or sleep disturbances, and almost 18% sleep less than 6.5 hours a night.

Dr Marshall says he found these figures worrying, particularly as a lack of sleep can affect "everything from work safety to productivity and is even thought to promote obesity and diabetes."

Worse still, tiredness seems to be on the rise. Sydney GP Alf Liebhold says tiredness "is a very common presentation." Liebhold, who's been practising for 45 years, says the number of people complaining of tiredness increases every year.

Invigoration products are also on the rise. Sales of 'energy' drinks – caffeine and sugar-loaded soft drinks – have grown by 28% over the last

year. Clearly Australians feel as though they need an extra boost to get them through the day.

## A QUESTION OF SLEEP

If you're feeling fatigued, it's important to establish the most basic of issues: Are you getting enough sleep? While everyone is able to function on less sleep than they prefer, if you are consistently under-sleeping, ongoing tiredness will be the result.

Dr Darren Mansfield at Melbourne's Epworth Sleep Centre specialises in sleep disorders. He draws an important distinction between sleepiness and fatigue. "Fatigue is more of a listless, lethargic sense of reduced energy but not necessarily increased sleep propensity during the day."

People with insomnia, he says, are fatigued, but not sleepy. So if you feel tired and find you can drop off to sleep at will, you are probably under-sleeping. "Not all of us need eight hours' sleep," he says. In fact he believes the eight hour figure is ultimately unhelpful for many people. GP and co-author of *Why Am I So Tired?*, Dr Ginni Mansberg, agrees. "I think that eight hour figure that gets bandied around does far more harm than good because people get stuck on it. They can have an eight hour sleep and wake up feeling exhausted and

think: 'What's wrong with me? I've had eight hours'. It may simply be a matter of saying: 'Well I need nine'," says Mansberg.

She adds that women, on average, need an hour more sleep than men.

## WHY DO WE SLEEP?

"There is a lot of evidence to suggest that sleep has an important learning and memory function," says sleep expert Darren Mansfield.

"If you demonstrate a complex task and then sleep deprive people afterwards, there is very good data now to show that the sleep deprived have a poor retention of that task or slower learning of the task."

Mansfield says that the seemingly random electrical impulses running through someone's brain while they're asleep are actually reinforcing important connections between brain cells. He describes that as your brain 'rehearsing' its thoughts. "Information that's in long-term memory tends to disappear unless it's in some way rehearsed," he says.

And because we can't rehearse old information while simultaneously learning new information, we hop into bed, turn out the lights and shut our eyes in order to minimise external stimuli that would otherwise need to be processed. There, free from distractions, our brain deals



with all the information that's been absorbed over a lifetime.

## INSOMNIA

Some people, however, want to sleep, but simply can't – it's estimated that 80% of Australia's adult population will go through a sustained period of insomnia at some point in their lives. Mansfield says insomnia often arises when people are going through a stressful life period, or are suffering from depression or anxiety. Even when these triggers have been resolved, insomnia can linger, having become ingrained in the individual's sleep routine.

"People almost forget how to go about getting off to sleep," Mansfield says. They need to be re-educated. He teaches relaxation techniques before bedtime and says that if you find yourself wide awake at three am, you should forget about trying to continue sleeping. Instead, get up, read a 'trashy novel' that is entertaining, but not over-stimulating, until you become naturally tired again.

Only then should you return to bed. Having a strategy like this helps dissipate the frustration, he says.

He also recommends keeping your body clock regular by going to bed and rising at similar times every day, and "not guzzling too much caffeine".

"People find themselves in a vicious cycle where caffeine contributes to a sleep disturbance, but because of the sleep disturbance, they feel tired and want more caffeine," he warns.

A bit of vigorous exercise earlier in the evening and a warm shower before bed also help send you to the land of nod. The slight fall in body temperature that follows these 'warming' activities can trick the body into feeling sleepier. And don't discard the old wives' tale of a glass of hot milk before bed. Milk contains the amino acid, tryptophan, which has been shown to help induce sleepiness.

## MEDICAL SOLUTIONS

Sometimes, tiredness is the result of a treatable medical problem. Mansberg says she checks for a series of common complaints as her first order of business when seeing a tired patient. "The top three are depression, iron deficiencies and thyroid disease," she says.

The thyroid is a gland that controls a person's rate of metabolism, so if it is not functioning properly, tiredness can be a result. A simple blood test can check if the thyroid is functioning properly.

Sleep apnoea is another possible medical cause that can be definitively diagnosed only through overnight monitoring in a sleep lab. In sleep apnoea sufferers, the muscles holding open the airways become too relaxed and collapse. The person wakes, their muscles retension, and they continue breathing normally.

The trouble is, the brief but frequent waking prevent them reaching the deep, restful phase of sleep. And often, the person falls asleep again so quickly, they have no memory of the event and, therefore, no idea why they feel so exhausted in the morning.

Some other suggested causes are: (take a deep breath here because it's a long list) stress, low oxygen levels in offices, poor diet, infection, parasites, hormonal changes, allergies, poor spinal adjustment, anaemia, boredom, weight problems, anxiety, heart valve problems, lupis, and environmental toxins.

However, it's most likely that the cause is not one of these, but a combination of two or more. The problem is that tiredness is a symptom of just about every kind of illness. Even the common cold makes people feel lethargic. When it is such a non-specific problem, it makes tracking down the culprit all the more difficult.

## ENDURING FATIGUE

If ongoing or persistent tiredness is present, a diagnosis of chronic fatigue syndrome might be considered. This poorly understood illness affects up to one in 100 people who are struck down with a lethargy that just doesn't seem to go away.

Chronic fatigue often follows an infectious illness such as glandular fever and is accompanied by other symptoms like muscle and joint pain, concentration and memory difficulties and general irritability. Worst of all, even the experts are not sure what causes it.

"We know a fair bit about what chronic fatigue is not and not too much about what it is," says University of NSW expert Professor Andrew Lloyd. By a process of

elimination, researchers have tracked the site of the problem to the brain. Lloyd believes it's a problem with the proper functioning of the brain, rather than any structural abnormality. He suspects chronic fatigue may actually be several different diseases that simply have the same symptoms, meaning that the hunt for the source will be long and difficult.

But the news isn't all bad – most people with chronic fatigue make a full and spontaneous recovery within six months of being diagnosed. For those that do not get better by themselves, a range of management techniques and support groups ease the burden of the disease.

## LIFESTYLE

Liebhold's pet theory on the increase in tiredness is that the rat race is sapping Australians' 'vim'. "I think that much more is expected from some people than used to be," he says.

"There's an epidemic of people who are financially on a treadmill. I see people who haven't had a holiday in three years. I see people who don't want to take time off when they've got the flu. They're afraid of losing their jobs," says Liebhold. It is true that Australians have the second longest working hours in the OECD (the Organisation for Economic Cooperation and Development), behind the USA.

Liebhold says that constant pressure means we're not relaxing properly and are always running on half-charged batteries. "The sort of thing people used to do in order to regain their energy was have a bit of fun, have a holiday. They're even too tired to do that."

Mansberg agrees people should limit the number of activities they try to cram into their lives, but cautions that people can't simply drop out of society in order to get a bit more shut-eye. "I've actually never met a woman who could say: 'What will I lop off my busy schedule? I think I'll just give back my children'," she says.

"We have morphed into a 24-hour society. That could be a good thing. There's no point in saying that's a terrible thing because it's here and it's more about learning to survive in that society than trying to change it."

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## DIETARY ISSUES

A poor diet is often the most basic of lifestyle issues and can be fixed relatively simply. Dr Trent Watson, spokesman for the Dietitians' Association of Australia, says that iron is a key ingredient to maintain energy levels. He says red meat, green leafy vegetables and whole grains are all foods that give red blood cells the building blocks for optimum performance in their role of delivering oxygen to muscles.

Carbohydrates also power the body along on its daily tasks. Found in fruit, breads and pasta, it is the food most easily converted to energy.

Dehydration is another factor: "If you become dehydrated, you reduce your blood volume so your heart's got to work harder to pump the same volume around," says Watson.

Similarly, being overweight puts a lot of strain on your heart. And as a nation, we're the fattest we've ever been. At least 60% of men and 42% of Australian women are overweight or obese. The staggering statistic concerns Watson.

"A recent study in the US of 16,000 people showed a distinct correlation between obesity and excessive daytime sleepiness," he says, adding that people with a body mass index over 32 (anything higher than 25 is considered overweight), reported double the incidence of tiredness during the day.

Alcohol, like caffeine, is a drug that can lead to a vicious cycle of tiredness. "Some people drink alcohol to put themselves to sleep, but alcohol can disturb your sleep cycles, so you don't get your normal pattern of sleep during the night. You may get your eight hours, but because the quality of sleep has been reduced you still wake up fatigued," says Watson.

Tiredness can be an immensely frustrating condition, not least because the very generalised nature of it makes the cause difficult to pinpoint. Nonetheless, some solution – be it lifestyle, psychological, or physical – can usually be found. And if all else fails, it's a really good excuse for a holiday. **H**

*Going through hepatitis C treatment can be a challenging experience, for family and carers as well as the person with a bleeding disorder who has hepatitis C. Many family members and carers say how important it is to hear from others who have been through the same experience, both when planning for treatment and during treatment.*

*The following story was published in "The Hep C Review", December 2006, Edition 55, the journal of the Hepatitis C Council of NSW.*

# THINGS FOR A CARER TO BE AWARE OF

*Emi, NSW*

During the 24 week HCV treatment of pegylated interferon and ribavirin my daughter experienced a number of side effects. We found that actually going through it all was different to reading about the treatment. Some people don't have any, or many, side effects, however the following may be useful information for you.

I found that it is so important as a carer to really listen to what the person says about their pain, their frustration, and what it is they are feeling. What the person says is happening for them, is happening for them. It is so hard for the carer to see their loved one in pain, or shouting angry outbursts, or in tears. The struggle to try and be as 'normal' as possible is difficult, and it takes a lot of courage for them to keep going when there is so much being coped with. The carer can feel so helpless at times too for not being able to 'make it better'.

Things to watch for:

- Severe body pain – joint and muscle pain, skin dry and itchy and sensitive to touch, muscles aching, internal organs aching, fever (feeling hot and cold) – ask the person if they would like to have massage (no guessing!!) as at the right time, when the pain eases, massage can be really helpful.
- Severe nausea – not wanting to eat (loss of appetite). Sometimes the person feels like eating what the carer may consider is junk food. However if it helps the person to feel

more 'normal', then offer what is being asked for. This also slows down the weight loss. To help the immune system it is important not to cut out healthy food altogether of course.

- Severe headaches – needing to lie perfectly still – my daughter found that decaffeinated coca cola helped, as well as the doctor-suggested medications.
- Hair loss – it is scary to find hair in the bottom of the shower, or on the carpet, and patches on the head where hair is no longer there. Sometimes cutting the hair shorter helps to cover the loss, and a new hair style can give a bit of a lift.
- Forgetfulness, brain fog, time distortion – not remembering to take medication or to self inject. The carer needs to make sure, either by giving the medication and the injection (I didn't have to do this thank god), or watching that the medication is being taken and the injection is done. It's helpful to keep a diary and mark in appointments to be kept, chores to be done, family commitments to be followed through. The brain fog experienced makes it difficult for the person to think. It is so very important for the carer not to take over, but to give gentle reminders of what is to be done. It is important to help build self confidence, and to support actions that also help build self confidence.
- Anger outbursts – happen out



of frustration with the self, with the ongoing symptoms, with not feeling 'normal', with the brain fog, with feeling out of control of the treatment/situation, feeling as though going crazy. Sometimes the carer feels that they are the target of the volcanic eruptions, and sometimes they are, however imagine how you may feel if you were in the same situation.

- Sensitivity to sound, tinnitus (constant or periodic ringing/whistling sound in the ears) – loud noise may feel painful. Need to be on their own to cope (either in silence or with music), in peaceful surroundings. Listen to what the person says they need to do.
- Tiredness, no energy (fatigue) – may be due to anaemia (lack of iron in the blood) or from the body and spirit fighting the virus and coping with the treatment. Rest, peaceful surroundings, time to stare into space, music or silence, withdrawal from the family, help. Understand that you the carer are not being rejected, the body heals when it is relaxed and resting. Help with the household jobs.
- Not being able to sleep, sleep disturbance – at night as well as during the day. Music, staring into space, medication, meditation, may help.
- Mouth ulcers – painful, can prevent enjoyment of food.
- Blurred vision (difficult to focus eyes) – can continue three months after the treatment ends.
- Depression – not wanting to go on, feeling that no-one understands, constant tiredness, unable to sleep, feeling isolated even when surrounded by caring people – antidepressants needed, during and for 12 months after treatment. Some

people may choose not to use antidepressants. Whether taking these or not the carer needs to watch carefully how the person is acting and how they are handling their situation, especially if there is a family history of depression. Encourage regular contact with the HCV support group network (daily, if able to use a computer) [[www.hepcaustralasia.org](http://www.hepcaustralasia.org) – the internet forum for people affected by hepatitis C in Australasia], HCV nurse, doctor/specialist. Regular contact with the haemophilia social worker/counsellor may also be valuable.

- Muscle wasting – massage helps to try to keep muscle tone.
- No emotional energy (very often not able to support partner or children) – all the energy the person has is needed to defeat the virus and cope with the treatment. It is not a rejection of loved ones, there is just nothing left over. It may seem selfish but it is a real fact. Being able to talk about this with each other is important for understanding, and to work together for the best possible results.

The carer has needs too and it is important that you have a support network for you as well. A lot of energy is needed to be able to be helpful to the person dealing with the treatment. It is ok to feel tired, angry, etc, and you need to have someone to 'have a grizzle' to about this – not the person going through the treatment though.

Despite all of the above, it is a special time for all concerned. Deeper and heartfelt understanding, and compassion, for each other and others, seeing the funny side of some moments, and possible clearance of the virus, can be some of the rewards.

Thank you for reading this, good luck, many good wishes. H

I found that it is so important as a carer to really listen to what the person says about their pain, their frustration, and what it is they are feeling.

# HIV UPDATE

Suzanne O'Callaghan

National Association of People Living with HIV/AIDS/Australia (NAPWA) and the state-based People Living with HIV/AIDS (PLWHA) groups have taken several opportunities recently to acknowledge HIV issues for people with bleeding disorders.

## HIV WORKSHOP, MELBOURNE

Leonie Mudge, Haemophilia Social Worker at RPAH, NSW, was invited to speak about the haemophilia community and HIV at the Psychosocial Perspectives of HIV/AIDS Workshop in Melbourne in May 2007. Her presentation included a brief background about haemophilia, the impact of HIV on people with bleeding disorders and how treatment and support services have adapted to their needs. Peter Canavan, the HIV Living Program Co-ordinator for NAPWA and the Convenor of the AIDS Treatment Project Australia (ATPA), attended the session, as did David Menadue, Associate Editor of Positive Living. David is keen to publish some articles about the experiences of people with bleeding disorders in Positive Living.

## HIV/HEPATITIS C CO-INFECTION

Marcus Younger, who provides peer support services at the Positive Living Centre, Melbourne, discussed with me the common themes that arose from peer support groups for people who are co-infected:

Depression is more common in hepatitis C and in co-infection than in HIV.

Many will not consider treatment as they fear it will fail and that the side-effects will be worse than HIV treatment; they comment that hepatitis C is too much of an extra burden to think about.

Diet and lack of appetite are big problems. People who are co-infected appear to drink more coffee than those with HIV.

Sleeping patterns become disjointed, which can create a problem with managing adherence with HIV drugs.


It is difficult to motivate people who are co-infected to seek support.

There are few new resources on co-infection.

This highlights some common problems that HFA will need to follow up in people with bleeding disorders who are co-infected, particularly around health promotion, access to counselling services and information.

## VIRACEPT (NELFINAVIR) RECALL IN AUSTRALIA

After consultation with the Therapeutic Goods Administration, Roche Pharmaceuticals is recalling all forms of the drug Viracept (Nelfinavir). This is because of possible contamination of the active substance by an impurity called methane sulfonic acid ethyl ester.

If your drug regime includes Viracept, contact your HIV physician. For more information you can also contact Jo Watson, Executive Officer at NAPWA on 1800 259 666 or read the PDF on [www.napwa.org.au](http://www.napwa.org.au). 



Sunday 27 May 2007, New Farm Park, Brisbane

Over 200 runners and walkers participated on Sunday 27 May 2007 for the inaugural Red Run Classic. The event was the first of its kind for Haemophilia Foundation Australia and Haemophilia Foundation Queensland.

Congratulations to the following winners:

### Men's Division

- 1st 176 Nathan Flint 17.08
- 2nd 186 Jeremy McDonald 17.19
- 3rd 118 Ross Nicholls 17.48

### Women's Division

- 1st 53 Clare Geraghty 17.28
- 2nd 42 Carley Ekert 20.54
- 3rd 133 Sarah Prestridge 22.45

### Child Divisions

- 1st Girl 84 Emily Leydin 25.21
- 1st Boy 44 Liam Fogarty 25.28

Thank you to all who participated and supported the 2007 Red Run Classic. We look forward to seeing you again next year.

### Gold Sponsor – Golding Contractors

### Supporter – In Training

Thank you to:

Athletics Australia B105	Shop Novo Nordisk Red Bull
Baxter	Rendezvous
Brisbane City Council	Hotel Brisbane
Dario Vescovi	The Marque Hotel, Brisbane
In Training	The Valley Police Station
Jonathon Fogarty	Wyeth
New Farm Fruit	

Buy a RRC t-shirt today

1 for \$10, 2 for \$18 or 3 for \$25

Don't miss out!!

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*The Haemophilia Counsellor from Western Australia, Sharon Hawkins, posed some questions to Anthony Vernede about his experiences of transferring from the Disability Support Pension to start full time employment.*

# MOVING FROM DISABILITY SUPPORT PENSION TO WORK

**What prompted your decision to move off the DSP and seek avenues to ultimately getting employment?**

Well originally I went onto the DSP after several unsuccessful surgery attempts on my knees and found I could barely walk (which made it almost impossible to even consider working). For a while this seemed not so bad but I began to find myself very bored and feeling very down (having little purpose or structure to my life). I realised that the only way I would start to feel a bit better about myself was to get back into the workforce. I spoke with Centrelink and requested that I be referred to CRS (Commonwealth Rehabilitation Service).

**What was your situation prior to making this decision?**

I was pretty much like most on the DSP (always poor) but it wasn't really this factor that motivated me. It was more about feeling good about myself and doing something constructive with my time.

**What, if any, reservations/concerns/fears did you have about your decision?**

I was always being told by relatives that if I go off the DSP I would not get back on, and what would happen if I couldn't continue to work? I spoke with Centrelink about this and they advised me that given my situation there would be no problem whatsoever returning to DSP if I was unable to continue to work. I think though my biggest concern was more to do with my own self-confidence (or at that time, lack thereof).

**What help did you seek, if any, in making the decision or finding out where to go next?**

I spoke with the Haemophilia Counsellor, Centrelink and CRS themselves as they have very good caseworkers.

**What was the process you went through with CRS and then finding employment?**

CRS had many options available such as courses in looking for work, writing great resumes and even on the job training. To begin with they review your individual case and send you to an occupational therapist to prepare for any special requirements you may have with an employer. You then speak with a caseworker about the type of work you want to get into and they then help in finding ways to get you into that work. (In my case it was with an on the job training course at Telstra.) Once you are employed or in a training program they continue to review you (for up to two months) and make sure that any needs you may have (such as special chairs or equipment) are provided for.

**How would you describe this transition to full time employment for you?**

I found my transition back into the workforce very successful and very rewarding (not only financially, but in my own feeling of self worth).

**What was there, if anything, in hindsight, you would have done differently?**

No, to be honest it was a very good experience and I look back on this often and am very glad that I made this choice and that there were people out there who were very supportive and helpful (not just the people at CRS but my employers).

**What is your situation like now and has this been a positive step for you - in what way?**

I actually was given a long term contract with Telstra who I did my on the job training through and even though this at the time proved short lived (as everyone in my department was made redundant), this experience proved to be a very good launching board into bigger and better things. I moved from Telstra to Unisys and stayed there for nearly two years before resigning to move to Bankwest where I am currently. They have plans to move me into a senior management position very soon. I am MUCH better off in every way thanks to this experience. I have more money, self-confidence and self esteem. **H**



The following story was published in "The Hep C Review", December 2006, Edition 55, the journal of the Hepatitis C Council of NSW.

# CRS AUSTRALIA SERVICES

CRS Australia provides vocational rehabilitation services to people with all kinds of injuries and disabilities.

Andrew Clarke, Regional Manager, Eastern Sydney CRS Australia says, "Our main aim is to assist people with disabilities get back into mainstream work. We identify sound job matches, and give our clients the skills and confidence to get a job and keep it."

"Each CRS Australia client is allocated a Case Manager who gets to know them and helps them develop achievable goals. The Case Manager then provides services and support to help them achieve their goals."

"Our vocational rehabilitation services are provided by allied health professionals including rehabilitation counsellors, occupational therapists and psychologists."


Vocational rehabilitation programs are tailored to a job seeker's individual needs and may include:

- assessment of functional and physical work capacity
- vocational assessment and counselling to determine suitable job options
- counselling to support adjustment to disability
- supervised on-the-job training and/or a short vocational course
- fitness and work conditioning programs
- confidence building/self esteem

groups or individual sessions

- employer incentives
- assessment of workplace suitability


Referrals to CRS Australia are made from a Job Capacity Assessment, which is organised by Centrelink. There is no cost for the service for people who are receiving a Centrelink Pension or Benefit.

CRS Australia has offices located across Australia. A full listing of CRS Australia's services and locations can be found at the website [www.crsaustralia.gov.au](http://www.crsaustralia.gov.au). 

## DAWN THORP TRAVEL GRANT

The Dawn Thorp Haemophilia Nurses' Travel Grant was announced by CSL Bioplasma at the National Haemophilia Conference on the Gold Coast in 2003. Since 2004, these Awards have enabled several haemophilia nurses to attend a haemophilia related conference or other clinical activity for the benefit of the bleeding disorders communities in Australia and New Zealand. The annual Travel Grant is valued at AUD\$8,000 and may be shared by one or more applicants.

Although the grants are usually provided for nurses to attend international education and training courses and visit haemophilia centres, the 2007 grants have been made for two specialist haemophilia nurses to attend the 14th Australian and New Zealand Haemophilia Conference in Canberra and visit other haemophilia centres.

Grainne Dunne of the Sydney Children's Hospital and Daryl Pollock of Midcentral Health, Palmerston North, New Zealand, have each been awarded a grant to enable them to attend the 14th Australian and New Zealand Haemophilia Conference in Canberra. 

### Dawn Thorp

*Dawn Thorp commenced work at the Transfusion Medicine Unit at the Institute of Medical and Veterinary Science in Adelaide in 1971. Dawn combined with great success two very complex areas of haematology – optimum haemophilia treatment and plasmapheresis. In 1984 Dawn was elected to the committee of Haemophilia Foundation South Australia. Dawn formed the Haemophilia Foundation Australia (HFA) Nurses' Association in 1988 and acted as convenor for five years. In 1993 Dawn was elected to the HFA Executive Board, and became a Life Governor in 1995 in recognition of outstanding service to HFA. Dawn retired in 2001 and maintains an active interest in haemophilia nursing.*

# INHIBITORS STILL A MAJOR COMPLICATION BUT NEW TREATMENT PRODUCTS ARE ON THE HORIZON

*Dr Paul Giangrande*

Improved donor testing and screening, and the development of physical methods for viral inactivation have effectively eliminated the risk of transmission of pathogens, such as HIV and hepatitis C, by modern clotting factor concentrates. By contrast, the threat of the development of inhibitors (antibodies to infused coagulation factor) remains a potential and serious complication. Genetic engineering and clinical trials of new products, however, suggest that better management is on the horizon.

The problem is significantly more common in haemophilia A than in haemophilia B. Data from the UK registry show that 16% of all patients with haemophilia A and 6% of those with haemophilia B had developed inhibitors by the age of five years. It is now clear that the major factor that determines the predisposition to inhibitor development is the underlying molecular defect.

Certain types of gene defects in haemophilia are definitively associated with a significantly increased risk of inhibitor development. However, there is also additional evidence from family and twin studies that other subtle genetic factors play a role. Race may also influence the risk of inhibitor development. Several studies have shown that people of Afro-Caribbean origin are more susceptible to inhibitor formation

There is controversy as to whether the risk of inhibitor development in

haemophilia A is higher in subjects who receive recombinant products than in those who receive conventional plasma-derived products. Although several studies seem to support this assertion, no prospective comparative study has yet been undertaken. International initiatives to pool data, which could help to resolve this issue, have been proposed.

Although patients with inhibitors do not usually experience more bleeds than those without, the episodes can be much more difficult to control. The treatment strategy for patients with inhibitors has two distinct aims: to control individual bleeding episodes and to eradicate the underlying antibody through immune tolerance therapy. Infusions of conventional factor VIII concentrates are unlikely to be of any value in patients with a significant inhibitor titre.

The two therapeutic products used most widely to control bleeds in patients with inhibitors are activated prothrombin complex concentrates, such as FEIBA® (Baxter) and recombinant activated factor VII (NovoSeven® by Novo Nordisk). The recent FEIBA NovoSeven Comparative (FENOC) study found both products to be comparable in efficacy for treating joint bleeds, although a minority of patients appear to respond better to only one of these agents.

Immune tolerance therapy involves the regular administration of high doses of factor for up to two years.

An international study is currently underway, which will assess whether the outcome can be influenced by the dose of concentrate given ([www.itistudy.com](http://www.itistudy.com)). The immune tolerance regime can be very demanding for a child and family. In many cases it is also necessary to insert an in-dwelling central venous line, which carries with it risks of bacterial infection and/or thrombosis.

Patients with haemophilia B and inhibitory antibodies, though rarer, pose a particular challenge. Severe allergic reactions may develop after infusions of factor IX concentrate and the response to immune tolerance induction is also poor. The total cost of treatment for patients with inhibitors can be very high and stretch a hospital budget, even in affluent countries.

Looking to the future, it is likely that genetic engineering will help prevent inhibitors through the design of novel factor VIII molecules that are less likely to provoke an antibody response because of their modified structure. Clinical trials of a recombinant porcine factor VIII are expected to begin in the near future. The rationale for the use of this product is that the molecule is sufficiently similar to the human form to promote clotting while, at the same time, being sufficiently different enough to avoid inactivation by circulating antibodies. **H**

# GENERIC MEDICINES – THE

Jan Donovan

## INTRODUCTION

Over the last twelve months the National Prescribing Service Limited (NPS) has been exploring the benefits and risks of increasing prescribing and use of generic medicines. Information has been prepared for prescribers and disseminated through the NPS News 44 on Generic medicines. The NPS Community Quality Use of Medicines Program (CQUM), in partnership with the Consumers' Health Forum of Australia, has been actively researching consumer views of generics. Key messages for consumers are part of a module on generic medicines developed by COTA organisations and NPS as part of a national peer educators' program for seniors. The key messages will also be included in the national awareness media campaign planned by NPS for later this year.

This article acknowledges that work and provides a brief analysis of recent government policy announced as part of the PBS Reforms, which seek to further lower the cost of generic medicines for Australian consumers.

## GOVERNMENT POLICY

In developing countries the issue of access to generic medicines has focused on one devastating disease, HIV/AIDS. The availability of low cost generic anti-retroviral medicines has contributed significantly to the establishment of major health and social programs in poor countries such as Brazil<sup>1</sup> that aim to provide all HIV positive people with access to life saving generic medicines.

Citizens and civil society groups in developing countries such as Brazil applied significant pressure on governments to supply low cost, generic medicines to the poor and sick and save lives. The Australian Government was not under the same immediate pressure; however, the prescribing of low cost generic medicines is significantly lower in Australia (28%) than the USA and the United Kingdom (50%).

Despite government attempts to encourage the use of lower cost brands, the under-prescribing and low use of lower cost generic medicines has contributed to significant growth in the cost of the PBS (2.7% last year) and cost taxpayers \$6 billion<sup>2</sup>. A policy response was required and the government recently changed its policy on generic medicines to ensure the PBS remains sustainable for future generations.

The most significant consequence of the policy is to lower the cost of generic medicines further and require price disclosure and price reductions for companies listing new brands of existing medicines on the PBS. Together with recent increases in the general and concessional co-payments and safety nets, this policy should make generic medicines an attractive alternative to higher priced brand name medicines. At best, consumers who are not concession card holders will pay less than the general co-payment (\$30.70) for many generic medicines and, at worst, pay no more than the co-payment. The policy changes are intended to increase savings on medicines for individual consumers, tax payers and the government who fund the PBS.

The Australian policy context for encouraging greater use of generic medicines is more complex than the clear case of access to generic medicines for the poor of developing countries. The social and economic context is also different. Australia is a developed country but affordability of health services and medicines is a growing problem for those on low fixed incomes with chronic illness and for many families with children. In addition, new medicines for chronic diseases such as cancer, diabetes and Alzheimer's disease are being developed and will need to be listed on the PBS to ensure they are affordable. Since August 2006, new drugs worth \$1 billion have been added to the PBS<sup>2</sup>.

Price disclosure is also an important element of the PBS reforms. From 1 August 2007 suppliers of a new brand of a listed medicine will be required to disclose the actual price at which they sell that brand to wholesalers and/or pharmacies. All other suppliers of that medicine (brands, forms and strengths) will be invited to volunteer to disclose the prices at which they sell their medicine.

In the future, generic medicines will be available for a much wider range of conditions. Over the next decade patents will expire on over 100 medicines<sup>2</sup>. All consumers and prescribers will be encouraged to save on medicines by using generics (when they are available) for both short term illness and for chronic diseases. The government is also planning a public awareness campaign to encourage more use of generic medicines.



The most significant consequence of the policy is to lower the cost of generic medicines further and require price disclosure and price reductions for companies listing new brands of existing medicines on the PBS.

# MYTHS AND REALITIES

Mechanisms such as 'brand premium' (substitution) have been used in Australia for more than a decade to encourage consumers to choose the lowest priced medicine in a class of medicines or pay the extra cost associated with choosing a more expensive brand, which does not count towards the safety net. The implications of such policies for consumers and for the practice of doctors and community pharmacies, gathered from the literature and consumer consultations, are that the burden of cost is on the consumer of brand premiums when they are unable or uncomfortable to use a lower cost generic medicine; for example, people with mental illness with heart disease and diabetes. Possible scenarios include some consumers not buying their prescription medicines or taking them less frequently than prescribed.

## WHAT IS STOPPING CONSUMERS?

There are many reasons Australian consumers are not using generic medicines as much as UK and USA consumers. Their doctors may not recommend a generic and/or may be happy with the current medicine. Research undertaken by NPS and by CHF shows that consumers lack clear understanding about when they should choose a lower cost generic medicine over a brand of the same medicine prescribed by their doctor. Prescribers may not recommend people change to a generic medicine for a number of reasons; for example, they may be stabilised on a particular medicine and at risk

of being destabilised due to very slight variations in the fillers (excipients) of an alternative.

## CONCLUSION

It is essential for Australian consumers to have much clearer information about generic medicines. More information about generics will be required before substantial changes in prescribing and use will occur, including availability, quality and bio-equivalence with brand named medicines. Consumers will lead the way for changes in prescribing to occur. For example, the work of the NPS to develop key messages for the generic medicines module for the national peer educators' program for seniors is designed to empower older consumers to ask their doctor and pharmacist for the lowest cost generic medicine.

The role of pharmacists will also be an important component of the change process. Consumers will need advice from pharmacists to reassure them that the safety, quality and efficacy of generic medicines in Australia are regulated by health authorities. The majority of Australian consumers also value highly the treatment advice of their general practitioner and specialist.

In the future, prescribers generally will also need to be encouraged to prescribe the lowest cost generic to consumers to ensure that the policy is fully implemented and that the PBS has a healthy future.

Janette Donovan gave this presentation to the Pharmacy Guild of Australia Australian Pharmacy Professional 2007 Conference as the

Consumer Director on the NPS Board. Jan was the inaugural Consumer Director and her term finished in March 2007. She is currently the Vice Chairperson of Consumers' Health Forum of Australia.

Thanks and acknowledgements:

Hannah Baird, NPS CQUM Program

Helen Hopkins, Consumers' Health Forum of Australia

Fran Hagon, NPS Corporate Public Affairs and Marketing 

- 1 Petryna A, Lakoff A, Kleinman A. Global Pharmaceuticals: Ethics, Markets, Practices. Joao Biehl. Pharmaceutical Governance p.206-239 Duke University Press. Durham and London. 2006.
- 2 Australian Government Department of Health and Ageing. Strengthening Your PBS – Preparing for the Future. December 2006.

The following article was published in "Hemophilia World", May 2007, Vol 14 No 2, the journal of the World Federation of Hemophilia.

Jack Finn has haemophilia, but the New Zealand native never allowed his medical condition to discourage his dream of kayaking around the Auckland Islands.

## NEW ZEALANDER KAYAKS SUB-ANTARCTIC SEA TO BOOST HAEMOPHILIA AWARENESS

Never mind that the Aucklands are in the middle of volatile sub-Antarctic seas nearly 500 kilometres off New Zealand's southernmost coast. Never mind that sea lions and penguins are the only inhabitants of what is considered one of the planet's bleakest and most rugged destinations. "The region is a cold, harsh, and furious environment," Jack Finn says, noting that these rocky coasts have proved fatal for several ships over the years.

Still, despite bouts of seasickness and a history of bleeds, like the one that eventually thwarted his expedition, the 24 year old kayak instructor was determined to paddle around the desolate archipelago. The resolute Finn never envisaged this as an easy journey, but he knew it was an important one. "This expedition was a way to break down stereotypes around what society thinks about people with haemophilia."

About one-third into his 220 kilometre journey, Finn experienced a painful bleed in his back. His nurse, part of the support crew aboard the yacht Tiama that accompanied him, recommended Finn end his quest. "It's unfortunate that I had a bleed," he says, "but my experience shows that bleeds are inevitable for people with haemophilia."

Despite the disappointment, Finn stresses that he achieved his principal goal – raising awareness about haemophilia through a campaign he called 'Bloody Can Do It.'

"We got loads of good media attention, which allowed us to describe haemophilia and how the

condition affects people," he recounts.

The Auckland Islands campaign was Finn's second awareness-raising effort since 2004, when he cycled the length of New Zealand in support of the Haemophilia Foundation of New Zealand. Both journeys, Finn explains, were vehicles to inspire others. "These were personal challenges and ways to encourage other people with haemophilia to realise their dreams," he says.

"Haemophilia is not easy to live with, but people with the condition can go the extra mile to realise their goals, whether that's writing a book, starting a business, going to university, or taking on a new sport."

As the first person with a bleeding disorder ever known to attempt kayaking around the Auckland Islands, Finn is a big advocate of physical activity. His attempt coincided with World Haemophilia Day on April 17 and the theme chosen by the World Federation of Hemophilia this year, on the importance of physiotherapy in haemophilia care.

"Being fit and healthy enables people with haemophilia to lead better lives," Finn says. "Not everyone with haemophilia should attempt to kayak in sub-Antarctic seas, which was really hard on my body, but there are all sorts of sports worth trying, such as swimming."

New projects are already rushing to Finn's mind to further promote haemophilia awareness, such as a speaking tour about his kayaking experience. But he's in no hurry to get started until he confronts his next great personal hurdle – a 12 month treatment regimen that will, hopefully, cure his hepatitis C.

## WORLD HAEMOPHILIA DAY 2007

Haemophilia Foundation Australia marked World Haemophilia Day with two special events.

On April 17 Morgan Stanley hosted a special dinner for 24 people at the Westin in Melbourne. Guests included business community representatives and HFA donors and supporters. The night was most successful.

On April 18 UBS hosted a morning tea in Sydney which provided guests with a great insight about the challenges and issues facing the haemophilia community.

Guest speakers at both events were A/Prof Alison Street and Rob Christie who spoke about international care and treatment and WFH programs and activities, highlighting the needs of the global haemophilia community. **H**

"I got so much support for the 'Bloody Can Do It' campaign," he says, noting his adventure would not have been possible without sponsors including Roche Products (New Zealand) Ltd, North Auckland Johnson Outdoors, and Bayer Healthcare.

Finn is philosophical as he recounts how pushing his physical boundaries enabled him to ponder his condition in a different light. "I think having haemophilia can transform a human," he says. "I see haemophilia more as a difference than as a burden."

To read more about Jack Finn's 'Bloody Can Do It' campaign, please visit [www.haemophilia.org.nz](http://www.haemophilia.org.nz). **H**

# HAEMOPHILIA FOUNDATION RESEARCH FUND

The Haemophilia Foundation Research Fund was established in 1990 to fund Australian based research in the area of haemophilia and related bleeding disorders. Since then, a range of medical, scientific and social research projects have been funded throughout Australia, amounting to \$422,592. Many of these projects have resulted in positive outcomes including improved treatment, care and services.

A boost to the Fund came in 2004 when the Country Women's Association of New South Wales made a commitment to haemophilia as its medical project for the year. The Country Women's Association of New South Wales is a part of the largest voluntary women's organisation in Australia and each year undertakes a consultative process with members to select the research area where it will direct fundraising efforts. A valuable contribution of \$30,400 was presented by Mrs Judy Richardson, State President of the organisation in

May 2005, followed by \$26,778 in May 2006 and in May 2007 a final donation of \$29,912 was made to the Haemophilia Foundation Research Fund. A total amount of \$87,090 was donated to the Fund over the three years by the Country Women's Association of New South Wales.

The Country Women's Association of New South Wales commitment to fundraising for haemophilia research has made a significant difference to the capacity of HFA to provide opportunities for research. Although the Fund can only support small to medium research projects, it is nevertheless valued by researchers in Australia.

Haemophilia Foundation Australia values the generous donation and support from the Country Women's Association of New South Wales over the past three years and particularly thanks the many individual members who have each worked so hard in their local communities to raise these funds needed for vital research. **H**



(l-r) Mrs Judy Richardson (CWA of NSW State President), Sharon Caris (HFA Executive Director) and Robin Godwin (CWA Member)

Closing Date 27 July 2007

## Grants: medical, scientific or social research

Applications are invited for grants for medical, scientific or social research relating to haemophilia, von Willebrand disorder and related coagulation disorders, and/or medically acquired blood borne viruses.

An amount of \$50,000 will be allocated and grants will be made to one or more projects in this 2007 funding round.

Application form and conditions of funding may be downloaded from Haemophilia Foundation Australia web site at [www.haemophilia.org.au](http://www.haemophilia.org.au) or a hard copy may be obtained from:

Haemophilia Foundation Australia  
1624 High St  
Glen Iris 3146  
Tel 03 9885 7800  
Fax 03 9885 1800  
[hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)





## global feast in support of people worldwide with bleeding disorders

Haemophilia Foundation Australia will join other international Haemophilia Foundations - Argentina, Iran, Nepal, Netherlands, New Zealand, Nigeria, Portugal, United Kingdom and World Federation of Hemophilia (Canada) for GLOBAL FEAST 2007.

You are invited to be an official Global Feast host. Time your event around the month of August 2007. Invite your family, friends and work colleagues. Ask them to bring a donation instead of flowers, wine or a gift. Explain that the proceeds will go to HFA programs and services and to support people worldwide with bleeding disorders. Make sure you add that every dollar donated will make a difference to the lives of people struggling with lifelong and often disabling disorders.

Hope in Zimbabwe comes in small packages. Ten-year-old Mthandazo Ian Bhebhe is like every other child, except he needs haemophilia treatment and often goes without it.

Bhebhe lives in Zimbabwe, a country devastated by civil, political and economic turmoil. Life expectancy is less than 40 years, according to recent UN estimates. Most children with haemophilia in the country remain undiagnosed and untreated. They do not live beyond their teenage years. Yet, there is hope for Bhebhe. He has a world of people who care for him, the haemophilia community.

Recently Bhebhe fell at school and injured his knee, which swelled to the size of a large grapefruit. Without available treatment, doctors gave Bhebhe morphine for three weeks and considered amputating his leg. The World Federation of Hemophilia responded quickly by delivering donations of blood treatment products to the Zimbabwean National Blood Transfusion Service, which determined that Bhebhe was the patient in most need of treatment. Within days, Bhebhe was able to walk using crutches. The week after receiving proper treatment, he went home. Although he continues to need crutches, Bhebhe is able to walk on his own from home to the bus stop and make his way to school.



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. Be creative and have fun!

If you are interested in participating in GLOBAL FEAST please contact us. We will send you everything you need to make your event a success; brochures, promotional items, posters and tax deductible receipts for your guests.

It's so easy, but it will make a huge difference to the lives of others.

### What can you do?

- Organise a morning or afternoon tea at your workplace.
- Organise a sausage sizzle outside your local supermarket (please seek permission).
- Contact your local restaurant and ask them to participate. Invite your closest friends for a meal.
- Organise a dinner with members at your Haemophilia Foundation.
- Host a BBQ street party
- A cooking demonstration party to share the secrets on how to prepare a favourite dish.

All members of the Haemophilia Foundation Australia Executive Board are hosting their own Global Feast event – why don't you follow their lead and participate in this national and international event.

**For more information or to register please call Natasha Coco on 1800 807 173, email [ncoco@haemophilia.org.au](mailto:ncoco@haemophilia.org.au) or visit the official GLOBAL FEAST website [www.globalfeast.org](http://www.globalfeast.org).**

Choose to make a difference this year.

Join Global Feast. **H**

Most people get back pain, everyone has an opinion, but what are the simple facts? Matthew Beard is a physiotherapist who has clinical involvement with haemophilia and spinal clinics at the Royal Adelaide Hospital. He is a member of the Australian and New Zealand Physiotherapy Haemophilia Group.

# BACK PAIN MYTH BUSTERS

Matthew Beard



## X-RAY – EVERYONE SHOULD HAVE ONE?

Findings described on X-Ray reports are not necessarily related to symptoms

X-Rays do not necessarily assist in diagnosis

Complex tests and scans are not always necessary

## BED REST, IS IT THE BEST THERAPY



Too much will delay recovery

Routine activities should be continued where possible

Exercise is best for both prevention and treatment of low back pain



## SLIPPED DISC – DO YOU NEED SURGERY?

Few people require surgery

Bulging discs are common and do not always cause pain

Surgery is a last resort- always seek a second opinion

## DOCTORS – SEE ONE IMMEDIATELY?



Most cases improve quickly

The best treatment is to keep active

Simple pain tablets can be useful

Seek immediate medical attention if experiencing leg weakness or loss of bladder/bowel control

## WANT TO KNOW MORE? FOR MORE INFORMATION:


[www.informedhealthonline.org](http://www.informedhealthonline.org)

[www.nhmrc.gov.au](http://www.nhmrc.gov.au)

[www.betterhealth.vic.gov.au](http://www.betterhealth.vic.gov.au)

[www.cochrane.org](http://www.cochrane.org)

### DISCLAIMER

The author has endeavoured to ensure the information is accurate, however makes no representation or warranty to this effect. 

Illustrations have been adapted from Microsoft clip-art.




## WFH CONGRESS, ISTANBUL - FUNDING APPLICATION

HFA and State/Territory Foundations will again fund several people to attend Hemophilia 2008 in Istanbul, Turkey, 1-5 June 2008. HFA has selected a group of haemophilia community volunteers and health professionals to attend the Congress and encourages these people to bring back new ideas, information and knowledge to share in Australia. It is a great opportunity to get to the peak international haemophilia meeting, so if you fit any of the following categories, and wish to consider making an application for funding, please contact [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) or telephone HFA on freecall 1800 807 173.

Funding is available for:

- one person who is a member of a Haemophilia Foundation and is affected by a bleeding disorder. The application must be endorsed by the applicant's local Haemophilia Foundation.
- haemophilia nurse
- haemophilia social worker/counsellor
- haemophilia physiotherapist

Please note applications must be made on the relevant application form which can be obtained from HFA and must be received at HFA by 10 August 2007.

For more information on Hemophilia 2008, and to register online, visit [www.hemophilia2008.org](http://www.hemophilia2008.org). Note that early bird registration closes 31 October 2007. 

# Calendar

## 4th IAS Conference on HIV Pathogenesis, Treatment and Prevention

Sydney 22-25 July 2007  
email [info@ias2007.org](mailto:info@ias2007.org)  
web [www.ias2007.org](http://www.ias2007.org)



Canberra 4-7 October 2007  
ph 03 9885 7800  
fax 03 9885 1800  
email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
[www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences)

## Haemophilia Awareness Week

7-13 October 2007  
ph 03 9885 7800  
fax 03 9885 1800  
email [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)  
[www.haemophilia.org.au/conferences](http://www.haemophilia.org.au/conferences)



13th International Congress of the World Federation of Hemophilia  
Istanbul, Turkey, 1-5 June 2008  
web [www.wfh.org](http://www.wfh.org)

## 6th Australasian Viral Hepatitis Conference

Brisbane 20-22 October 2008  
ph 02 8204 0770  
fax 02 9212 4670  
email [conferenceinfo@hepatitis.org.au](mailto:conferenceinfo@hepatitis.org.au)  
web [www.hepatitis.org.au](http://www.hepatitis.org.au)

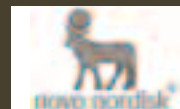
## Corporate Partners

Haemophilia Foundation Australia (HFA) values the individuals, Trusts and Corporations which donate funds to support our objectives.

Among our valued donors are our Corporate Partners who provide unrestricted grants to HFA to support our programs:

**Baxter**

**CSL Bioplasma**



**Wyeth**

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