

National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 170, June 2010




Red Run Classic

Sunday 16 May 2010, New Farm Park, Brisbane

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HEALTH PROFESSIONALS' MEETINGS

Haemophilia Foundation Australia (HFA) continues to support the annual meetings of the Australia and New Zealand Physiotherapy Haemophilia Group, Australian/New Zealand Haemophilia Social Workers' and Counsellors' Group, Australian Haemophilia Nurses' Group and provides executive support to each of these groups throughout the year.

These meetings are one of the important ways for specialist health professionals to share knowledge and experiences and to contribute further to clinical excellence in their area of expertise.


Contact HFA or the Co-Chairs of the groups for further information about the annual meetings:

- **Australian and New Zealand Physiotherapy Haemophilia Group (ANZPHG)**
Wendy Poulsen (QLD) - Acting Co Chair and Ian D'Young (NZ) Co Chair
- **Australian/ New Zealand Haemophilia Social Workers' and Counsellors' Group (ANZHSWCG)**
Sharon Hawkins (WA) Maureen Spilsbury (QLD) – Co Chairs
- **Australian Haemophilia Nurses' Group (AHNG)**
Janine Furmedge (VIC) Stephen Matthews (NSW) – Co Chairs 

HFA FUNDRAISING - TAX APPEAL 2010

Haemophilia Foundation Australia sent out a special tax appeal in May to our entire database. This was a once off special appeal. Generally our appeals are only sent to donors. The appeal gave all our supporters an opportunity to consider making a contribution to the programs and services we provide in the community. All donations over \$2 are tax deductible and it is not too late to make a donation.

You can donate online at <https://www.haemophilia.org.au/donation> or call 1800 807 173.

We thank everyone who has already donated this time for their very special thoughtful donation. 

HEMOPHILIA 2010

Sharon Caris



Hemophilia World 2010 Congress

Buenos Aires • ARGENTINA

Saturday, July 10 - Wednesday, July 14

An item of great interest to Australians this year is the HFA bid for the Congress to be held in Melbourne in 2014. HFA's bid has been strongly supported by all stakeholders in the Australian bleeding disorders community.

By the time you receive this edition of *National Haemophilia* a number of Australians will be at the World Federation of Hemophilia (WFH) Congress in Buenos Aires, Argentina, which starts on 10 July 2010.

The World Congress has a diverse and interesting program of meetings, presentations and posters on the latest findings about bleeding disorders. You will be able to see some details of the program on the WFH Congress website www.hemophilia2010.org, and Haemophilia Foundation Australia (HFA) will publish the reports written by our delegates and some of the presentations from Congress in *National Haemophilia* in September.

The HFA delegation is also represented in the Congress program: some of our delegates have had abstracts accepted for publication as posters and these will be displayed in the Poster exhibition at Congress.

Just as HFA conducts the Annual

General Meeting and Council Meeting after conference, the General Assembly of WFH is held at the end of the WFH Congress. This meeting is conducted in several languages, with a voting representative from each National Member Organisation (NMO) seated at tables behind their national flag, with an alternate voting delegate sitting in the row behind. At the General Assembly this year, HFA will be represented by Gavin Finkelstein, President and Peter Fogarty, Vice President.

At the General Assembly items of WFH business are reported to National Member Organisations and NMOs may make recommendations or raise issues for discussion.

An item of great interest to Australians this year is the HFA bid for the Congress to be held in Melbourne in 2014. HFA's bid has been strongly supported by all stakeholders in the Australian bleeding disorders community. The Melbourne Convention & Visitors Bureau has provided resources and services to a high level to enable HFA to submit

a strong bid. Although six countries initially bid for the Congress, it has come down to a contest between HFA for Melbourne and the National Hemophilia Foundation (USA) for Miami. National Member Organisations will vote at the General Assembly on 15 July.

Thank you to all our supporters from the bleeding disorders community, governments and industry who have supported our bid. Regardless of the outcome, we will work strongly with WFH to ensure all future congresses are successful for WFH. In case you are not aware, Hemophilia 2012 will be held in Paris. **H**

DOES HIV DISCRIMINATION LIVE ON?



David Menadue

David Menadue recently consulted with HFA on behalf of the National Association of People Living with HIV/AIDS (NAPWA) about stigma and discrimination experienced by HIV positive people with bleeding disorders. This was part of a larger national consultation on stigma and discrimination by NAPWA and the Australian Federation of AIDS Organisations (AFAO). He reports here about NAPWA and AFAO's findings.

A friend said to me recently that he thought stigma and discrimination against HIV positive people must have decreased in recent years in direct proportion to the way our treatments and prognoses had improved.

'Surely society is more accepting of people with HIV in an era when it is not such a fearful disease and when people are more out about their status?' he asked.

I would like to agree with him. But while acknowledging that things are generally better in the lives of HIV positive people, recent research into levels of stigma and discrimination against us suggests that in some ways, it may actually have got worse.

A report prepared by consultants for AFAO [1] and NAPWA last year came up with some rather startling findings about the attitudes of HIV negative gay men towards people with HIV. [2] These findings were supported by a survey conducted by NAPWA and co-

authored by Ronald Woods and myself. The survey found high levels of stigma were still being experienced outside the gay community, and that many felt that negative attitudes had not changed much in the last twenty years. [3]

The consultants found a particular lack of awareness and knowledge of HIV amongst gay men in their early twenties, and this only changed for people in their late twenties and older if they knew people with HIV. According to the report, 'those who claimed to have little or no personal experiences of anyone living with HIV were often openly negative and discriminatory in the way they discussed PLHIV [4]. [5]

WHY COULD STIGMA AND DISCRIMINATION BE INCREASING?

When I read the above report, I was quite shocked about its findings.

Personally, I don't feel this level of ostracism from the gay community or society in general. I think that most HIV positive people feel safer and more accepted now, compared with the early years of the epidemic. HIV is treated far more sympathetically by the media these days and there is less general fear about the ways it is transmitted.

The consultants give their reasons about why they believe stigma and discrimination is increasing. They suggest there is less need for gays

and lesbians to come together as a community. Greater social and legal acceptance means gays and lesbians mix more freely with mainstream society – and that this leads to less exposure to HIV positive people.

There is also the impact of the Internet online dating sites. This anonymous environment makes it easier for people to express opinions and to discriminate against those who are prepared to identify as HIV positive.

The consultants also suggest that the improvements in HIV treatments — and the reduction in their side effects (such as the tell-tale signs of lipodystrophy) — have possibly contributed to HIV positive people not feeling the need to tell others about their status. If you can't tell by looking or you are not likely to become seriously ill with HIV, do you need to tell the world?

In my opinion, this is where the implications of stigma and discrimination really impact. If you are not going to disclose for fear of very negative repercussions then you are caught in a bind if an episode of unsafe sex happens, maybe by accident for instance. If you get serious with a sexual partner, there is no hiding the need to disclose at some stage in your relationship.

The psychological effect of holding secrets inside you can be detrimental. I'm not suggesting that everyone needs to come out to all and sundry (as I have done over the years, with no

real regrets) but having a good group of friends (and family) who know and who are supportive is a wonderful backstop in your life. It can give you the confidence to accept being HIV positive and to not to develop feelings of shame or worthlessness because of your status — negative sentiments that some of the participants in the survey above expressed.

Many of us have built up such a fear about people's reactions if we disclose that we imagine all sorts of repercussions that are not likely to happen at all.

LIVING WITH HIV IN DIVERSE COMMUNITIES

NAPWA asked Ronald Woods and me to interview a range of HIV positive people around the country to complement the research done by the consultants on gay men. We conducted 20 in-depth interviews with representatives from the following affected communities: women, heterosexual men, people from a culturally and linguistically diverse (CALD) background, Aboriginal and Torres Strait Islanders and people with haemophilia.

Our interviews revealed that a more pervasive stigma and discrimination is still being experienced by people living with HIV outside the gay community. Without the awareness in the broader community created by prevention campaigns about HIV, positive heterosexuals report a much greater sense of isolation about their HIV status and a great fear of increased stigma and discrimination if these details were to become known.

Positive women still have to deal with ill-informed medical professionals making judgments about their lifestyle when told about their status. Positive heterosexual men we interviewed expressed the huge difficulty they experienced finding partners with whom they felt confident enough to disclose.

People from CALD backgrounds live in constant fear of rejection by their families and communities if their status becomes known, with parents refusing to seek out childcare or translators from their communities in case details of their HIV are somehow revealed.

People with haemophilia and HIV will often not tell anyone but their immediate family for fear that they will be ostracised by their community. Most people with haemophilia are not HIV positive (with the blood supply now protected) but misinformed community perceptions from the eighties still affect this population.

HOW CAN WE CHANGE THIS SITUATION?

Many interviewees we spoke to said there had been no mainstream anti-stigma and discrimination campaigns around HIV since the early nineties and they think the time is ripe to remedy this situation. AFAO and NAPWA are working with the Federal Government to develop responses that will address the issues during the implementation of the next national HIV strategy.

What form these responses will take and what outcomes they will deliver is going to be a major talking point for HIV sector agencies over the next year or so. The consultants suggest that, to begin with, the equation of 'HIV=Prevention' which has so dominated AIDS Council campaigns for years needs to be changed in subtle ways so that the negative perceptions of HIV do not include people with HIV. Basic information about how HIV is transmitted and the experience of people living with HIV needs to be included in these messages. A staged campaign, which sets about showing people the ugliness of HIV-related stigma and discrimination, could follow with messages that promoted inclusiveness and openness.

TURNING AROUND SOCIETAL ATTITUDES IS NEVER SIMPLE.

I was heartened to see a website called StigmaWatch developed by SANE Australia to try to combat the stigmatising descriptions and portrayals of mental illness in the media – and to read that, by using personal stories from a number of celebrities and others, the experience of living with depression has become more accepted by the community than in the past.

Maybe it will be possible to influence broad community perceptions and ignorance around HIV as well through similar means?

I do think that any campaign must also concentrate on giving positive people the confidence to tackle their own internalised sense of stigma about having HIV. Many of us have built up such a fear about people's reactions if we disclose that we imagine all sorts of repercussions that are not likely to happen at all.

Despite the negative emotions expressed by some people in the surveys above, there are many people who will be totally supportive if you reveal details of your status.

If AIDS Councils, PLHIV organisations and other HIV sector agencies can come up with ways to support people on disclosure, people may find it easier to get rid of their own sense of stigma about having HIV. **H'**

1. V. Parr, C. Burkitt, and A. Jennings, *Formative Research for the National HIV Stigma and Discrimination Precampaign Development*, Qualitative Research Report prepared for AFAO and NAPWA, GfK bluemoon, August 2009

2. R. Woods and D. Menadue, *Stigma and Discrimination towards HIV-positive people in diverse communities around Australia*, Report to NAPWA, October 2009

3. Op cit. Parr et al, p 6

4. Ibid. Parr et al pp 6 and 7

5. Ibid. Parr et al, p 7

TAKING PART IN RESEARCH

Suzanne O'Callaghan

Have you ever wondered about participating in research or wanted to know what types of research studies there were for people with bleeding disorders?

TYPES OF RESEARCH

Research is often categorised by its approach and the research methods used:

- Human research: includes clinical trials, social and psychological research that study human participants
- Health services research: asks participants for their preferences and opinions on the way health services work or might work in the future
- Market research: asks consumers about their preferences for services and products.

WHY BE INVOLVED IN RESEARCH?

In Australia decisions about health services, treatment and care are strongly influenced by research in the area. Taking part in research can give you a voice in decisions that might affect you in the future. Your contribution might lead to future improvements in health care or treatments for you and others.

Clinical trials can also give you access to newer treatments or care not generally available.

WHAT ARE THE RISKS?

Generally medical or human research is very carefully controlled and in Australia all human research studies need approval from a Human Research Ethics Committee before they can go ahead.

However, there can be some risks or disadvantages for participants and it is important to know what these are before you agree to participate. It could be that you might receive the placebo or standard treatment, rather than the new experimental treatment; there could be side-effects or regular testing involved; sometimes social or psychological research can stir up deep emotions and you may need to be prepared for that and know what steps to follow if this happens.

Market research is not as highly regulated as human research but if it relates to pharmaceutical products it must follow the Medicines Australia Code of Conduct. You may need to check with the market research company about the professional codes of practice they follow and how they will protect your privacy.

HFA WEB SITE RESEARCH SECTION

Where do you find out more information about research, codes of practice, or the questions to ask? HFA has recently added a new section on research to the web site:


www.haemophilia.org.au – look in the **Bleeding disorders** section, under **Research**

It covers:

- What research is for
- Different types of research
- Current research studies for people with bleeding disorders
- Questions to ask if you are thinking of being involved
- What to do if you have concerns about a research study.

The aim of this section is to give you some information about research studies into bleeding disorders and some tools to make informed decisions about being involved if you are interested.

Information about current research studies will be added as it becomes available.

We'd be interested in your feedback - email us at hfaust@haemophilia.org.au. 

WORLD HEPATITIS DAY: THIS IS HEPATITIS...

Suzanne O'Callaghan

World Hepatitis Day was celebrated globally on 19 May 2010. This year the bleeding disorders community campaign message was:

This is hepatitis....

For people with a bleeding disorder and hepatitis C, it's another life challenge.

If you are a young person or parent of a child with haemophilia or von Willebrand disorder, you might not be aware of why hepatitis C has been so important in the history of bleeding disorders in Australia. A real challenge this year for the Haemophilia Foundation Australia (HFA) Hepatitis Awareness Week Working Group was to work out how to promote awareness about hepatitis C to people in the bleeding disorders community who are not directly affected by it.

WHY IS HEP C RELEVANT?

Most people with haemophilia now use recombinant clotting factor treatment products. These are genetically engineered and have very little or no animal or human material in them – and there have been no reports that viruses have ever been transmitted by them.

But that wasn't always the case. Before 1990 many children and adults with bleeding disorders in Australia acquired hepatitis C from their clotting factor treatment products - before HIV testing was introduced in 1985, some also acquired HIV. They were using clotting factor concentrates made

from human blood plasma and some of the blood carried hepatitis C virus and some blood carried HIV. In 1990, as soon as a hepatitis C test became available, Australian blood banks started testing for hepatitis C and could exclude blood carrying hepatitis C virus from their blood products. By 1990 manufacturers had also developed and included extra steps to remove or inactivate hepatitis C when they made factor VIII treatment products. By 1993, these steps were used for factor IX treatments as well.

Some of these people have now cleared the hepatitis C virus from their blood naturally or through treatment, but others still live with hepatitis C. For many this is an ongoing challenge.

WHAT CAN WE DO ABOUT IT?

The bleeding disorders community in Australia is small. Hepatitis C might affect you, or your family members, friends, other people you know, or people you don't know, but are members of your community. We can all help by knowing more about hepatitis C, what effect it has on people with bleeding disorders and what needs to be done to improve people's lives.

Although until recently people with bleeding disorders have not spoken much about hepatitis C, it has had a very serious impact on people who are affected by it. It is important to take every step possible to make sure this situation never happens again. This is why HFA remains vigilant about



**This is Hepatitis...
GET THE FACTS!**

hepatitis
australia





the safety of treatment products and works closely with government and manufacturers to make sure treatment products are as safe as possible and that safer products like recombinant products can be available to all Australians.

HOW DOES IT AFFECT PEOPLE?

These are some personal stories of people with bleeding disorders and hepatitis C:

My son was actually very ill when he was first diagnosed with hepatitis C. He was off school for quite a long while and it was difficult to go back - how do you explain why you've taken this period of time off school? He had incidents where his hepatitis C was used against him at school with people he thought he could trust. They threw it back at him or let the whole world know about it, then no one wanted to be around him. So that made him withdraw even more into himself. That's when the depression started, in his late teenage years.

Looking back I would say I probably contracted hepatitis C when I was about 16. My first experiences with alcohol were disastrous - not so much drunk as ill. But apart from that, I had no obvious symptoms until 10, 15, 20 years later when I got increasing fatigue and that was the biggest thing - the fatigue and just feeling drained of energy and going to sleep.

There are more personal stories on the HFA web site.

BLEEDING DISORDERS CAMPAIGN

In 2010 the national Hepatitis Awareness Week campaign focussed

Hep C - my story

Contents
 Terry's story P.1
 Ben's story P.2
 About bleeding disorders P.3
 Leo's story P.4

This is hepatitis...
 For people with a bleeding disorder and hepatitis C, it's another life challenge

Three Australians with haemophilia and hepatitis C tell their story

Terry's story
 How did you find out you had hepatitis C?
 In the early 1980s, after the first factor VIII and IX concentrates were developed, the Federal Government funded the first hepatitis C research program. Terry had hepatitis C, and he had been told he had hepatitis C for a long time.

How has hepatitis C affected you over the years?
 From the day I was diagnosed with hepatitis C, I was told that I had hepatitis C and that I would have to live with it for the rest of my life. I was told that I would have to live with it for the rest of my life. I was told that I would have to live with it for the rest of my life.

Can you tell me how you lived over many years because of the treatment you're taking?
 I was told that I would have to live with it for the rest of my life. I was told that I would have to live with it for the rest of my life. I was told that I would have to live with it for the rest of my life.

By the way, what's happened since you found out you had hepatitis C?
 I was told that I would have to live with it for the rest of my life. I was told that I would have to live with it for the rest of my life. I was told that I would have to live with it for the rest of my life.

AM I NUMBER 12?

H+

The Parliamentary Secretary for Health, Mark Butler, launching World Hepatitis Day at Federation Square, Melbourne



...HFA remains vigilant about the safety of treatment products and works closely with government and manufacturers to make sure treatment products are as safe as possible and that safer products like recombinant products can be available to all Australians.

on raising awareness in young people. It was an opportunity for the HFA Hepatitis Awareness Week Working Group to develop an awareness campaign specifically for young people with bleeding disorders, particularly those who are not directly affected by hepatitis C. Over the last two years the HFA Youth Committee has worked with the Working Group to develop a youth-based campaign, with advice on what hepatitis C issues young people with bleeding disorders are interested in and how to present them.

As a result, on World Hepatitis Day (19 May 2010), HFA launched two new resources on its web site (www.haemophilia.org.au). These resources give simple answers to questions about hepatitis C:

- **Hep C – what is it all about?** Web pages for young people about hepatitis C and why it is relevant to the bleeding disorders community. Includes what hepatitis C is; how it is passed on; how to support someone with hepatitis C (www.haemophilia.org.au > Kids and Youth > About bleeding disorders > Hep C)
- **Hep C – my story** – a PDF booklet of inspiring personal stories of people with bleeding disorders and hepatitis C

(www.haemophilia.org.au > Bleeding disorders > Hepatitis C > Hep C personal stories)

Thanks to the HFA Hepatitis Awareness Week Working Group for their work on the Bleeding Disorders campaign - Dave Bell, HFWA; Peter Mathews, HFNSW; Pamela Punch, HFV; Chris Poulton, HFA Youth Committee (2010); Erin James, HFA Youth Committee (2009); Suzanne O'Callaghan, HFA.

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GLOBAL CAMPAIGN

In 2010 the worldwide theme was **“This is hepatitis...”** and focused on personal stories of people’s lived experience of hepatitis B and C. The aim was to increase community understanding and awareness of hepatitis and generate action.

In Australia the national focus was on hepatitis testing and management. There were also “Love Your Liver Lunches” with liver-friendly food – some aiming to raise funds for hepatitis C research and awareness.

The National World Hepatitis Day launch was held at Federation Square in Melbourne. Parliamentary Secretary for Health, Mark Butler, spoke at the event and launched the new national hepatitis B and C strategies. The national launch also included a rock concert for young people.

FOR MORE INFORMATION:

World Hepatitis Day –
www.worldhepatitisday.org

Australian campaign –
see the Hepatitis Australia web site -
www.hepatitisaustralia.com **H**



GROWING OLDER WITH HEPATITIS C

David Iser

GROWING OLDER WITH HEPATITIS C? WHAT WILL THIS MEAN FOR ME?

The good news about growing older with hepatitis C is that the vast majority of people infected with hepatitis C will not develop severe liver injury (cirrhosis) in their lifetime. The other good news is that there is no upper age restriction for current treatment with pegylated interferon and ribavirin, so treatment centres are now considering treatment in people well into their sixties and sometimes beyond. However, as we age we may require medications for other health issues. In this article we aim to discuss some issues facing people growing older with hepatitis C.

Australia's population is ageing, with 13% currently over the age of 65 and an expected 24% over the age of 65 by the year 2056 (www.abs.gov.au). Currently an estimated 210,000 are living with hepatitis C. Although fewer people are acquiring hepatitis C than ten years ago, the number of people with hepatitis C-related liver injury is increasing. An estimated 20% of people infected with hepatitis C will develop cirrhosis in 40 years (www.health.gov.au), but this proportion may increase as our population ages.

Treatment may be more likely to be successful in younger people with hepatitis C. However, successful treatment and cure can still be achieved in older people. New agents such as specifically targeted anti-viral therapy for hepatitis C (STAT-C) are currently only available in clinical trials, which usually exclude people over 65 years. However, they are likely to benefit people with hepatitis C of all ages in the near future.

As we age, we may be asked to take medications for a variety of medical problems. Adverse reactions, including elevated liver function tests (LFTs) may occur, which may be confused with a 'flare' of hepatitis C. Whether elevated LFTs are more likely in people with hepatitis C is unclear. However, this has occurred in some trials, such as those for newer anti-HIV therapy. Almost any medication, including many herbal preparations may cause elevated LFTs. Some of the more common ones include cholesterol-lowering drugs ('statins'), certain antibiotics, anti-inflammatory drugs (NSAIDs) and anti-convulsants for seizure disorders. Other

common medications such as hormone replacement therapy (HRT) may be associated with increased risk of gallstones, but do not commonly interact with hepatitis C.

Unfortunately the incidence of most illnesses increases with age, so the longer we live, the more likely we are to need to consider treatment for conditions like diabetes, cancer, hypertension, high cholesterol. Both medication use and adverse reactions increase with age. Therefore, new medications should be discussed with a local doctor in this context. After a new medication (including herbal therapy or non-prescription medication), is commenced then monitoring of LFTs every few months may be appropriate. A sudden rise in LFTs may be more likely due to a new medication than hepatitis C itself.

In some situations, a significant rise in LFTs may lead to the medication being ceased. In other circumstances a small rise in LFTs, with no associated symptoms may be tolerated. Each situation is different, and the decision to stop or continue a new medication depends on a variety of factors including the risk of pre-existing liver injury, the degree of LFT rise, the original need for the particular medication, and whether suitable alternatives are available. These decisions should be made with a local doctor, and occasionally with advice from a liver specialist.

It is important to remember that most people with hepatitis C do not develop cirrhosis. Factors most likely to impact on our health in ageing are alcohol, smoking, obesity and inactivity, not hepatitis C. **H**

LOOKING AFTER YOUR EMOTIONAL WELLBEING

Jon Colvin

I've always liked the saying that it's difficult to appreciate the sun if you've never experienced the rain.

Our ability to feel a range of emotions is a part of being human. Joy, fear, sadness, excitement, anxiety, happiness – our emotions influence the way we conduct our lives and can help motivate us to make changes or drive us to pursue our goals.

Our emotions can also disrupt our social and personal relationships and alter our ability to have a sense of control over our lives. Everyone feels sad or anxious from time to time particularly as a reaction to an event such as a relationship breakdown, job change or the loss of a friend or family member. Having an awareness of our emotional wellbeing is crucial to being able to look after ourselves. Recognising and being prepared to make changes or seek support is essential in maintaining good health.

Feeling sad or anxious decreases our motivation and often creates an inability to function socially. These feelings can make us struggle to perform at work and also creates problems with our friends, family and partners. Most importantly, they stop us having fun.

So when should we be concerned? Some indicators that might prompt us to ask for assistance are:

- Feeling sad most of the time, most days

- Losing interest in things you used to enjoy
- Feeling lethargic, tired or unmotivated
- Crying easily or often
- Feeling flat or not feeling any emotion ("feeling empty")
- Feeling restless and unable to sit still
- Worrying excessively
- Feeling helpless, lacking a sense of control over your life
- Suicidal thoughts or actions
- Rapid weight gain or loss
- Loss of sex drive
- Poor quality sleep or excessive sleep
- Trouble with concentration and memory.

So how do we move forward when we notice we are feeling this way? Particularly while we are experiencing a sense of helplessness, that "there is nothing I can do to feel better" or "there is nothing I can do to fix my problems".

SOME IDEAS ARE:

- There can be a great sense of satisfaction in conquering a problem using your own resources. Sourcing information from self help type books or from reliable internet sites can help you take control (there is

an abundance of information available on the internet about anxiety and depression; some sites that may be useful are listed at the end of this article)

- Speaking about your emotions with someone you trust can help reduce the impact of negative emotions
- Physical exercise – exercise decreases our level of stress hormones and increases endorphins, which are the body's natural feel good chemicals. When endorphins are released, your mood is naturally boosted. As well endorphins, exercise also releases adrenaline, serotonin, and dopamine These chemicals work together to increase your sense of well being.
- Relaxation and breathing control through practices like meditation or yoga. Slowing down your breathing reduces symptoms of anxiety and panic attacks. Regularly practiced relaxation assists with disregarding or disengaging from fearful thoughts. Regularly practiced meditation also calms the mind and improves sleep
- Reducing your intake of alcohol and other drugs
- Professional support – medical practitioners are often a good place to start for advice. A GP is also best placed to tell you whether a psychiatrist,

Having an awareness of our emotional wellbeing is crucial to being able to look after ourselves. Recognising and being prepared to make changes or seek support is essential in maintaining good health.

psychologist or other professional is likely to be able to help. Therapists can help you find more effective ways of approaching problems in a safe and non-judgemental way. Professional counselling can help you learn to recognise fear or anxiety inducing thoughts, and then train your mind to challenge or disregard those thoughts, thus reducing their power

- Medication - your doctor can assess your need for medications and discuss what is available and the pros and cons of using them. Sometimes finding the best medication to treat conditions such as anxiety and depression can take time, as not all medications suit everyone. Always discuss with all your doctors any medications (prescribed, herbal or over the counter) you are considering taking as they might interact with your other medications. Some may also increase bleeding if you have a bleeding disorder.

The sooner you recognise negative emotions and start to deal with them the faster your outlook will improve. The longer you are feeling down, the harder it becomes to recover. It is important to not lose hope and be persistent. There is a huge amount of information and support available if you are willing to access it.

USEFUL WEBSITES:

www.beyondblue.org.au

www.adavic.org

www.napwa.org.au contains a number of articles about emotional well being (use the search box and type in 'depression')

COUNSELLING:

Speak to your Haemophilia Social Worker or Counsellor for information about your options for counselling.


Some options include:

- Medicare rebated counselling is available with a referral from your GP
- There are a variety of counselling services available specifically for PLHIV. Contact your state/territory PLHIV organisation for more information
- 24hr Telephone Counselling is available from Lifeline (ph: 13 11 14).

RELAXATION TECHNIQUES:

- Check first with your Haemophilia Centre physiotherapist and/or rheumatologist if you have any questions or concerns about appropriate relaxation and physical exercise programs
- Exercise, yoga and t'ai chi classes have been developed specifically for people with arthritis and joint problems. Arthritis Australia can direct you to local information

(www.arthritisaustralia.com.au, ph 1800 011 041)

- Some state/territory PLHIV organisations offer services such as massage and naturopathy or classes in yoga, meditation and exercise to members – go to www.napwa.org.au or phone NAPWA on 1800 259 666 for information on PLHIV services in your area
- Local City and Shire Councils also provide a range of exercise and relaxation classes to their local community. Contact your local Council form more information
- Good self care also begins with a healthy diet and monitoring your sleep pattern. If you would like further advice on these matters, talk with your GP and/or the staff at your local Haemophilia Centre. 



NATIONAL CONFERENCE IN SYDNEY 2011

Sharon Caris

The national Haemophilia Conference is held every two years, usually in a capital city in Australia. Our very first conference was held in Melbourne in 1980 and the conferences have been held regularly ever since, with the most recent in Brisbane in October 2009.

The Conference is relatively unusual in that it is both for people with bleeding disorders and their families and for health professionals involved in their treatment and care and usually equal numbers of each group attend. As a result, presentations are focussed on topical issues for both groups and can be so memorable they are still discussed some years later. The Conference also attracts people involved in the planning of health services, including government officials who are involved in decision making about how health services are organised and managed, and how clotting factor and other treatments will be purchased and supplied to the people who need them.

Feedback from people who attend conferences is usually positive. One of the most important things many of them report is how useful it is to meet others who have a bleeding disorder or who are affected by a bleeding disorder in some way. For some people with bleeding disorders or their families, it might be the first time they have met many others who live with the same sorts of issues. For some health professionals it may be a new area of work, or they may be located where there are not many patients, and they may have little support from other medical and allied health colleagues to share experiences with. Even when people have been to many conferences over the years, they report how valuable it is to attend further conferences to hear about new developments and to meet others face-to-face.

Conferences are combined with other meetings to make the most of the opportunity. For example, Haemophilia Foundation Australia (HFA) hosts the annual meetings of the national groups of social workers and counsellors, physiotherapists and specialist nurses alongside the Conference. In 2009, for the first time there was also a meeting of data managers from Haemophilia Centres around the country. These groups, as well as the Australian Haemophilia Centre Directors' Organisation,

traditionally meet on the day before the first day of each Conference to discuss treatment and care issues relating to their area of specialty. Along with the Conference, these meetings each aim to improve treatment and care to people with bleeding disorders and to promote excellence in their area of work.

The next Conference is already being planned for Sydney at the Novotel at Olympic Park 20-22 October 2011. Save the date!

The program is developed by HFA with representatives of State/Territory haemophilia foundations and health professionals from around Australia to give us a mix of ideas and to ensure we cover all areas of interest. We will soon tell you more about the program and some of the fun and entertaining social activities to be held at the same time.

We are also planning an additional workshop for people affected by inhibitors on 23-24 October. This will be of special interest to parents of children who have developed inhibitors and to youth and adults who live with inhibitors. The program will be more detailed than conference sessions on inhibitors and we hope it will enable people to learn more about care and treatment and living with inhibitors. **H**

BUILDING ON THE STRENGTHS OF AUSTRALIAN MALES

Suzanne O'Callaghan

What's expected of an Australian man? If you follow Australian films or TV dramas, it can be a tough call: strong, silent, resilient, stoic and uncomplaining if injured, inventive and humorous to overcome difficult situations – a stereotype of the "indestructible Aussie male".

Taking care of his health does not seem to appear on the list. So when the Australian government compared the research on life expectancy – 78.7 years for Australian males compared to 83.7 years for females – it became clear that an Australian male health strategy was a priority.

AUSTRALIAN NATIONAL MALE HEALTH STRATEGY

The Australian Government Department of Health and Ageing released the first National Male Health Strategy in May 2010. The Strategy was built on months of consultation with men and male health experts across Australia, as well as an extensive review of the research literature, and came forward with two clear messages:

- The strategy should be a positive strengths-based policy
- It should cover Australian males of all ages.

The Strategy has four basic points that underpin its recommendations:

- The health of Australian males is important
- There are health inequities between males and females

- Not all male population groups have the same health outcomes
- Health is holistic.

PRIORITY ACTION AREAS AND GROUPS

The Strategy is focused on pragmatic ways to improve the health of Australian males. While it encourages males to take individual action to improve their own health, it also recognises that there needs to be new initiatives to overcome barriers and provide support. These initiatives work on men's strengths, rather than generally aiming to change men's behaviour.

There are six priority areas for action:

- Promoting optimal health outcomes for males – by recognising the important roles males play in their family and community life, eg "fathering"/mentoring as fathers, grandfathers, brothers, uncles, friends, community or club leaders or mentors; and developing policies and programs that specifically consider male health
- Promoting health equity between population groups of males – including health messages that males can relate to
- Promoting improved health for males at different life stages – particularly focussing on practical approaches at life transition points, eg starting or leaving school, unemployment or retirement,

marriage or a relationship breakdown, having children or grandchildren

- Promote a focus on preventive health for males – health checks, programs and health promotion messages designed for males, monitoring workplace hazards
- Building a strong evidence base on male health – prioritise research on male health
- Improved access to health care for males – encouraging health services to make services responsive to male needs, including later operating hours and being available where men are, eg workplace or club visits.

The Strategy also identified five priority groups that are considered at high risk of poor health outcomes:

- Aboriginal and Torres Strait Islander males
- Males from socioeconomically disadvantaged backgrounds
- Males living in rural and remote areas of Australia
- Males with a disability, including mental illness
- Males from culturally and linguistically diverse backgrounds.

SOUND FAMILIAR?

As people with haemophilia are nearly all male, Haemophilia Foundations around Australia have been active for many years in looking at ways to promote health among male members.

The Men's Groups and some Youth activities have grown out of a recognition of the important relationships between older and younger men – men's breakfasts, Boys' Day Out activities, eg fishing trips, go-karting, etc that include males of all ages from the haemophilia community, older mentors at Youth Camps. The Strategy highlights the value of healthy social networks such as 'men's sheds' – these are also to be found in groups like the haemophilia Old Boys Groups.

Some of you who contributed to the

consultation for the HFA hepatitis C needs assessment will recognise some of the themes in the Strategy – a holistic approach to health and accessible health services that took into account the need to keep working were key issues raised in the Double Whammy report. The Wellbeing Weekend was based on a men's health approach recommended by the community: activities were practical and participants could try things out rather than just learn about them; there was time to talk together socially while relaxing or doing some activities; and the program focussed on a holistic approach to wellbeing.

It is exciting to see that these approaches have been recognised as "male-friendly" and healthy and have been incorporated into the Male Health Strategy. This will guide future government policy directions and funding and we can look forward to the development of further innovative strategies and programs.

HEALTH PROGRAMS

As men with bleeding disorders grow older, their health needs become more complex. They start to experience the health conditions related to lifestyle and ageing that are also common in the general population and good generalist medical care becomes very important. Over recent years Haemophilia Centres have been working with their patients to make sure they have a general practitioner (GP) who forms part of their medical team.

The new Male Health Strategy is committed to working with GPs to improve men's access to good health care and health promotion, including annual check ups, health assessments, information and support. This means that we are likely to see more health initiatives such as the Royal Australian College of General Practitioners' M5 Men's Preventive Health Program, which encourages men to take five minutes and five preventive steps to improve their health:

- Share your family history with your GP
- Know your healthy weight
- Check your blood pressure
- Stop smoking – it's the only health option
- Maintain a healthy mind and a healthy body **H**.

45- 49 MEN'S HEALTH CHECK

Suzanne O'Callaghan

The 45 – 49 year old men's health check is part of the Australian Better Health Initiative (ABHI) announced by the Council of Australian Governments (COAG) in February 2006. ABHI aims to improve the capacity of the health system to promote good health and reduce the burden of chronic disease.

A health check at this stage of life can help men to make the necessary lifestyle changes to prevent or delay the onset of chronic disease. The aim of this health check is to encourage men to work with their GPs to assess and improve their health at mid-life to make for a healthier future.

ELIGIBILITY

To be eligible, you need to be a male aged from 45 to 49 years who is at risk of developing a chronic disease. The GP will make a clinical decision whether you are at risk of developing a chronic disease, but the GP must identify at least one risk factor. These can include:

- Lifestyle risk factors such as smoking, physical inactivity, dietary or nutritional problems or substantial alcohol use
- Biomedical risk factors such as high cholesterol, high blood pressure, impaired glucose metabolism or being overweight; and
- Family history of a chronic disease.

The GP will discuss what the health check involves with you and obtain your consent to participate before going ahead.

WHAT THE HEALTH CHECK INVOLVES

In a health check, the GP will:

- Collect information about your health: take your patient history, examine you physically and follow up with tests and investigations where appropriate
- Make an overall assessment of your health. This includes how ready you are to make lifestyle changes
- Start medical treatments or interventions and make specialist referrals to deal with specific medical problems if any are found through the health check
- Provide you with advice and information, including strategies to achieve lifestyle and behaviour changes.

THE ROLE OF THE GP

The health check should generally be undertaken by a GP who is your 'usual doctor', that is the GP who has provided the majority of your GP services in the past 12 months, or likely to provide the majority of services in the following 12 months.

Practice nurses, Aboriginal Health Workers and other health professionals may also be involved in assisting GPs to perform the health check. This may include

- Collecting information (such as measuring height, weight, blood pressure and lifestyle risk factors)
- Providing you with information about recommended interventions, such as information about community resources and support services in the local area and your referral options.

For more information about the Health Check, speak to your GP. **H**

LIVEWIRE – WHERE TO NEXT?

Suzanne O'Callaghan

Over the last few months, Livewire has attended several state Haemophilia Camps to demonstrate Livewire and help people to register. Quite a few young people, parents and siblings have taken the opportunity to register and join the specific online member, parent and sibling communities.

GETTING STARTED

Livewire is a great way for people to catch up with others they met at the Camps and continue friendships they have started – and to connect with others from around Australia. For young people with bleeding disorders, this is a two-stage process – firstly to register, then to action their parental consent form. The first stage of registering gives members access to games and entertainment, but completing the parental consent form gives access to the full community so that young people can link their profile to the bleeding disorders group and chat with their friends online.

PARENTAL CONSENT

While obtaining written parental consent is part of Livewire's careful security, Livewire is aware that for young people it can be a barrier to completing the full registration process. Paper parental consent forms are often lost or don't quite complete their journey to the Livewire office and, although Livewire is only too happy to send out more forms, some members



never complete the registration process and can't join their friends in the online community. To make full registration easier, Livewire is currently looking at other ways to verify and document parents' consent.

WHAT ELSE IS IN THE PIPELINE?

The next step is to organise some welcome and interesting or fun online activities for young people with bleeding disorders. Some ideas include:

- Welcome pack for new members with personalised stationery, stickers etc
- Online chat events to catch up with friends met at Haemophilia Camps
- Celebrity Livewire Ambassadors to host online chat events
- Online interactive games with other members of the bleeding disorders group.

ANY SUGGESTIONS?

We would be interested in your ideas – if you have any suggestions about online activities for Livewire members, siblings or parents from the bleeding disorders group, contact Suzanne O'Callaghan on socallaghan@haemophilia.org.au.

Livewire registration packs are available from:

- HFA or your local Haemophilia Foundation
- Directly from Livewire – go to www.livewire.org.au or contact the Livewire Support Team on (02) 8425 5971

And, if you are 18 or under – remember to send in your parental consent form! **H**



Red Run Classic

Sunday 16 May 2010, New Farm Park, Brisbane

The fourth Red Run Classic was an overwhelming success with 645 runners, walkers and families participating on the day to raise money for people with haemophilia and other inherited bleeding disorders.

The run is a fantastic fundraiser for the community and it was wonderful to see many members volunteering and supporting the event. Special thanks to the OBE group for co-ordinating the BBQ and to all our volunteers that helped on the day.

Congratulations to the following winners –

5KM

Men's Division

1st	John Agyik # 1	17:20.2
2nd	Stuart Bowden #322	17:37.3
3rd	Shaun Robinson #173	18:04.7

Women's Division

1st	Libby Clarke #33	19:49.6
2nd	Renae Jones #96	20:13.8
3rd	Bree Russell #177	21:27.4

Child Division

1st Boy	Harrison Smith #190	28:12.2
1st Girl	Clare Donker #55	20:28.0

10KM

Men's Division


1st	Matt Cooper #367	37:50.5
2nd	Martin Murray #546	37:51.5
3rd	Mark Connick #361	38:35.6

Women's Division

1st	Clare Geraghty #415	35:40.6
2nd	Roxie Schmidt #590	36:55.7
3rd	Annette O'Shea #552	40:40.8

Child Division


1st Boy	Jack Hatfull #438	1:06:06.6
1st Girl	Jess Hatfull #437	1:34:29.7

Other thanks to **In Training** and event sponsors **Brisbane City Council, BMAG,** and **Bayer Healthcare.** 



FACEBOOK

Haemophilia Foundation Australia is on Facebook.

Become a fan to stay in touch with the latest on HFA activities, publications and events and be connected with others in the bleeding disorders community! 



Life Challenges the real issues

Haemophilia Awareness Week 10-16 October 2010

Haemophilia Foundation Australia (HFA) and Haemophilia Foundations around the country work together to raise awareness about inherited bleeding disorders from 10-16 October 2010. The theme this year is "Life Challenges ~ the real issues".

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 such as stickers, tattoos, silicone wrist bands, posters, 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 (click on the logo on our homepage to be directed or under events and awards) or email hfaust@haemophilia.org.au. Please note that stocks are limited. 



global feast in support of people worldwide with bleeding disorders

The colder weather is upon us, with lots of eating and drinking – why don't you incorporate Global Feast into your winter get togethers....

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).

Incorporating Global Feast into your get togethers is a great and easy way to raise money for people with bleeding disorder internationally. It's easy, you can ask your guests for a donation or place a money tray at the front entrance and your guests can drop in a few coins (or notes!) – HFA can send you promotional material and forms.

Global Feast benefits people around the world with bleeding disorders. All monies are donated directly to WFH with funds spent on providing safe and effective treatment products free of charge to people in urgent need in more than 50 developing countries, and programs, services, educating families and training doctors and nurses in some of the poorest regions of the world. For more information on WFH programs and services visit www.wfh.org.

For more information and promotional items, contact at HFA on 1800 807 173 or hfaust@haemophilia.org.au. 

CALENDAR



XXIX International Congress of the World Federation of Hemophilia

Buenos Aires, Argentina,
10-14 July 2010

www.wfh.org

22nd Annual ASHM Conference

20 - 22 October 2010

Phone: 02 8204 0770

Fax: 02 9212 4670

email info@hivaidconference.com.au

www.hivaidconference.com.au

7th Australasian Viral Hepatitis Conference

Melbourne 6 - 8 September 2010

ph 02 8204 0770

fax 02 9212 4670

email info@hepatitis.org.au

www.hepatitis.org.au

Haemophilia Awareness Week

10-16 October 2009

ph 03 9885 7800

fax 03 9885 1800

email hfaust@haemophilia.org.au

www.haemophilia.org.au

2011 Haemophilia Conference, Sydney

20 - 22 October 2011

Novotel, Sydney Olympic Park,
Sydney NSW

ph 03 9885 7800

fax 03 9885 1800

email hfaust@haemophilia.org.au

www.haemophilia.org.au

CORPORATE PARTNERS

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

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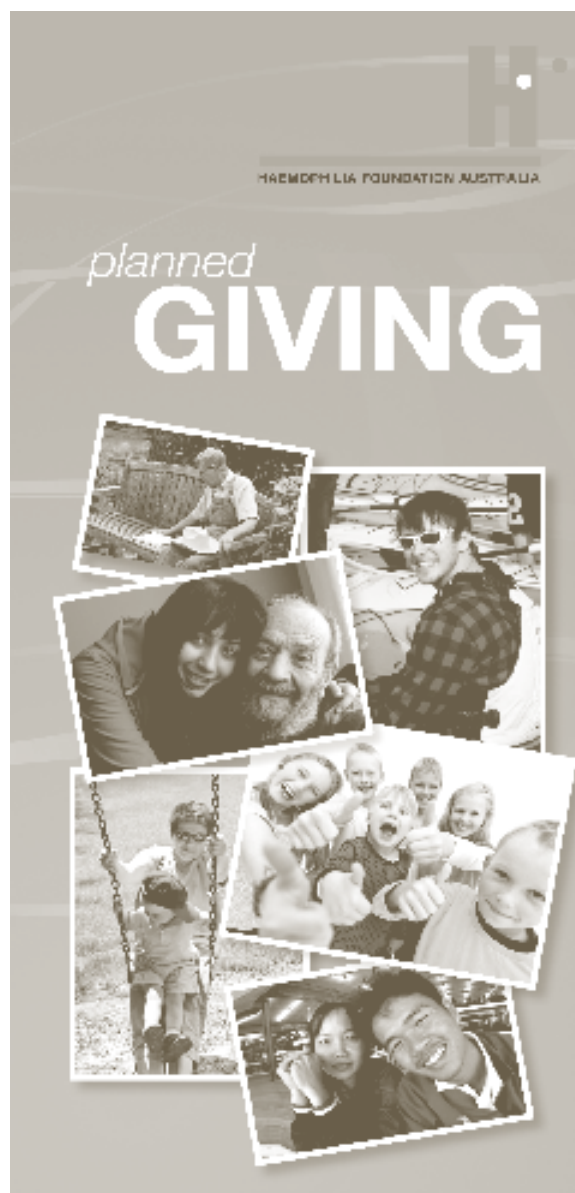
PLANNED GIVING

Haemophilia Foundation Australia's (HFA) work is only possible because of the donations and support received from our very special donors, service clubs and corporations. An important part of our future income is the bequests we receive when people remember HFA in their Will. Every gift, large or small, makes a real difference to our work and the people we help.

Your Will is important and shows how you care about those you love.

Making a Will can give you peace of mind, knowing that your wishes for family and friends and community organisations close to your heart have been identified and addressed.

HFA has recently developed an updated brochure on Planned Giving. If you are interested to find out more call 180 807 173 or email hfaust@haemophilia.org.au. **H**



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