National Haemophilia
Haemophilia Foundation Australia www.haemophilia.org.au
No. 162, June 2008

Red Run Classic

Sunday 25 May 2008, New Farm Park, Brisbane

Over 120 runners and walkers participated in the second Red Run Classic on Sunday 25 May 2008 at New Farm Park. The event followed on from last year's success and is a fundraiser for Haemophilia Foundation Australia and Haemophilia Foundation Queensland.

Congratulations to the following winners:

Men's Division

1st	376	Salvatore Mazzullo	19.26
2nd	343	Grant Rogerson	19.57
3rd	369	Rick Mclaren	20.07

Women's Division

1st	354	Charlotte Nunn	20.25
2nd	306	Saleena Roberts	21.29
3rd	283	Inga Savage	22.54

Child Division

1st Boy	255	Angus Douglas	24.35
1st Girl	373	Kelsie Guerden	25.57






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Thank you to all who participated and supported the 2008 Red Run Classic. We look forward to seeing you again next year.

Our thanks to:

Athletics Australia

Brisbane City Council

Brisbane Marketing

Cr David Hinchliffe

Gale Force Running

I-subscribe

Jonathon Fogarty

McDonald's

Wotif

THE VISION AND LEADERSHIP AWARDS

Applicants were encouraged to consider what would make a difference to their life and seek assistance.... to achieve sucess or reach a new goal...

The Haemophilia Foundation Australia Vision and Leadership Awards were established in 2007 to provide people affected by bleeding disorders with an opportunity to undertake an education activity or project to enhance their personal development or career, or develop skills for leadership and participation in the bleeding disorders community. The Awards are generously supported by Wyeth through a pledge of up to $10,000 each year for the Awards. The Vision and Leadership Awards are administered solely by HFA under a Memorandum of Understanding with Wyeth.

The assessment panel for this second funding round included Craig Goodhand, Manager Training & Organisation Development, Elders Limited, Adelaide; Chris Bonnor, who has wide experience as a principal of secondary schools in NSW; Gavin Finkelstein, HFA President; and Sharon Caris, HFA Executive Director.

The Awards are available to people of all ages and two specific categories were established to encourage young men and women aged 15-25 and adults aged 26 yrs and over who have a bleeding disorder to apply.

Applicants were encouraged to consider what would make a difference to their life and seek assistance through this award opportunity to achieve success or reach a new goal or objective.

Unfortunately many excellent projects could not be funded this time, however we are pleased to announce the 2008 recipients.

OUR CONGRATULATIONS TO:

Neil Boal	for a laptop to use to write his autobiography
Katherine Nalder	for establishing a small business
Kumar Wickremasuriya	for a computer education course
Sharyn Wishart	for an education course

A further award was given to a person with haemophilia to undertake an education course.

WFH CONGRESS, ISTANBUL, TURKEY 1-5 JUNE 2008

NATIONAL MEMBER ORGANISATION TRAINING

Haemophilia Foundation Australia (HFA) President, Gavin Finkelstein, represented the organisation at the National Member Organisation (NMO) Training, 28-31 May 2008. The NMO Training is conducted by World Federation of Hemophilia every two years. Robert McCabe from Western Australia attended the training on a WFH Youth Fellowship. Over 100 member organisations were in attendance and sessions were provided for member organisations in groups designed for emerging countries, established organisations and Spanish speaking patient organisations. The sessions included patient representation, advocacy and lobbying, pharmaceutical relationships, medical research and other topics of interest to national patient organisations around the world. Sharon Caris (HFA Executive Director), Penny McCarthy (Nurse, Alfred Hospital, Victoria), and Prof Alison Street (Alfred Hospital) facilitated a workshop on Haemophilia and Ageing, which is an emerging issue for established organisations with a membership which includes increasing numbers of older people.

L-R: Gavin Finkelstein, Sharon Caris and Robert McCabe

HEMOPHILIA 2008

The XXVIII Congress of the World Federation of Hemophilia (WFH) was held in Istanbul, Turkey, 1-5 June 2008. The Congress was attended by more than 4,200 people with bleeding disorders, health care professionals and others interested in the state-of-the-art care and treatment of people with bleeding disorders. Challenging scientific and clinical issues were presented by world experts, and the experiences of people with bleeding disorders or their families were presented for delegates to learn, share ideas and new understandings.

Issues included controversies about prophylaxis, quality of life of people with bleeding disorders, recombinant versus plasma derived products, the safety and supply of treatment products, inhibitors, hopes of longer acting clotting factor concentrates and new delivery systems and technologies. Promises that gene therapy, although quite possibly further delayed, might offer hope in the future, were tempered with the reality for many parts of the world that there is still little treatment available. Nevertheless, in these countries some wonderful work is being done to improve the lives of people with bleeding disorders, including haemophilia centre and organisation twining and training, and other initiatives to increase access to treatment and care, from laboratory and clinical work, to patient registries, and outreach.

We will bring you reports and summaries of various sessions from the Congress in the next newsletter. It is anticipated that presentations will be available on the WFH web site in upcoming weeks.

Gavin Finkelstein at the General Assembly

WFH GENERAL ASSEMBLY

The Assembly is the biennial meeting of members of WFH held immediately after the Congress. The WFH Board and staff reported on a strong two year period and described future plans and objectives to support its mission, *Treatment for All*. HFA was represented by Gavin Finkelstein as voting delegate, and Peter Fogarty (HFA Treasurer) as alternate delegate.

The meeting was chaired by Prof Alison Street (Western Pacific) who was elected unopposed as Vice-President Medical to succeed Dr Paul Giangrande whose outstanding voluntary work for WFH over the last eight years was acknowledged with a standing ovation as he completed his term of office. Current President, Mark Skinner (America North) was elected unopposed for a further term and Rob Christie (Western Pacific) was re-elected as Vice-President Finance. The Assembly elected Carlos Safadi (America South) and Mohamed Aris Hashim (Asia South East) as lay members to the Executive, and Dr Paula Bolton Maggs (Europe West) and Dr Johnny Mahlangu (Africa) were elected as incoming medical members.

Further reports of WFH achievements will be provided in upcoming newsletters.

Far Left: Mark Skinner, WFH President
Left: Prof Alison Street and Rob Christie

Mark Brooker is Senior Policy Officer at the World Federation of Hemophilia. This article was published in "Hemophilia World", April 2008, Vol 15 No 1, the journal of the World Federation of Hemophilia.

DEFINING GENE THERAPY

Mark Brooker

Two leaders in the field, Professor David Lillicrap of Queen's University, Canada, and Dr Glenn Pierce, founding co-chair of the National Hemophilia Foundation Gene Therapy Workshops (now Vice-President, Preclinical Development, Bayer HealthCare) spoke about progress in gene therapy at the WFH Global Forum in Montreal in September 2007.

DEFINING GENE THERAPY

Gene therapy is the insertion of a working gene into a patient to replace the disease-causing gene. As a well-characterised disease with specific genetic mutations, haemophilia is an ideal candidate for gene therapy. People with haemophilia have a genetic mutation which prevents the liver from producing clotting factor. Knowing what the functioning gene for factor VIII (or IX) is, if we could over-ride the mutation, the liver would produce clotting factor. While gene transfer experiments in dogs have been successful in curing haemophilia, they have not yet been successfully reproduced in humans.

FIRST STEPS

Genes for factor VIII and IX were cloned in the early 1980s, helping to establish the concept of gene therapy. The preferred way to deliver factor VIII or factor IX into cells is by using viruses that have been genetically altered to carry a new gene derived from normal human DNA. These carriers are called vectors, and they deliver the working gene to the patient's target cells. Target cells, such as those in the patient's liver, are infected with the vector. The vector then unloads its genetic material containing the human gene into the target cell.

The interactions between the human immune system and the virus, and the processes involved in getting the DNA into the nucleus are complicated and still not well understood. An adeno-associated virus (AAV) seems to be the best vector for delivering genes effectively based on animal experiments. However, as many as 80 per cent of humans have been exposed to this virus previously and when we are exposed to a virus that our body recognises, the body fights back. Researchers will have to get around this immune response, possibly by suppressing the immune system (immunosuppression) before inserting the vector.

Six clinical trials have taken place involving 43 patients: three trials using factor VIII gene transfer and three using factor IX gene transfer. Outcomes show that gene transfer works in humans, although in lower levels and only for several days to weeks, with no significant negative effects. Research into AAV-mediated gene transfer for haemophilia B with 15 patients showed some evidence of gene transfer but the patients did not have enough factor IX in their blood to cure haemophilia. Injecting the vector into the liver rather than into muscle tissue increased the level of factor in the blood high enough to cure the disease but the levels dropped over time because of the body's immune response.

> Gene therapy is the insertion of a working gene into a patient to replace the disease-causing gene

SAFETY ISSUES

Gene therapy is a very new field. For many of the diseases where it is used, there is no other treatment available. Since gene therapy for any disease has been used on so few patients, every setback is a cause for concern for the research community. A patient death attributed to adenoviral therapy (not for haemophilia) in 1999 had an enormous impact on this research as did the subsequent deaths of a child from leukaemia following his cure (from severe combined immunodeficiency) by gene therapy.

More recently, AAV has been in the news. In a gene transfer trial in the United States of America, 127 patients with severe inflammatory arthritis had an AAV vector injected into their joints. One patient – a 36 year old woman with a 15 year history of rheumatoid arthritis – died in July 2007. The role of gene therapy in this particular patient's death is not clear. Vector-related disease may have contributed in a small way but was certainly not a direct cause. A recent review of this case by the National Institutes of Health Recombinant DNA Advisory Committee discussed issues of informed consent and conflict of interest, and had very positive comments about the haemophilia community's efforts to educate patients about gene therapy.

NEXT STEPS

The next steps for gene therapy include new research hypotheses, new DNA delivery vectors, designer molecules, and means of avoiding immune response in the patient.

Two planned haemophilia factor IX gene transfer therapy trials are set to begin this year. One will use four months of immunosuppression to try to remove the immune response. The second study involves using a different AAV vector and immunosuppression will only be used as a second-line therapy in the event of problems.

Other approaches being considered include using other AAV vectors, systemic delivery with other viruses, using genetically modified stem cells, and targeted integration strategies to avoid mutation caused by inserting new genetic material into a normal gene. Continuing challenges include host immune response to both the vector and newly introduced gene, achieving high enough levels of the new gene to cure disease over a longer period of time, and avoiding mutations caused by the new genetic material. These are very complicated issues that will probably not see results within the next five years, but the work towards a cure continues.

Our thanks to Australasian Society of Thrombosis and Haemostasis (ASTH) for permission to reprint the following article which was published in the ASTH newsletter, Vol 14 No 2. Dr Megan Sarson Lawrence is Project Officer at Australian Haemophilia Centre Directors' Organisation. She and her family spent a year in Ethiopia during 2007.

ETHIOPIAN HEMOPHILIA SOCIETY

Dr Megan Sarson Lawrence

Prof Amha Gebremedhin (back right) with nurses and some of the patients and family members.

> ...they explained that the current situation for people with a bleeding disorder (in Ethiopia) is very bleak.

One of my personal aims during my year in Ethiopia, stemming from my professional interest as the Australian Haemophilia Centre Directors' Organisation (AHCDO) Project Officer, was to locate the clinicians treating bleeding disorders and their patients and encourage a relationship with the World Federation of Hemophilia (WFH). In 2004 Ethiopia's neighbour, Eritrea, had become a National Member Organisation of the WFH during the World Congress and I hoped that Ethiopia could also benefit from similar membership. I spoke with WFH staff member, Assad Haffar, and he gave me a few old contacts which I tried to follow up. After several false leads I finally caught up with Prof Amha Gebremedhin at the austere Soviet-built Black Lion Hospital, the main teaching hospital in Addis Ababa. Prof Amha introduced me to Dr Abulaziz Abubeker, another haematologist and Sister Ayelech, the blood bank nurse. They explained that the current situation for people with a bleeding disorder is very bleak.

With Ethiopia's population of over 75 million there should be around 7,500 cases of haemophilia A alone, however the Black Lion is the only institution offering treatment of any kind. Whereas here in Australia people with haemophilia have access to a comprehensive range of both recombinant and plasma derived treatment products and are treated according to their clinical requirements, the only products available in Ethiopia are fresh frozen plasma and cryoprecipitate, and these are in very limited supply. There are, however, no reagents available within the hospital laboratories to perform any diagnostic tests and so the most many patients know is only that they have some kind of bleeding disorder. Notwithstanding the poverty, with the lack of treatment product and diagnostic facilities and the lamentable communication and transport systems in the city, it's no wonder that few patients actually go to the hospital for treatment, and even fewer return for follow up appointments. Those who do go are seen in cramped, over-flowing rooms in the general haematology clinic - there is no haemophilia treatment centre here, and 'comprehensive care' is non-existent.

Nevertheless, having said this, Prof Amha did arrange for some patients and family members to come to a meeting at the hospital and everyone appeared to have the greatest respect and appreciation for the services that were offered by the medical staff. Several years ago Sister Ayelech made an attempt to set up a paper based registry of bleeding disorders and had about 30 mainly paediatric patients listed. At the meeting and with the help of interpreters I distributed some WFH literature and encouraged them to form a society. One father with two small affected boys was particularly enthused and with help from the clinicians and emails between Addis Ababa and Melbourne, a proposal to set up the Ethiopian Hemophilia Society (EHS) was submitted to the Ethiopian Ministry of Justice. Certification was received in late March and the EHS had its first meeting symbolically on 17 April, World Haemophilia Day. The Society will work to become a National Member Organisation of the WFH and hence be eligible to participate in the Humanitarian Aid Program whereby donated treatment product is distributed on humanitarian grounds. They will also raise funds locally to establish an office in the hospital, set up networks to offer mutual support and distribute newsletters and purchase items like crutches and wheelchairs.

I'm also extremely pleased to report that AHCDO has established a new Partnership Grant which has been awarded to Dr Kalid Asrat, another haematologist at the Black Lion, and this has allowed him to attend the recent WFH Congress in Istanbul.

Carley Ekert is a physiotherapist at the Royal Brisbane and Women's Hospital, and a former member of the Australian and New Zealand Physiotherapy Haemophilia Group.

EXERCISE - WHAT'S NEW?

Carley Ekert

As a physiotherapist, part of my job has always been to encourage any physical activity possible, and I am a true advocate for the positive benefits of exercise. Apart from the well known effects of improving cardiovascular fitness, increasing general endurance and energy and helping to control weight, exercise has specific benefits for those people with bleeding disorders.Traditionally many forms of physical activity were discouraged in people with bleeding disorders to decrease risk of trauma, but with modern therapy and a better knowledge of injury prevention, the importance of exercise for people with bleeding disorders has been recognised.

I thought some of these research studies to do with exercise were interesting...

A 2007 German survey of people with haemophilia showed that 75% of adolescents and 55.5% of adults rated physical activity as playing an important role in their lives[1]. The most common activities were cycling, swimming, tennis, soccer and walking/hiking. The interesting thing about this survey was that when asked about bleeding complications there was no significant correlation between the rate of bleeds and severity of haemophilia or type of sport practised. To me, this highlights the point that every individual is suited to different activities depending on factors like altered range of movement, target joints, muscle strength and general fitness. What may be a safe activity for one person may not be for the next. The most important thing is that all possible steps are taken to avoid injury – protective equipment, appropriate footwear, timing prophylaxis with physical activity, gradual build up of activity and proper warm up and down are all things that can help to minimise your risk of having a bleed.

Another 2007 study looked at maximum strength of muscles around the knee in people with haemophilia compared to those without[2]. They found up to 50% less strength in people with moderate or severe haemophilia and these people were less able to maintain a constant level of force when asked to. This not only highlights the lack of joint stability that would be associated with this decrease in strength but also makes me wonder that if the muscle strength is fluctuating, what is the control around the joint like when stressed? The authors of this study recommend a specific program to increase muscle strength and thereby decrease risk of injury during any physical activity, including everyday living.

Other studies have also shown that progressive resistance training can decrease the incidence of spontaneous bleeds. In a 2002 study, a group of people with severe haemophilia A were given an individually tailored program of stretching and strengthening exercises and reported a significant decrease in bleeding episodes and pain[3]. It's worth noting also that participants reported an increase in bleeds if they stopped their training for longer than two weeks. Anecdotal reports from some people in our own community would also seem to support this.

FOR THOSE PEOPLE WITH EXISTING JOINT DAMAGE

When you have an arthritic joint, the muscles surrounding the joint start to waste away as they are not being used properly. This weakness then gives the joint less support and causes that "fragile" feeling that is often described, leading to either further pain or recurrent bleeds. Exercise can help with stiffness, maintain movement and can improve muscle strength around the affected joint, which aids in joint stability. This makes it less vulnerable to stress and often less painful. Numerous studies on arthritic populations consistently indicate that specific exercise programs do not exacerbate pain or disease progression and will help with strength, stability and pain.

FOR THOSE PEOPLE WITH MINIMAL OR NO JOINT DAMAGE

Those people who have been on prophylactic therapy hopefully have been able to control their joint bleeds better and haven't suffered the amount of joint destruction that those in the past have. There will be a wider array of activities you are able to participate in, but it is important to always be aware of injury prevention strategies in your chosen activity. Before starting a new sport or form of physical activity you should ensure you have enough general fitness, technical skills and appropriate strength to perform the activity safely. Even if you haven't got joint damage, if you have haemophilia and have had recurrent bleeds into a joint, then you are at risk of developing arthritis. One of the best ways to prevent or delay onset of arthritis is to strengthen the muscles around joints, thus further protecting them from damage.

I would really encourage anyone who is interested in starting an exercise program or who wants an update on their current program to contact the physiotherapist at their local Haemophilia Treatment Centre for advice and/or assessment. As the old saying goes – move it or lose it!

References

1. A Fromme et al, "Participation in sports and physical activity of haemophilia patients". *Haemophilia*; Volume 13, Issue 3; p323 - 327; May 2007

2. L Gonzalez et al, "Force Fluctuations during the maximum isometric voluntary contraction of the quadriceps femoris in haemophilic patients". *Haemophilia*; Volume 13, Issue 1; p65-70; January 2007

3. R Tiktinsky et al, "The effect of resistance training on frequency of bleeding in haemophilia patients". *Haemophilia*; Volume 8, Issue 1; p22-27; January 2002

The bleeding disorders community includes people at all ages and stages of life. Some are well and living active lives, others have a load of health problems and are not sure what to deal with first. HIV infection in particular has highlighted the need to make sure your lifestyle and diet helps to look after your heart and prevent problems such as high cholesterol or diabetes. Then there are those who are experiencing all the usual complications of growing older. We can be a bit fatalistic about our health. But can making changes to your lifestyle in middle-age make a difference?

The following article is abridged from "ABC Health News", 12 July 2007. The author is a staff writer with the ABC. It was published in "The Hep C Review" Edition 60, March 2008, the journal of Hepatitis C Council of NSW and is reprinted below with permission.

MID-LIFE RECOVERY

Peter Lavelle

So you could drink Jack Kerouac under the table; there's a cigarette in your mouth so often people refer to you as Bogart; you need two seats in an aeroplane, and every year the fast food industry thanks you for personally contributing so much to their financial bottom line.

All this is precious little consolation for reaching middle age in terrible shape, headed for an early grave.

But maybe not. You can make dramatic improvements in your health and life expectancy in middle age, even if you've burnt the candle at both ends over the years, say US researchers. The researchers from the Medical University of South Carolina followed 15,700 adults aged between 45 and 64 for ten years.

Every three years, the researchers looked at the participants' lifestyles – things like whether they smoked, played sport, what they ate and whether they suffered from illness and disease. Specifically, they looked to see how many did one or more of the following things:

- Ate at least five fruits and vegetables daily;
- Exercised a minimum of 2.5 hours per week;
- Kept their body mass index between 18.5 and 30 kg/m2 (body mass index is weight divided by height then squared. It's a rough measure of obesity – if BMI is over 30, a person is considered obese);
- Refrained from smoking.

The idea of the study was to see whether adopting these measures reduced the participants' risk of dying or getting heart disease.

At the beginning of the study, only 8.4 percent were doing all four healthy things.

As time went on, more of the participants voluntarily adopted healthier lifestyles (without being encouraged). Eating more fruits and vegetables was the most common lifestyle change, followed by getting more exercise, quitting smoking, and losing extra weight. Six years into the study, a further 970 participants (8.4 percent) had joined the ranks of those who did all four things.

At the end of the ten-year study, the researchers calculated that people who switched to doing all four things were 40 percent less likely to have died and 35 percent less likely to have developed heart disease than those who didn't make the change.

The benefit was there regardless of the person's age, race, gender, or whether they had pre-existing disease – a history of high blood pressure, high cholesterol, diabetes, or heart disease.

In other words, the effect was prompt – evident within four years – despite damage from a reckless lifestyle in the past.

The results support other large studies looking at the effects of lifestyle changes on groups of men and women, the researchers say.

It's not an excuse to hit the bottle, the ciggies and the chicken nuggets, thinking that a bit of healthy living down the track will make up for it. But, on the other hand, if you're regretting those years of hard living, it's not too late to change.

Dr Paul Giangrande is former Vice-President Medical of the World Federation of Hemophilia. This article was published in "Hemophilia World", April 2008, Vol 15 No 1, the journal of the World Federation of Hemophilia.

GENETIC RISK FACTORS FOR INHIBITOR DEVELOPMENT IN HAEMOPHILIA

Dr Paul Giangrande

Increasing knowledge about the role of molecular genetics in inhibitor development will hopefully lead to new strategies to prevent and treat patients with inhibitors or even prevent their development in the first place.

Now that the risk of transmission of viruses by coagulation factor concentrates is essentially eliminated, the risk of inhibitor development is perhaps the principal danger faced by people with haemophilia.

Inhibitors are antibodies (specialised immune proteins) which are developed in the body to respond to a foreign substance, in this case the foreign factor protein. Inhibitors bind to the factor protein needed to stop bleeding and can make clotting factor concentrates ineffective.

The strongest risk factor for inhibitor development is the type of mutation, or structural alteration, in the factor VIII (or IX) gene that causes haemophilia. Mutations where a large part of the gene is missing or inverted (such as intron 22 inversion) are more likely to develop inhibitors. However, there is more and more evidence that clearly indicates that other genetic factors may also influence the risk of inhibitor development.

A lot of important information has been collected from ongoing studies of brothers with haemophilia who share the same genetic mutation as the cause of their haemophilia. In an international study coordinated from Malmo, Sweden, information on the gene defect and inhibitor history were evaluated in 113 families in which two or more siblings had severe haemophilia A. In 79 of the families (70%) either all or none of the siblings had a history of inhibitors. In the 59 families with inhibitors, all the siblings with haemophilia had inhibitors in 42% of cases. For the 74 families with intron 22 inversion, in 63.5% of cases all or none of the siblings had a history of inhibitors and in 40% of cases with inhibitors, all the siblings had inhibitors. Such data show that the type of mutation alone is not enough to predict the risk for therapy-induced inhibitor formation and suggest that other factors play a role in stimulating inhibitor development.

Current research is focusing on the role of other proteins involved in immune response. Major histocompatibility complex (MHC) molecules on cell surfaces play a pivotal role in immune response reactions to foreign proteins but to date no strong association between any one particular MHC molecule and an increased risk of inhibitor development has been shown. In the ongoing Haemophilia Inhibitor Genetics Study (HIGS), also coordinated from Malmo, genome scanning is performed to identify genes outside the factor VIII (and IX) genes associated with the risk of inhibitor development. The aim of the study is to develop tools to predict the risk of inhibitor development and to open possibilities to prevent inhibitor development. Although the search for disease genes associated with complex diseases holds great promise, the task of discovering true causal genes among the multitude of genetic variants is certainly very challenging.

Recent publications from Jan Astermark and colleagues in Malmo have highlighted a link between structural variants (polymorphisms) in the genes of two important proteins involved in inflammatory and immunological responses, namely interleukin-10 (IL10) and tumour necrosis factor-alpha (TNF-α). These variants might have an impact on inhibitor development by increasing the production and secretion of chemicals that ultimately enhance the production of antibodies directed against factor VIII. In the case of interleukin-10, one particular polymorphism (134-base pair long variant of a CA repeat microsatellite in the promoter region of the IL10 gene) was found to be associated with a 4.4-fold increased risk of inhibitor development. This same polymorphism has already been shown to influence the level of antibody production in such diverse diseases as myasthenia gravis, multiple myeloma, and systemic lupus erythematosus. More recently, the same group reported that a particular polymorphism (C/T at -318) in the cytotoxic T-lymphocyte associated protein-4 receptor of certain immune cells actually provides protection against inhibitor development.

Increasing knowledge about the role of molecular genetics in inhibitor development will hopefully lead to new strategies to prevent and treat patients with inhibitors or even prevent their development in the first place. However, environmental factors are also important and further work is needed to identify the impact of such variables as the type and intensity of treatment and age at first exposure to clotting factor concentrates.

Suzanne O'Callaghan is Haemophilia Foundation Australia (HFA) Policy Officer.

WHAT IS HFA DOING ABOUT HEPATITIS C?

Suzanne O'Callaghan

FINANCIAL ISSUES

Many people in the HFA hepatitis C needs assessment expressed concerns about financial and insurance issues and there were many personal stories of financial hardship.

In Australia, there is no single solution to this. There are a range of government benefits and services to help people with chronic health conditions with care and support. However, there are gaps which can affect people with bleeding disorders and often these benefits are not enough to support individuals or their families to live comfortably. Some of our members have also experienced difficulties with reviews and entitlements.

HFA is working on a number of strategies to improve the financial situation of the bleeding disorders community affected by hepatitis C. This includes:

- Advocating for people with bleeding disorders to have access to existing benefits and services.
- Advocating for resources to guide people with bleeding disorders to appropriate benefits and services.
- Highlighting the gaps and the difference between government benefits and services and community needs.
- Other strategies to achieve better outcomes to meet the financial needs of the bleeding disorders community.

Haemophilia social workers and counsellors specialise in negotiating the maze of benefits and services and can offer you valuable support. They have assisted many clients with financial issues. This includes Centrelink reviews to help their clients to have the best outcomes possible. If you have any questions, contact your local Haemophilia Centre.

Insurance and superannuation

Australian insurance law assumes that companies will use actuarial advice (ie, statistically, what are the risks involved in insuring this person?) to develop policies and premiums and allows discrimination where this is seen to be reasonable. Having a pre-existing medical condition such as haemophilia as well as a blood borne virus may severely impact on access to insurance. HFA has sought expert advice and is considering the best path for achieving change in this difficult area.

John Berrill from Maurice Blackburn Cashman has developed a national guide on insurance and superannuation for people with bleeding disorders and has been working with haemophilia social workers and counsellors nationally. The guide is available on the HFA web site. Your local haemophilia social worker or counsellor can also help you with accessing schemes and entitlements.

Hepatitis C treatment

In Australia costs for hepatitis C treatment are largely covered by the public health system. There have been some restrictions for people who have had treatment before. In large hepatitis clinics, treatment access is often managed so well that patients are unaware of any restrictions. However, HFA has had reports that some members needing retreatment in smaller hepatitis clinics have been unable to access government subsidised treatment. In April 2008, HFA made a submission to government for equal access to subsidised retreatment for all appropriate candidates, along with other recommendations about treatment support, education and care.

DOUBLE WHAMMY REPORT FEEDBACK

What has the community had to say about the *Double Whammy* Report? A copy of a *Your Say* form was included in the mailout with the Report and on the HFA web site to invite community feedback and HFA asked for comments by 18 April 2008. Only a few members took the opportunity to give feedback.

Of the responses received, all agreed or agreed strongly that their experiences were like those in the Report.

- Most agreed or agreed strongly that the current recommendations will meet the needs of people with bleeding disorders affected by hepatitis C. One didn't know.
- Some made additional comments. These included:
  - > Reading other people's stories helped to identify symptoms not previously associated with hepatitis C.
  - > Need more information for people who are HCV antibody positive but do not have symptoms.
  - > Need more information on preventing the spread of infection at home, around food.
  - > Would like updates on the progress of insurance issues. Financial problems are a daily battle.
  - > Helpful if HFA provided a secure chat room on web site to share feelings and experiences.
  - > Difficult to co-ordinate haemophilia needs in mainstream services when not at Haemophilia Centre. Haemophilia Centre access difficult for some, but not using Haemophilia Centre can result in poor care.

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> Disability and pain associated with haemophilia and hepatitis C is the major problem. Need for permanent full-time carer and supported accommodation with rehabilitation facilities at a relatively young age, especially if single.

> Hepatitis C has had a great psychological impact. Anger about the route of acquisition, silence in the family and among others due to their experiences of the HIV epidemic, and being informed casually when it was a serious issue have all left their mark.

There has been some feedback from haemophilia social workers/ counsellors that members mostly agreed with the Report. Some members thought that the people in the focus groups had probably understated how angry they really were. Others have come forward to tell more positive stories about treatment. Reading about other people's experiences had helped some members to see that they were not alone. They had looked at their liver health again and reconsidered treatment to improve their quality of life.

This is helpful information to have. We hoped that the personal stories in the Report would assist people feeling isolated, and the feedback confirms how important personal stories are. In response, HFA has included some personal stories from the *Double Whammy* Report in *National Haemophilia*. Personal accounts have also become a major part of information fact sheets.

HFA is also following up other issues raised in a number of forums:

- Revising the information booklet on hepatitis C and producing other updates to cover the questions identified.
- Discussions with haemophilia health professionals about issues and services. Some of the issues raised by members may be dealt with under broader work on a comprehensive care model for Haemophilia Centres.

STORIES FROM PEOPLE LIVING WITH HEPATITIS C

Suzanne O'Callaghan

What is it like to live with a bleeding disorder and hepatitis C? These are some of the personal stories from people who contributed to the Double Whammy Report.

PART 2. EVERYDAY LIFE

Living with others

What was the impact of hepatitis C on people's personal and social life?

People with bleeding disorders and hepatitis C were conscious of their responsibility to protect their family or partner from infection with hepatitis C. Some were not sure how it was transmitted in the home or whether it could be transmitted sexually.

If they had symptoms, they were unable to do their share of household and family duties and no longer socialised outside the home. Some people who lived alone stopped going out or seeing friends.

I found myself having to disclose to my partner early because we went out, [partner] stayed the night at my place and I walked in in the morning and there's my toothbrush in [partner's] mouth. And I'm just like, we have to have this talk right now. Because my being a haemophiliac as well, my gums bleed a bit when I clean my teeth, so chances are there's a bit of blood on the toothbrush.

I thought a lot about when I do get married, what impact it will have? At the clinic we never talk about it and I've never been told anything really about how it operates. I don't really know how it's going to work with [a partner] so I've been very conscious about that when getting into relationships.

It's had quite a big impact on my social life and my relationships with my wife and kids because various treatments that I've been on over the years, particularly the treatment with ribavirin and interferon, I was falling asleep in the lounge chair and in company which was not going to go down too well.

But basically the day-to-day workload increased for me on a consistent level. [partner]

Working and Finances

If people did not have symptoms, hepatitis C did not make much difference to their work or their finances unless they decided to have treatment.

If they had symptoms many had to reduce or stop work from their late 30s.

Treatment caused big disruptions to work.

Many people were unable to get personal, health, travel, income and mortgage protection insurance. This could lead to great financial hardship for them and their families.

Partners or family were usually actively involved in caring for the person. They cut down their own working hours to provide this support. They also needed to work to maintain the family income. This could put stress on the family. Partners and carers often felt very isolated.

Having hepatitis C resulted in many additional health costs, even when treatment was subsidised.

Have you got a gap of 6 months somewhere in your life where you can do that [treatment]? You need the space in your own life and probably your relatives, your family, your immediate family, because they need to help you through. [parent]

I took 12 months off work to have treatment, so did my Mum.

I find that the haemophilia is fairly well managed with treatment, but come

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lunchtime the fatigue that sets in does make it very difficult to go on.

I still manage to work full-time, although these days it tends to be clerical so I can sit down. There's times I wish I wasn't there and didn't have the stress and just the effort of doing it, but I do it. I've still got children at school. But you just do the best you can.

I had a really successful business and when I eventually got too ill, I had to sell all that, so financial-wise I actually suffered really badly when I then changed to what I'm doing now. I had to start again, which was a lot less struggle on my body physically.

Because of this medically acquired condition that I've got, that precludes me from getting income protection insurance and puts my family at risk - but if something happened to me, it would be good to know that there was some sort of recourse so that we don't end up destitute and on the street. I wake up at night about that.

It's all about quality of life. Ours is really poor now. I am self employed with a wife and 2 kids – I had two lots of unsuccessful interferon treatment for hepatitis C. Not sure if I can face combination therapy. We had to sell the house because of financial problems because I couldn't work a couple of years ago. I worry that I may not be able to look after my family. Hepatitis C has destroyed my quality of life and now endangers my family. My family has had to endure our decline from a normal lifestyle with security to not knowing what tomorrow will bring and living from day to day.

There's always that hidden cost of fuel, transport costs to and from the hospital while you're on treatment. Some people have a lot of panadol and that adds up while you're on treatment and other pharmaceutical costs, the costs of small fees you've got to pay at [hospital] or if you decide, I'd just better go to the GP, you've got your hidden costs with the GP.

More information and support

HFA has produced a basic information booklet on hepatitis C for people with bleeding disorders. This is available from your local Haemophilia Centre or Haemophilia Foundation. It is also on the HFA web site: www.haemophilia.org.au.

There is a lot of high quality information on hepatitis C available from Hepatitis Councils. HFA has developed a hepatitis C section of the HFA web site with links to selected information from the Councils and other sources. Haemophilia Centres and Haemophilia Foundations usually have a range of relevant resources as well.

For other information about services and support for people with bleeding disorders and hepatitis C near you, including financial assistance and insurance and superannuation schemes and entitlements, contact your Haemophilia Social Worker/Counsellor, your Haemophilia Centre, your state/territory Haemophilia Foundation or HFA. You will also be able to obtain valuable information from Hepatitis Councils.

Suzanne O'Callaghan is Haemophilia Foundation Australia (HFA) Policy Officer.

HEPATITIS

Suzanne O'Callaghan

World Hepatitis Day May 19
Hepatitis Awareness Week May 19 - May 25

On 19 May 2008 for the first time World Hepatitis Day was marked globally. The worldwide theme was *Am I number 12? 1 in 12 people worldwide are living with hepatitis B or hepatitis C.*

What does this mean for people with bleeding disorders? In Australia many people with bleeding disorders have been affected by hepatitis C. In 2008 HFA's Hepatitis Awareness Week message was about taking charge of your hepatitis C health by knowing your hepatitis C and liver health status:

HEP C 123
1 Take Control
2 Health Check
3 Know your status

For Hepatitis Awareness Week 2008 HFA published two new updates on hepatitis C for people with bleeding disorders:

- **Understanding your hepatitis C test results**
- **Hepatitis C treatment snapshot**

and also,

- **A summary of the HFA Hepatitis C information booklet.**

In a change from our usual practice with publications, these updates have been made available primarily as web pages on the HFA web site and were launched via the HFA email news alert on 19 May. It was quite exciting to click the "send" icon to launch the updates to our 297 email newsletter recipients! We have also included a print copy of the updates with this issue of *National Haemophilia* for those who don't have access to the internet or a printer.

AWARENESS WEEK

The updates are an effort to make the theme of Hepatitis Awareness Week meaningful to people with bleeding disorders as well as address some of people's key information needs relating to hepatitis C. They are the result of the work of the HFA Hepatitis Awareness Week Working Group (Robert Lamberth, HFQ; Dave Bell, HFWA; Melissa Morris, HFV; Suzanne O'Callaghan, HFA). My thanks to Robert, Dave and Melissa for their thoughtful input and ideas.

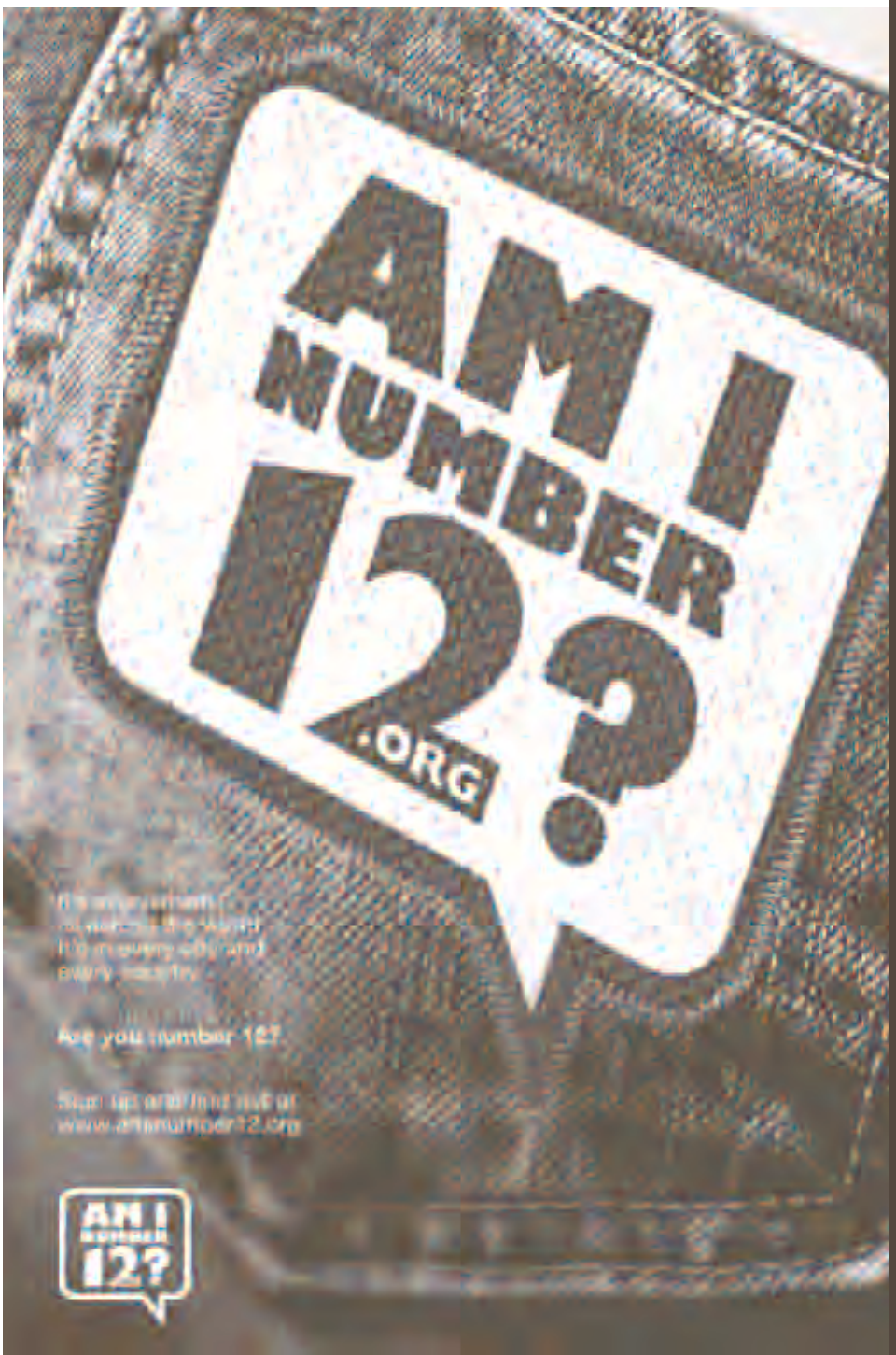
We aimed to reach members who prefer internet information as well as those who read newsletters. The updates are specifically tailored to the interests of people with bleeding disorders, and include personal stories from the *Double Whammy* Report.

At a global level hepatitis B and C is a major problem. More than 500 million people are affected and awareness is very low. The World Hepatitis Alliance has been established to achieve change internationally. World Hepatitis Day and the "12 asks of government" are the first concrete steps towards this.

For more information on the global campaign, go to www.worldhepatitisday.com. Details of the Australian Hepatitis Awareness Week campaign can be found on the Hepatitis Australia web site at www.hepatitisaustralia.com.

If you are interested in what HFA is doing about hepatitis C, check the regular update in *National Haemophilia* or go to the hepatitis C section on the HFA web site, www.haemophilia.org.au.

The World Hepatitis Alliance has been established to achieve change internationally. World Hepatitis Day and the "12 asks of government" are the first concrete steps towards this.



Ken's story originally appeared in the Spring 2007 edition of "Cfiles", the Hepatitis Council of Western Australia's quarterly magazine. This abridged version is published with permission from the author and the Hepatitis Council of Western Australia.

HEPCAUSTRALASIA - an internet journey

Ken

Instead of being home alone with hep C, I found myself involved with a family of wonderful people all dealing with aspects of living with it.

In 2006, I joined the *hepCaustralasia* forum and my experience of living with hep C was transformed. *hepCaustralasia* is primarily an internet support group. This is my story about joining a supportive internet community which ultimately helped me to understand about living with hep C.

I first became aware of my hep C status in 2002. My doctor told me I had hep C, gave me some pamphlets and sent me on my way. I was angry and confused about the diagnosis because a previous blood test in 1997 showed a negative result.

In the days after my diagnosis there were just three people in my life with whom I could discuss my hep C: my girlfriend, my therapist, and one close mate. It wasn't long before I turned to the internet and scoured the web for relevant information and resources. It felt safe accessing information in private, but at times it became overwhelming. I was alone, in front of my computer and surrounded by silence.

Over the next couple of years I changed my approach to diet and beer drinking, and convinced myself that through googling "HCV" on a regular basis I'd come to terms with hep C related denial.

One night in 2005 I stumbled onto a site called Hep C NSW. I was amazed and repulsed at what I found on the site. People were being very open about their symptoms and treatment problems. I remember the horror of seeing the Tx word and hearing about the severe side effects that people were experiencing. Treatment!

Even though I was experienced with posting on internet email lists, I remained a lurker on this new forum. I remember thinking, "I'm not ready for all this." Stepping back into my own secret world seemed much safer. I liked to approach things in my own way and decided to pull back from the forum.

I came back to the forum in October 2006 but by now it had expanded and become *hepCaustralasia*. Instead of scientific and medical sites with pages of facts, the forum offered me personal accounts of living with hep C. Reading the discussion posts, blogs and personal messages on *hepCaustralasia* opened up a very humanly-social way for my continuing acceptance of living with hep C. Even though my stomach churned with tension when reading some of the stories, I felt compelled to log onto the site as much as possible.

Each member of the forum had their own life story and seemed to deal with their virus differently. Instead of being home alone with hep C, I found myself involved with a family of wonderful people all dealing with aspects of living with it. Many of the conversations were about treatment, which was understandable, however discussions about disclosure, transmission, dealing with doctors, trial protocols, disability pensions, research projects, psychological issues and liver transplants built on and helped crystallise my previous fact finding missions.

On the forum I felt accepted - virus and all. This was something I hadn't found possible in other social or work environments.

Many thanks to the people who in the early days set up *hepCaustralasia*, and to the many members and contributors of the forum for their commitment to a very good internet support group and forum.

The *hepCaustralasia* web site is available at: www.hepcaustralasia.org.

HEPATITIS B & C AT THE CROSSROADS, 20-22 OCTOBER 2008

viral BRISBANE 2008
HEPATITIS
6TH AUSTRALASIAN CONFERENCE

The 2008 Australasian Viral Hepatitis Conference promises to be a challenging and stimulating forum on issues relating to hepatitis B and C.

It includes an array of notable invited speakers, including:

- Charles Gore from the UK Hepatitis C Trust
- Brian Edlin from the Center for the Study of Hepatitis C, New York
- Ching-Lung Lai from the University of Hong Kong
- Henry Lik Yuen Chan from The Chinese University of Hong Kong
- Stephen Locarnini from Victorian Infectious Diseases Reference Laboratory
- Jack Wallace from Australian Research Centre in Sex, Health & Society, Melbourne

The 2008 Conference will have a focus on the long-term impact of hepatitis B and C, addressing the issues from medical, psychosocial, government and community perspectives. This is of particular interest to the bleeding disorders community, which has been living with hepatitis B and C for more than 20 years. Presentations will discuss many of the concerns raised in HFA's hepatitis C needs assessment:

- Natural history of hepatitis C and factors altering disease progression
- Living with hepatitis C
- Government response
- Improving mental wellbeing with hepatitis C
- Self-management strategies
- Treatments and management for advanced liver disease

With four concurrent symposium sessions open for presentations on relevant issues, the Conference Convenors are encouraging the submission of abstracts. Deadlines are:

- Abstract submission deadline – Friday 18 July 2008
- Scholarship application deadline – Friday 18 July 2008
- Early bird registration deadline – Sunday 31 August 2008
- Registration deadline – Tuesday 30 September 2008

For more information, contact:

Australasian Viral Hepatitis Conference

E: conferenceinfo@hepatitis.org.au

P: (02) 8204 0770

F: (02) 9212 4670

The following article is abridged and adapted from "IAS 2007: promising signs" by Paul Kidd, published in "Positive Living", 15 October 2007, the newsmagazine of the National Association of People Living With HIV/AIDS, Australia. It is reprinted below with permission.

NEW HIV DRUGS

Paul Kidd

There is a lot of excitement about new treatments at the moment, with several new HIV drugs currently in late-stage clinical trials. Many are from entirely new drug classes. The good news is that many of these drugs are continuing to perform well, are effective and well tolerated by people with HIV.

Integrase inhibitor

Raltegravir (Isentress, formerly MK-0518 - Merck) is an experimental integrase inhibitor. Integrase inhibitors target a different part of the HIV life cycle to existing treatments – by interfering with the integrase enzyme, which HIV uses to insert its viral DNA into human cells. These are an entirely new class of HIV drugs, so if effective integrase inhibitors can be developed, this has the potential to radically improve treatment options.

Results from a major phase-2 clinical trial comparing raltegravir to efavirenz were presented at the International AIDS Society Conference in Sydney in October 2007. The objective was to see whether raltegravir was as effective as efavirenz for people who had not previously taken HIV treatments, and to find the most appropriate dose of the new drug. The trial was broken into groups of participants who took raltegravir and another group who took efavirenz. All also took Truvada (FTC plus tenofovir).

What were the results?

- Groups taking raltegravir and efavirenz had similar treatment responses: more than 83% of people taking raltegravir and 87% of people taking efavirenz had undetectable viral loads at 48 weeks.
- Very few people discontinuing treatment due to side effects or toxicity problems. Diarrhoea was more common among people taking higher doses of raltegravir compared with efavirenz, while CNS side effects such as abnormal dreams, and increases in cholesterol and triglycerides were more common in those taking efavirenz.

These are impressive results and show that this new treatment is very effective for people who have not had treatment before and relatively easy to tolerate. There are also signs that raltegravir is capable of producing much faster reductions in viral load compared to efavirenz. This suggests that if good results continue, this drug will have a big role to play in HIV therapy in the future.

These are an entirely new class of HIV drugs, so if effective integrase inhibitors can be developed, this has the potential to radically improve treatment options.

CCR5 inhibitors

Maraviroc (Celsentri - Pfizer) is a CCR5 inhibitor. This is another drug from an entirely new class.

CCR5 inhibitors work by blocking one of the co-receptors used by HIV to gain entry to human cells. There has been some concern about them because HIV is able to use an alternative co-receptor (CXCR4) in some people, and so the participants in this trial had been pre-screened to ensure they had 'R5-tropic' virus, which uses the CCR5 co-receptor. People with 'X4-tropic' or mixed virus were excluded from this trial and are unable to use this treatment.

At the same Sydney conference, there were results from the large phase-3 MERIT study, which compares maraviroc to efavirenz. Participants have not had HIV treatment before and are also taking Combivir (AZT plus 3TC). Results were:

- People taking maraviroc were slightly less likely than people on efavirenz to achieve undetectable viral loads (65% vs 69%).
- People taking maraviroc had fewer side-effects and fewer cases of malignancies (1 vs 4) than people on efavirenz. Severe liver toxicity was uncommon for both drugs.

Suzanne O'Callaghan is Haemophilia Foundation Australia (HFA) Policy Officer.

TREATAWARE

Suzanne O'Callaghan

Where can you find reliable, up-to-date information about HIV treatments?

Treataware is a new initiative from the National Association of People Living With HIV/AIDS, Australia (NAPWA) and the AIDS Treatment Project Australia (ATPA). It aims to help people make informed choices about their treatment and take effective action to maintain their health.

Three *Treataware* projects were launched on 19 May 2008:

1. *Treataware* Information Line (HIV treatments and research information) – 1800 817 713

A national 1800 freecall service. Callers can discuss HIV treatments and related topics with trained HIV treatment educators.

2. HIV Clinical Trials Database - www.treataware.info

A user-friendly web site for people living with HIV, their partners, carers and allied service providers with details of Australian HIV clinical trials. The web site is not intended to recruit people into trials but will be a source of independent information.

3. HIV Treatments Checklist (printed booklet)

This guide has been prepared to assist HIV positive people to make the best decisions they can about their health, care and treatment. It will provide a checklist of treatment issues and decisions for positive people to work through with their doctor and other health and support providers to make a clear, comprehensive plan for living well with HIV/AIDS.

Treataware is not meant to replace advice from a doctor or other health care worker. People living with HIV should see their doctor regularly, who can provide individual monitoring, up-to-date information, advice and counselling if needed.

For more information contact Kate DeMaere at NAPWA on (02) 8568 0311.

...it aims to help people make informed choices about their treatment and take effective action to maintain their health.

DAMON COURTENAY MEMORIAL ENDOWMENT FUND

The Damon Courtenay Memorial Endowment Fund was established by Bryce Courtenay and the late Benita Courtenay in memory of their son, Damon. The Fund was set up to provide care, treatment, education and welfare for people with haemophilia, and their families. Haemophilia Foundation Australia has been able to distribute the accumulated interest from the Fund approximately every 18 months to assist members of the bleeding disorders community. HFA was sad to learn that Benita Courtenay, who has supported our community for many years, passed away in 2007. We are pleased that Damon's brothers, Adam and Brett, have been able to continue this interest and support, and that Brett represented the Courtenay family to consider the applications this year. The assessment panel also included Barbara Volk who is a former President of HFA and HFA Life Governor, Gavin Finkelstein, HFA President, and Sharon Caris, HFA Executive Director.

Grants were made to seven people around the country for a range of activities which include a wheelchair and other equipment, computers, education courses and retraining and support for small businesses.

We expect to advertise the next funding round in *National Haemophilia*, in State/Territory foundation newsletters and at haemophilia centres in December 2008. Why not register for *E-News* so that you are sure to hear when applications are being received for the next funding round. Go to the newsletter sign-up on the home page of the HFA web site – www.haemophilia.org.au.

HAEMOPHILIA AWARENESS WEEK, 12-18 OCTOBER 2008

Haemophilia Foundation Australia and Haemophilia Foundations around the country work together to raise awareness about inherited bleeding disorders to the general community, community organisations and governments. A team of representatives from HFA and each of the State/Territory Foundations will develop a plan which will be implemented in the lead up to, and during Haemophilia Awareness Week in October.

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 foundation during the week
- Organise a casual clothes day at your workplace or school – try a Red and White Day in return for a gold coin donation
- Organise a luncheon, sausage sizzle or morning/afternoon tea

If you would like to receive promotional items for the week or are planning to run an event for Haemophilia Awareness Week contact HFA on 1800 807 173 or email ncoco@haemophilia.org.au.

HAEMOPHILIA FOUNDATION AUSTRALIA – WHO ARE WE?

Haemophilia Foundation Australia (HFA) formed in 1979. For 29 years we have represented the needs and issues of people and their families with haemophilia, von Willebrand disorder and other related bleeding disorders.

We receive funding for our administration and general expenses, but we are heavily dependant on the support of the community, trusts and foundations for funding to provide programs and services. These program and services include foundation camps, support groups, youth activities etc.

A Council made up of delegates from member State and Territory Foundations manages HFA. HFA Council meets annually for the purpose of reviewing and implementing policy and program plans.

The Executive Board, elected by Council Delegates, is responsible for the day-to-day management and conduct of the Foundation's affairs. A small staff implements these affairs.

Much of the early work of HFA was directed towards lobbying for improved treatment facilities, blood product supplies and counselling services. A great deal has been achieved.

Today our work is still directed to representing people with

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haemophilia, von Willebrand disorder and other related bleeding disorders and their families. We are committed to improving treatment and care through representation and advocacy, education and the promotion of research.

HFA supports a network of State and Territory Foundations in Australia and as a National Member Organisation of the World Federation of Hemophilia participates in the development of diagnosis, treatment and care around the world.

HFA STAFF

Executive Director
Sharon Caris
(Full-time)

Development Manager
Natashia Coco
(Full-time)

Policy Officer
Suzanne O'Callaghan
(Full-time)

Executive Secretary
Heather Lauder
(Part-time)

Administration Assistant
Joanne Luciani
(Part-time)

Accountant
Kevin Lai
(Part-time)

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(Western Australia)

Vice-President
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(New South Wales)

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Peter Fogarty
(Queensland)

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and Beth Large
Queensland

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Jonathan Spencer
Tasmania

Ann Roberts
and Judi Fisher
Victoria

Gavin Finkelstein
and David Bell
Western Australia

GLOBAL FEAST

Haemophilia Foundation Australia will join other international Haemophilia Foundations - for **GLOBAL FEAST 2008.**

You are invited to be an official **GLOBAL FEAST** host. Time your event around the month of September 2008. 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 international programs and services 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.

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.

For more information or to register please call Natashia Coco on 1800 807 173, email ncoco@haemophilia.org.au or visit the official **GLOBAL FEAST** website www.globalfeast.org.

Choose to make a difference this year. Join GLOBAL FEAST.

CALENDAR

20th Annual ASHM Conference
Perth 17-20 September 2008
ph 02 8204 0770
fax 02 9212 4670
email
conferenceinfo@ashm.org.au
www.ashm.org.au/conference

6th Australasian Viral Hepatitis Conference
Brisbane 20-22 October 2008
ph 02 8204 0770
fax 02 9212 4670
email
conferenceinfo@hepatitis.org.au
www.hepatitis.org.au

Haemophilia Conference 2009
Brisbane 8-11 October 2009
ph 03 9885 7800
fax 03 9885 1800
email hfaust@haemophilia.org.au
www.haemophilia.org.au

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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:

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NATIONAL HAEMOPHILIA – **ELECTRONIC VERSION**

Would you prefer to receive *National Haemophilia* electronically? You would be helping Haemophilia Foundation Australia save on production and postage costs – not to mention the environment. All you need to do is email your details to HFA at hfaust@haemophilia.org.au and we will set it up.

SEE

World Federation of Hemophilia Congress

See the next issue of *National Haemophilia* for reports from Hemophilia 2008.

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