

People with haemophilia

National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

No. 164, December 2008

HAEMOPHILIA AWARENESS WEEK COLOURING COMPETITION

Winners of the Haemophilia Awareness Week Colouring Competition were:

5 years and under – **Charlotte** from Mary Beck Preschool VIC

6-9 years - **Jack Jacobs** from Neerim South Primary School VIC

10 years and over - **Isabelle Inglis** from Albury NSW



That matter
HAEMOPHILIA AWARENESS WEEK
18 October 2008

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Gavin Finkelstein is Haemophilia Foundation Australia President

NEWS FROM THE PRESIDENT

Gavin Finkelstein

THE HFA Council Meeting and Annual General Meeting was held on 25-26 October 2008 in Melbourne. The meeting was attended by Delegates from our member Foundations and HFA staff.

We were pleased to welcome several Delegates who were representing their member Foundations for the first time and several observers to the meeting. In addition to Council Delegates, David Taylor, who was recently elected to the role of President of HFNSW was in attendance, as was Martin Raspin who is a Committee member of Haemophilia Foundation Victoria (HFV). Erin James, Co-Chair elect of Youth Committee attended the meeting and provided an update on activities of the group.

Erin Lames also provided a report about his participation in the Step Up Reach Out program in San Francisco, 12-14 October. Erin was one of 15 youth from around the world who came together for the first of two workshops aimed at fostering and encouraging the development of leadership skills of people with bleeding disorders. Erin will attend the second workshop in Montreal in March 2009. This is an excellent program and an example of several international leadership activities Australian youth may wish to participate in. I encourage anyone who is interested in knowing more about the HFA Youth

Leadership Program or international opportunities for youth leadership training to contact HFA for further information.

Council was updated on the progress of the Education and Resources Review being undertaken at HFA. All HFA education resources are available on the website and many are available in print version. However some have become outdated and need revision. HFA has commenced a review process, and due to the demand on our resources we have prioritized activities to make the process manageable. Where possible and appropriate HFA convenes small groups of volunteers from the patient community and health professionals and others for discussion and comment on specific topics to make sure the information in our publications is accurate and relevant.

We are working to develop a partnership with The Starlight Foundation to promote Livewire which is a highly interactive youth based web site to youth with bleeding disorders. We are keen to support and encourage the use of sophisticated and well moderated web sites to provide peer support and accurate information to our youth.

New education material on von Willebrand disorder, carriers of the haemophilia gene, hepatitis C and mild haemophilia are in development and we will publish these in early 2009.

We are always keen to hear of the experiences of people in the bleeding disorders community and encourage you to provide feedback to HFA. We are planning to undertake a community needs and membership survey in the first part of 2009, and will welcome the participation of *National Haemophilia* readers.

At the recent Council meeting Delegates provided reports of the key achievements and issues confronting their local foundations. Many of the issues raised which were common to several member Foundations related to community engagement, the impact of waiting lists on joint replacement surgery, progression of ill health of members due to hepatitis C, access to services including emergency department services, dental care and hospital parking, and increased requests for financial support for members.

It has been encouraging to hear of the progress being made by Haemophilia Foundation Tasmania (HFT) and Haemophilia Foundation South Australia (HFSA), two of our smaller member organizations which have experienced difficulties to build and maintain their membership base in recent years.

HFT has strengthened considerably, membership has grown and an exciting education weekend in Launceston was held in December

2008. We thank the HFT committee for working proactively to identify and respond to the needs of their members.

The HFSA membership drive has continued with great success since the HFSA Family Camp in September 2008. HFA has worked with HFSA volunteers to encourage membership and participation. We are delighted to be welcoming previous members back, and that a Special General Meeting for the election of a new Committee was held in conjunction with an end of the year social event in late November.

I sincerely thank health professionals at the Royal Hobart Hospital and those at the haemophilia treatment centres at the Royal Adelaide Hospital and the Women's and Children's Hospital in Adelaide who have supported HFT and HFSA volunteers in their respective States to encourage peer support and valuable education opportunities for the bleeding disorders community. It is only with these team efforts that we can build stronger communities and jointly provide the support our families need.

HFA has developed two new resources to assist HFA and Member foundations in their work. The first of these is a Style Guide which has been prepared to ensure HFA publications and campaigns present the Foundation's image in a consistent way, and for information to be presented in a uniform style. The second is a publication of information and guidelines for Council Delegates. This publication provides member Foundations and their Delegates to the HFA Council with information about the important role Delegates play in representing the views of their foundation and contributing to the development of policy and programs undertaken by HFA for the benefit of the bleeding disorders community around Australia.

The HFA Annual Report is available to download from the HFA web site www.haemophilia.org.au under newsletters and annual reports.

I wish everyone a happy and safe holiday season and look forward to our work together in 2009. **H**

Wendy Poulsen is haemophilia physiotherapist at Royal Children's Hospital, Brisbane QLD

THE ROLE OF THE PHYSIOTHERAPIST

Wendy Poulsen

The fundamental difficulty faced by people with haemophilia is bleeding into the joints and muscles. Emphasis is placed upon the early recognition and treatment of bleeds in order to prevent disability in later life.

The major role of the physiotherapist in the treatment of haemophilia is to maintain, or restore, muscle and joint status, thus minimising the potentially disastrous effects that can result from repeated bleeds.

What Can A Physiotherapist Do?

Physiotherapy can:

- > improve muscle strength and co-ordination
- > prevent or reduce complications from bleeds
- > reduce pain
- > assist with early resolution of a bleed
- > offer advice in prevention of further injury to susceptible joints
- > promote involvement in fitness and sporting activities

- > educate and stimulate people with haemophilia, their parents, friends and healthcare workers to take an active role in their care.

The physiotherapist does not work in isolation, but is part of a comprehensive team where we aim for children with haemophilia to grow up and lead as normal a life as possible, with the minimal number of interruptions to daily activity.

SO --- remember if you are treating a bleed above your normal prophylaxis dose that is taking longer to resolve than normal, contact the physiotherapist at your Haemophilia Treatment Centre. A thorough assessment will determine why the bleed is persistent and may offer solutions for earlier resolution. If this is an ongoing problem, then perhaps taping, bracing or an orthotic may be required for joint protection.

Don't hesitate to contact your physiotherapist. **H**



2007 / 2008 – HFA HIGH

As the year draws to a close, Haemophilia Foundation Australia reflects on some of our achievements during 2007/2008.

Major project – impact of hepatitis C on the bleeding disorders community

A priority for HFA has been its work to understand and address the needs of the bleeding disorders community affected by hepatitis C. Many people with bleeding disorders have now been living with hepatitis C for more than 20 years after being exposed to hepatitis C virus (HCV) through their clotting factor treatment in the 1970s and 1980s before viral inactivation and HCV antibody testing was introduced. HFA has been concerned for its impact on them and their partners, families and carers.

Milestones:

- HFA hepatitis C membership survey 2003
- HFA Hepatitis C Needs Assessment, involving wide consultation with the bleeding disorders community, health professionals and other community agencies, 2006-8.
- Needs Assessment Report released October 2007: *'A double whammy': living with a bleeding disorder and hepatitis C*."

HFA's response to these findings 2007-8:

- Successful submission to government on access to hepatitis C retreatment
- Brief fact sheets on hepatitis C/liver health tests and treatment

- Education sessions on hepatitis C issues at the 2007 Haemophilia Conference
- Expert advice on the complex finance and insurance issues facing people with bleeding disorders affected by hepatitis C
- Feedback from the bleeding disorders community and health professionals on HFA's hepatitis C work so far

Responding to the complexity of these issues is a challenge for HFA and involves a multidimensional strategy. Thanks to all who have been involved and supported HFA's hepatitis C work.

State And Territory Foundation Activities

HFA supports a range of programs and activities conducted by State/Territory Foundations for their members. During 2007-2008 full or part funding was provided by HFA for 25 programs and activities including:

- Camps
- Family, men's, women's and youth groups
- HIV and hepatitis C peer support groups
- Carers' and partners' support groups
- Rural visits

Haemophilia Foundation Western Australia (HFWA) Community Camp >>>

The HFWA Community Camp was held in March 2008 at Ern Halliday Recreation Camp. Forty three people, including eighteen children were in attendance .

The themed weekend included a range of activities which allowed people to challenge their fears and address concerns about living with,

or being affected by, a bleeding disorder. There was a giant swing and indoor climbing, and a range of team building exercises and workshops for parents with a child with a bleeding disorder.

Haemophilia Foundation Queensland (HFQ) Family Weekend

In May 2008, over 100 people came together at Noosa North Shore for the HFQ family weekend. The camp was attended by people who had been to previous camps and others who had been to camps before. The weekend was an opportunity for families to share experiences with others, to network, and for children to make new friends and learn from each other's experiences. Over the weekend the children participated in a high ropes course and archery, and everyone had an opportunity for beach walks and a trivia night.



LIGHTS

Haemophilia Foundation Victoria (HFV) Women's Group

African Tribal influences on Brighton Beach were the feature of the annual women's group as a group of women joined together to discover the satisfying, and liberating experience of the African beats.

Positioned with our Djembe (drum) between our knees we recreated the sounds of Ghana, beat away our stresses and made good music together. This was followed with lunch and massages – what a day! (Julie Boal, organiser, HFV)

The group meets in an informal setting to network and provide peer support to one another. This covers the key elements of support, information and discussion – and fun! The group includes partners of both older and younger men, carers and mothers of people with haemophilia. The group of women came with very different experiences but the key to the success of their group is the one thing they have in common, their experience of a bleeding disorder.

Haemophilia Foundation Tasmania (HFT) Family Fun Day

The HFT Family Fun Day & Barbecue in November 2007 at ZooDoo Wildlife Park was great for families to re-unite again after meeting the previous year, and to meet new friends, and talk about their experiences. It was a great day out for the children who could play together in a lovely environment.

Research

The Haemophilia Foundation Research Fund was established in 1994 to support Australian based medical, scientific and social research to benefit the treatment and care of people with haemophilia and related bleeding disorders. The Fund has provided for 21 research projects over its 13 year history, representing a total amount of \$467,592.

An allocation of \$45,000 was allocated to two research projects in 2008:

- > Ms Dilinie Herbert (Monash University, Victoria)
Social and ethical dimensions of genetic testing (\$20,000)
- > Professor Eric Gowans (Burnet Institute, Victoria)
The identification and analysis of antiviral agents which target the HCV IRES (\$25,000)

Twinning – Australia And Thailand

The twinning partnership between HFA, the National Hemophilia Foundation of Thailand (NHFT) and the Thai Patient's Club which commenced in 2006 with the support of World Federation of Hemophilia (WFH) progressed to the next stage with visits from Thai representatives to Australia. See the article in this edition.

Youth Leadership And Mentoring Program

The Youth Leadership and Mentoring Program aims to encourage and motivate young men and women to become more involved with the bleeding disorders community, to encourage leadership and to benefit from personal development and peer support.

The Youth Committee adopted processes to include more youth in decision making. The Committee met monthly via teleconference and undertook a range of tasks including the quarterly newsletter Youth News and worked with the Canberra Conference Program Committee to develop a program.

19 youth from around Australia attended the Youth Training weekend in South Australia from 19-21 September. The weekend was a great success and gave the young men and women participants a chance to learn more about living positively with bleeding disorders as well as develop new relationships and benefit from the peer support. You can read reports on the weekend in Youth News. **H**

Back (l-r) >>

Craig Bardsley (QLD), Anna Szynter (TAS), Luke Peters (TAS), Erin James (NSW), Kyle Peters (TAS), Sam Black (TAS), Helen Singer (WA), Robert McCabe (WA), Matthew Blogg (VIC), Kim Round (VIC), Scott Coulter (SA), Dale Spencer (WA), Max Janiszewski (VIC)

Front (l-r)

Hamish Robinson (NSW), Paul Bonner (SA), Andrew Selvaggi (VIC), Lauren Albert (QLD), Ashlee Amos (WA), Chris Poulton (VIC)



AUSTRALIAN HAEMOPHILIA CENTRE DIRECTOR'S ORGANISATION (AHCDO) UPDATE

Dr Megan Sarson

Clinicians honoured

Two executive committee members of AHCDO were honoured at the joint scientific meeting of the Haematology Society of Australia and New Zealand (HSANZ), the Australian and New Zealand Society of Blood Transfusion (ANZSBT) and the Australasian Society of Thrombosis and Haemostasis (ASTH) held in Perth in October 2008.


The HSANZ invited Prof Alison Street of The Alfred (Melbourne VIC) to present the Carl De Gruchy Oration, in recognition of her contribution to haematology over the years. Alison chose haemophilia as the subject of her oration and her abstract is re-printed below.

Dr John Rowell of the Royal Brisbane and Women's (Brisbane QLD) was invited by the ANZSBT to present the Ruth Sanger Oration for his contribution to blood transfusion medicine. Dr Rowell spoke about the development of external quality assurance programs since the 1960's and how they are used to continually assess and improve laboratory performance.

AHCDO 20th Anniversary

This year has seen AHCDO celebrate its 20th anniversary. First formed as the Medical Advisory Panel of Haemophilia Foundation Australia, AHCDO has developed over the years, and became an incorporated association in 2001. AHCDO operates independently out of HFA's corporate offices.

To mark this special occasion AHCDO held a dinner at the historic Como House, Melbourne. Current and past members of AHCDO (including members of MAP and HFA representatives) and industry colleagues were invited to attend and reminisce with Prof Henry Ekert as he spoke of his first introduction to haematology, his growing interest in haemophilia, his encounters with other colleagues who have, over the years, continued to address the clinical and social needs of people with bleeding disorders.

The AHCDO 20th Anniversary celebration was preceded by the Annual General Meeting and education meeting of AHCDO. 

Haemophilia, History and Hope

People with haemophilia, alive today, reflect a remarkable history of the medical and social revolutions of our times. They form a resilient community who, in the last fifty years, have experienced dependence on astute clinical observation and demanding early coagulation testing, for diagnosis of their condition and limited supplies of coagulation factor concentrate which provided the yin-yang of improved length and quality of life with attendant transmission of viral infection to carry as subsequent medical and psychosocial burdens.

Since the sequencing of the FIX gene in 1981 and FVIII gene in 1984, the genetic revolution has delivered plentiful and safe product. Patients with

haemophilia in Australia are now well-supported by government funding to receive treatment. Their biggest risk is development of inhibitors, secondary to product infusion. In our geographic region, however, 75% of patients are without diagnosis and/or sufficient product for care. The World Federation of Haemophilia, an international organisation with national member organisations in 113 countries, is committed to delivering hope and 'treatment for all' even beyond developed countries. Many volunteers are participants in programs supporting these activities.

(Kindly reproduced with permission from A Street (HSANZ))

HIGHLIGHTS OF THE AUSTRALASIAN SOCIETY OF HIV MEDICINE (ASHM) CONFERENCE

David Bell

On 17-20 September 2008 I attended the 20th Australasian Society of HIV Medicine (ASHM) conference on behalf of HFWA. The conference was held at the Perth Convention Centre. I was very surprised at the size of the conference, which over the few days had hundreds of people attending from the medical field internationally, nationally and locally and also from the community living with HIV.

The conference was well supported by the local medical field. As it was held in Perth, Perth's own treating immunologists were there, along with nurses from gastroenterology departments and a few familiar faces in the network agencies I have seen over the years through the hospitals or my involvement with HFWA.

There was a huge trade and poster display in the exhibition room with stands and posters belonging to drug companies, network agencies, clinical research departments or individual researchers which seemed to get a lot of attention throughout the conference. HFA also took advantage of the opportunity to raise awareness about how HIV and Hep C has impacted on the haemophilia community and had sent over some copies of the Double Whammy summary and other relevant resources to be placed on the information table for anyone interested in knowing more.

The presentations were very clinical, and I admit I struggled to focus and understand the abbreviations and text the presenters were using, especially with the urgency they felt

they needed to cover and finish their topic, which felt to me like light speed!

As with all conferences you hear an even balance of negative and positive things and this one was the same. One important point I understood from it was that as most people with HIV are on Highly Active Antiretroviral Treatment (HAART), and as a result are living longer, the doctors are seeing complications with ageing with HIV, the complexity of the virus and many other facets of HIV. This is something you wouldn't have seen a few decades ago as expected lifespan was not good.

But I felt the view shared by the doctors was that many people with HIV can expect to live a relatively long life with good medical management and monitoring of the virus and by looking after their general health. Research is ongoing, new HIV drug trials are being developed and some are trialling different ways to suppress the virus. Ultimately if they are shown to be safe and to work well, the new drugs may be registered for use in managing HIV.

I felt I came away from the conference with a more positive outlook about HIV. Sometimes it doesn't seem right when you remember back to the 1980s and the impact HIV had and still does have on the bleeding disorders community, both medically and in the stigma and discrimination people have experienced. However, it just shows how much progress has been made in understanding this virus since then. We can look forward to learning more about it in the future.

CONFERENCE HIGHLIGHTS

Treatment

> **Clinical trials:** reports on new types of HIV drugs were good news for people who have already had HIV treatment.

CCR5 antagonists: maraviroc has had good results. Vicriviroc is being evaluated.

Integrase inhibitors: raltegravir has performed well. Elvitegravir is under investigation.

Other new types of HIV drugs are also in development: CD4 attachment inhibitors and maturation inhibitors.

> **At the test tube stage:** a new type of therapeutic vaccine to control HIV in people who are already HIV positive. This looks promising for people with a low HIV viral load. People would possibly have the vaccine along with their other HIV therapy.

> **Treataware:** this project highlighted how important it is for people with HIV to work in partnership with their health care team to make clear, comprehensive and up-to-date plans for living well with HIV. Treataware is a national HIV treatment information service available via phone (1800 817 713) or internet (www.treataware.info)

Australian long-term non-progressors update

> This remarkable group did not have HIV symptoms for at least 8 years after diagnosis and many have had HIV for more than 20 years now. Of the 111 people who have participated in the study, 30 are no longer in contact, 3 died, 9 developed AIDS, 35 started HIV treatment and 34 remain untreated and mostly have normal CD4 and t-cell counts, showing their immune system is still controlling HIV well.

HIV and healthy ageing

> Now that people with HIV are living longer, doctors are considering medical guidelines to prevent conditions associated with ageing, such as heart disease, diabetes, lipodystrophy, osteoporosis, mental decline and cancers. The guidelines would cover questions such as when to start treatment, which HIV drugs to prescribe to decrease the risk of diabetes and heart disease, and lifestyle factors that contribute to health risks, such as smoking.

> Some studies show that older HIV positive people have better wellbeing, if not better health, than other people of the same age in the general community. **H**

ARE YOU ELIGIBLE FOR CENTRELINK PAYMENTS?

Carer Allowance

As the carer of a child or adult with a disability, you may be eligible for Carer Allowance.

Caring for an adult – 16 years or older – you may get Carer Allowance if you personally provide full-time care on a daily basis for up to two adults who need a lot of additional care because of a disability and/or severe medical condition. A number of carers of adult members of state/territory Haemophilia Foundations who have HIV or severe haemophilia complications, eg very severe arthritis, have been successful in obtaining Carer Allowance.

To be eligible for Carer Allowance you must provide daily care for the person you are caring for, but there is no longer a requirement to live in the same home with them.

Carer Allowance is not income or assets tested and it is not taxable.

A Claim for Carer Allowance needs to be completed together with a Health Professional Assessment (adults) or Treating Doctor Report (children).



Mobility Allowance

You may be eligible for a mobility allowance if you are a person aged 16 or over who cannot use public transport without substantial assistance and where you are required to travel to and from your home in order to undertake any combination of paid, voluntary work or vocational training for 32 hours every four weeks. Under particular circumstances a person undertaking job search activities, a person receiving Newstart Allowance, Youth Allowance or Austudy payments may also be eligible.

Mobility Allowance is not income or assets tested.

Sickness Allowance

You may be eligible for Sickness Allowance if you are aged 21 or over but under Age Pension age and you are temporarily incapacitated for work or full time study. You must have a job or full time study to return to. You must provide a medical certificate from a qualified medical practitioner.

Sickness Allowance is income and assets tested.

For further information call 13 1021 or check the web site:
www.centrelink.gov.au



15TH AUSTRALIAN & NEW ZEALAND HAEMOPHILIA CONFERENCE

The 15th Australian & New Zealand Haemophilia Conference will be held at The Sebel, King George Square Brisbane from 8-11 October 2009.

Our biennial conference offers people with bleeding disorders and their families, as well as health professionals and policy makers an opportunity to come together to learn more about treatment and care, and future directions for the bleeding disorders community in Australia and New Zealand.

The Conference Program Committee has representatives from all clinical disciplines and community representatives from both Australia and New Zealand, and is chaired by Dr James Daly of Royal Hobart Hospital in Tasmania.

The program will be diverse with sessions of interest to everyone. There will be presentations on the treatment and care of children and adults with bleeding disorders, treatment and management of inhibitors, specific issues such as ageing, youth, women's health, hepatitis C and HIV, international treatment and care, access and funding for healthcare services and treatment, treatment product supply and safety, as well as models for

psychosocial support and wellness for people affected by bleeding disorders of all ages.

Who Should Attend?

- > People with haemophilia, von Willebrand disorder or other bleeding disorders and their families - parents, siblings, partners
- > Youth – topics relevant to youth will be integrated throughout the program
- > Health professionals – doctors, nurses, physiotherapists, counsellors and other health care providers
- > Treatment product producers, suppliers and service providers
- > Policy makers and government officials
- > Haemophilia Foundation volunteers and staff

Sponsorship


Sponsorship packages will soon be available. Contact HFA for details if your organisation wishes to participate in this exciting education event.

Exhibition Area

An excellent space will be available throughout the Conference for exhibitors to showcase new developments, ideas and successes.

Registration Of Interest

To register your interest and receive regular updates about abstracts, poster opportunities and special events at the conference email your contact details to hfaust@haemophilia.org.au or call 1800 807 173.

The web site will be regularly updated with information about the conference. Registration forms will be available in early 2009 and full program details will be published in mid 2009. 

DENTAL CARE

Suzanne O'Callaghan



We often overlook caring for our mouth, teeth and gums when we think about looking after our health, but regular dental care is an important part of maintaining health. The condition of our mouth, teeth and gums can have a big impact on our wellbeing, including our comfort, diet, self-esteem and heart and lung health.

The World Federation of Hemophilia recommends that people with bleeding disorders aim to prevent dental problems so that they can keep good health and reduce the need for dental procedures. People with bleeding disorders are usually advised to have 6-monthly dental check-ups, but talk to your Haemophilia Centre and your dentist about making a plan for regular dental care.

How else do you prevent dental problems? The Australian Dental Association has these tips for adults:

1. Today's dentistry tries to avoid dental fillings by preventing dental disease before it goes too far. It is important to ask your dentist how often you need a check-up to avoid costly and more complex treatment.

2. To prevent gum disease, which can often lead to loss of teeth, it is important to use a small, soft toothbrush (and a non-harmful technique of brushing), together with daily use of dental floss.

3. Brush your teeth at least twice a day (after meals) and use a fluoride toothpaste. This fights the decay process and helps the enamel to resist acid attack.

4. It is not too late for you to have orthodontic treatment to straighten your teeth and correct the way they bite together. Ask your dentist's opinion whether any treatment is necessary and/or what can be achieved.

5. Watch your diet and limit your intake of sweet food and drinks to mealtimes only, when you can follow up with toothbrushing to remove plaque and prevent acid attack.

Sometimes lifestyle factors and other health conditions can result in problems with teeth and gums. Gum disease can be accelerated by smoking, immune depression and diabetes. Dry mouth and gum disease can also be caused by HIV and hepatitis C and can lead to mouth infection and loss of teeth. Seeking advice from a dentist and dietitian with experience in the particular health condition can help with strategies to keep mouth, teeth and gums in good health.

There is no legal requirement to disclose HIV or hepatitis C status to a health care provider such as a dentist and all dentists should be using standard infection control procedures for all their patients. However, if you have HIV or hepatitis C, it can cause specific oral problems and disclosing to a dentist you trust or who has particular expertise in the area can improve your health care.

You may find it helpful to talk about disclosing to a dentist with other people in the same situation or your Haemophilia Social Worker/Counsellor.

Poor oral health can also cause mouth and gum bleeding. For people with bleeding disorders, most mouth bleeds can be managed by tranexamic acid and this is often the recommended treatment. Treating mouth bleeds with factor is costly and often not as effective. Your Haemophilia treatment team will be able to advise you on the best way to treat your mouth and gum bleeds.

If you have a bleeding disorder, there may need to be extra care with some dental procedures, especially

- > oral surgery
- > tooth extractions
- > some injections
- > other procedures that could cut the gums or the mouth.

This could involve factor replacement, tranexamic acid mouthwashes and/or tablets and taking extra care with procedures to prevent accidental damage to the mouth.


It is important to get advice from a haemophilia specialist and see a dentist who has an interest in working with people with bleeding disorders. Make sure you tell your



global feast in support of people worldwide with bleeding disorders

dentist that you have a bleeding disorder – this is very important for your safety. Factor replacement if required should be monitored by your Haemophilia Centre.

To know more, talk to your Haemophilia Centre. Consult your haemophilia specialist or haemophilia nurse about your dental health needs so that you can take your own specific health issues into account. Some haemophilia centres are also able to refer their patients to specialist dental services. Others recommend that you have a general dental practitioner who can liaise with your haemophilia treatment team about special precautions when you have dental treatment.

The Australian Dental Association web site also has a lot of useful information: www.ada.org.au . 

Further reading

Brewer, A, Correa, ME. Guidelines for dental treatment of patients with inherited bleeding disorders. Treatment of Hemophilia, No 40. World Federation of Hemophilia, Montreal, 2006.

Scully, C, et al. Oral care for people with hemophilia or a hereditary bleeding tendency. Treatment of Hemophilia, No 27. World Federation of Hemophilia, Montreal, 2002.

Australian Dental Association web site, November 2008. Dental health information. www.ada.org.au/OralHealth/dentInfo.aspx

Global Feast

Australians participated again in Global Feast in September 2008. Global Feast is run by World Federation of Hemophilia (WFH) with several of its member organisations, including HFA. Thank you to the following people and organisations for hosting Global Feast events:

- > The Bates family in Victoria hosted a dinner and raised \$300



- > Haemophilia Foundation Queensland hosted a Global Feast get together after the AGM on Sunday 14 September and raised \$250



- > HFA staff members organised functions with family and friends raising \$300
- > CSL Bioplasma hosted a "lunch n learn" session for staff with a presentation from a person who lives with von Willebrand disorder. Staff donations were matched by CSL and together they raised \$242
- > HFNSW raised \$77 at the November 2008 Family Camp.

Would you like to participate in 2009 Global Feast?

A decision has been made by the HFA Council that it will create opportunities for people to hold a Global Feast event at any time throughout 2009.

Without treatment, 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 make a difference by working with WFH.

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

Remember, Global Feast benefits people with bleeding disorders around the world who need our help. All monies are donated directly to WFH. WFH uses the funds to provide safe and effective blood 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 and promotional items, contact Natasha at HFA on 1800 807 173 or ncoco@haemophilia.org.au 

Haemophilia ~ Factors that matter was the successful theme adopted to raise community awareness about haemophilia and other bleeding disorders in October.

HFA and Haemophilia Foundations around the country worked together to develop a campaign to raise awareness about inherited bleeding disorders to the general community, community organisations, governments and service providers. Thank you to organisations and the many individuals who helped promote the week with information stands and fundraisers in many different venues around Australia.

The week attracted 26 radio interviews, 5 Community Service Announcements & 20 print articles. Positive feedback and interest was expressed by people in the community who did not previously know very much about bleeding disorders. H

A collage of three photographs. The top left photo shows a man with glasses and a mustache. The top right photo shows a baby in a striped shirt. The bottom photo shows a small dog, possibly a Chihuahua, looking up. The photos are slightly tilted and have a soft, artistic feel.

A collage of three photographs. The top left photo shows a man with glasses and a mustache. The top right photo shows a baby in a striped shirt. The bottom photo shows a small dog, possibly a Chihuahua, looking up. The photos are slightly tilted and have a soft, artistic feel.

Just one in 5000

A blood-clotting ailment affects one in 5,000 males. With no family history of the disease, Sam's case was one of those few that must be diagnosed by chance.

Mrs. Dennis says that after finally locating the word, she said her son was stronger than she thought.

"I thought, 'Oh my god, I've got a million-worth tube,'" Mr. Dennis said.

But Sam will never do swimming, goes on play day every thing a boy should do.

With a bit of help from Westland Hospital, most of the disease is regular part of the daily routine.

"We just put the Wizard on TV and the results takes three minutes," Mrs. Dennis said.

Currently Samuel has a part in his class to get the first clotting-factor injections.

When his clotting-level improves, the family will start less frequent vein injections in "normal" will continue in his life.

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Mrs. Morris says that after finally locating the word, she said her son was stronger than she thought.

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But Sam will never do swimming, goes on play day every thing a boy should do.

With a bit of help from Westmead Hospital, no part of the disease is a regular part of the boy's daily routine.

"We just put the Wizard on IV and the needle takes three minutes," Mrs. Manning said.

Currently Samuel has a part in his class to get the daily clotting-factor injections.

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Georgia (6)

Vein of hope

for sufferers



HEALTH PROFESSIONALS' MEETINGS

Sharon Caris

An important part of HFA funding agreements with the Federal Department of Health and Ageing is the component which enables us to auspice and support health professionals groups of nurses, physiotherapists and counsellors who work with the bleeding disorders community at haemophilia treatment centres around the country. Although HFA funds the groups to operate, each group sets its own agenda and priorities.

Australian Haemophilia Nurses' Group, the Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group and the Australian and New Zealand Physiotherapy Haemophilia Group each work to foster excellence in their disciplines. Some of their activities include the development of terms of reference, guidelines for treatment and care, and materials used for the education and support of patients and their families. Increasingly, governments consult with each of the groups to inform policy and decision making.

HFA also works with the Australian Haemophilia Centre Director's Organisation (AHCDO) and other organisations to improve and strengthen care and treatment and other services needed by people with bleeding disorders throughout Australia.

Some of their activities include the development of terms of reference, guidelines for treatment and care, and materials used for the education and support of patients and their families.

HFA values the contribution of the nominees of each group to the Haemophilia Foundation Research Fund Committee, HFA Conference Program Committee and the HFA Hepatitis C Advisory Committee and for their informal advice and expertise frequently provided to HFA, especially when new resources are being developed or when HFA needs information about specific health issues.


For several years, HFA has been able to use some of its fundraising income to support a nurse, counsellor and physiotherapist as well as patient representatives to attend WFH Congresses to increase skills, knowledge and networking opportunities.

The Australian Haemophilia Nurses' Group annual meeting was held 30-31 October in Sydney. The meeting was attended by nurses from haemophilia treatment centres around Australia. Maria Baccala (Royal Perth Hospital WA) and Janine Furmedge (Royal Children's Hospital VIC) were elected as Co Chairs of the group.

The Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group annual meeting was held 11-12 September in Melbourne. Co-Chairs for the group are Leonie Mudge (Royal Prince

Alfred, Sydney NSW) and Kelly Brady (Queensland Haemophilia Centre, Royal Children's Hospital, Brisbane QLD).

The Australian and New Zealand Physiotherapy Haemophilia Group annual meeting was held 15 August in Melbourne. Current Co-Chairs for the group are Brendan Egan (Royal Children's Hospital, Melbourne, Vic) and Debbie Kermode (Women's and Children's Hospital, Adelaide, SA).

In 2009 each of the health professionals annual meetings will be held on Thursday 8 October in Brisbane before the 15th Australian and New Zealand Haemophilia Conference. 

THE BENEFITS OF PHYSIOTHERAPY

Wendy Poulsen

Physiotherapy is an important component in the care of people with haemophilia, especially in the prevention of long term joint and muscle damage.

The techniques used by a physiotherapist include splintage, plastering and, compression. Ice and electrotherapeutic devices can also be used to ensure early resolution of a bleed. Specific exercise programs are used to strengthen, and improve range of movement after a bleed.

Exercises, including hydrotherapy help to:

- > Relieve pain and protect a bleeding joint or muscle
- > Restore muscle power and joint movement
- > Prevent further injury to a susceptible joint
- > Promote involvement in fitness and sporting activities

In other words we aim to keep the joints and muscles supple and strong.

For those with moderate to severe haemophilia, who have recurrent or frequent bleeds particularly into one or a few joints – this is paramount!!

With prompt, effective and comprehensive care during and after a bleeding episode, people with haemophilia should be able to lead a normal life with minimal restrictions.

Remember that replacement therapy is not the only solution to resolving a bleed.

When should you see a physiotherapist?

- > Regular clinic reviews – you should see your therapist for musculo-skeletal assessment
- > After an acute bleed – once replacement therapy has been given
- > If the bleed is severe, painful, and/or disabling and is not responding quickly to factor replacement
- > If full range of movement (ROM) has not been restored to a joint or muscle

Anytime that you need advice on looking after your joints and muscles, exercise, general fitness or sports participation, or just if your joints feel a little stiffer than normal, or your muscles feel a little weaker – you should give us a ring!!

How can a physiotherapist help?

- > Advice on involvement and preparation for specific sports
- > Prevent and/or assist recovery from sports injuries
- > Advice on modifying recreational and sporting activities to help maintain a health lifestyle

What is so special about fitness?

Being strong and active makes children self confident and prevents the secondary disability caused by the feeling of being different.

Exercising regularly increases the circulating clotting, enhances relaxation, better sleep patterns, and generally contributes greatly to a sense of well-being. Therefore, there are both physiological and psychological benefits to exercise.

Regular exercise maintains muscle power, and therefore abnormal stresses on joints are reduced and therefore bleeding episodes may be made less frequent. Regular exercise will help improve general physical fitness and well being which is often reduced in people with haemophilia.

Today, regular physical exercise is gaining acceptance as a prescription for the prevention, management and rehabilitation of diseases. **H**



HFA HEPATITIS C NEEDS ASSESSMENT – EVALUATION AND IMPLEMENTATION

Suzanne O'Callaghan

In October 2007 HFA released its national Hepatitis C Needs Assessment Report – “A Double Whammy”: living with a bleeding disorder and hepatitis C. HFA then began the evaluation and implementation stage of the needs assessment. This involved focus groups in two states and consultation with state/territory Haemophilia Foundations, health professionals and community agencies to:

- > Check that needs in the two states were consistent with the Report and see if there were other needs
- > Ask for feedback on HFA's hepatitis C work
- > Start implementing the Report's recommendations.

Results

Most of the findings from the consultation were consistent with the Double Whammy Report. What information was different, new or extra?

Health and treatment

- > More discussion about the effect of having hepatitis C as well as a bleeding disorder and other health conditions. Health problems become more complex and impact on each other as people grow older. Some people have overload with health conditions and health services. Fatigue and mobility problems make it difficult for them to manage all of their health conditions. They deal with the most pressing issues and let others slip, sometimes with serious consequences for their health.

- > What would help? A more holistic approach to their care, having appointments co-ordinated, eg a multidisciplinary clinic. Help to keep track of multiple health problems, to deal with the health system and negotiate social services.
- > There has been a greater focus on hepatitis C care and liver health review in Haemophilia Centres over last 12 months. Still concerned about the liver health of people with hepatitis C who no longer keep contact with the Centres, mainly people with moderate or mild haemophilia or von Willebrand disorder.
- > Haemophilia Social Workers/Counsellors are vital in providing networking and communication between hepatitis clinics and Haemophilia Centres.
- > What helps with hepatitis C monitoring and treatment? Hearing other people's experiences, reminders from the Haemophilia Centre to review your liver health, support from family/friends and social workers/counsellors, a good relationship with your specialist.

If you ask about the perfect consultation, I think these haemophiliacs, they're like sports cars. They need to come into the pitt lane. We get the arthritis, we get the hep C, we get the HIV, and those when they combine, create a mental health issue. And also there's counselling you need if you are in work. You are going to need some support to stay there. You need someone to help you get out of bed in the morning sometimes. You need rails in your bathroom. Other times you need other things.

There's far, far more being done about hepatitis C than I've ever really seen before. And I have seen quite a bit over the last few years.

Living with hepatitis C

- > There needs to be more work on how to deal with unsuccessful treatment or not being able to have treatment.
- > Finances: need a financial advisor to help make ends meet and flexible working arrangements to manage erratic health problems and appointments.
- > Support: men rarely ask for support directly. Many single men find it difficult to start new relationships. Carers also need support but sometimes do not know where to go for help. Would like a comfortable and facilitated environment to talk about clinical issues with other people.
- > Young people need education on hepatitis C, relationships, disclosure, finances, diet and exercise

I just think as a teenager it's difficult because you know you're different but you don't want to be different. And you're at a stage when you want to form relationships with the opposite sex or whatever and it's a difficult situation to be in. Do you say something, don't you say something? And that's been very hard for my son. [parent]

When you actually speak to someone who's gone through it – I've compared notes with people who've been on it – you get a clearer picture of what it is, you can relate better to them, than the way it was explained to you by the doctors.

Feedback on HFA hepatitis C publications

- > HFA hepatitis C information booklet: useful, concise, relevant. Some had not seen it before the focus groups. Add information on doctor-patient relationship.
- > 'Double Whammy' Report: nearly everyone had received a copy. Too big for some, others found depth useful. Personal stories powerful; felt connected, encouraged to take action on health. Good to see HFA taking action on hepatitis C and providing evidence for government and health services. Break report down into shorter "bites" on topics and republish. Re-release summary as many missed it – was placed in front cover of report. Most had similar experiences; some had more positive experiences. Recommendations appropriate.
- > Hepatitis C updates: good format and information. Liked personal stories; need more positive stories about treatment. Need to promote.

[The Report] was an eye-opener for me. I appreciated actually seeing some of the harsh things that were in it. It made me aware that hey, I've had a similar experience.

We should hear more of these positive things that people actually do to get over the side-effects.

What has HFA done about hepatitis C?

- > Distributed 'Double Whammy' Report widely
- > HFA Council Hepatitis C Working Party developed strategic response to recommendations
- > Successful submission to government to subsidise retreatment for hepatitis C
- > Continuing work with health professionals to follow up key findings of report
- > Produced hepatitis C updates on priority issues (treatment and test results). Newsletter articles on topics from 'Double Whammy' Report with personal stories
- > Sought funding for other resources and wellbeing workshop
- > Sought expert advice on insurance and superannuation issues. Guide circulated.
- > Made presentations to health professionals to raise awareness about hepatitis C issues for people with bleeding disorders
- > HFA recommended financial recompense to the Senate Inquiry into Hepatitis C and the Blood Supply in 2004. Although the Senate Inquiry made recommendations about financial issues, governments have not acted on them. HFA Board is currently addressing the financial support needs of members.

More information and support

Some sources of high quality information on hepatitis C:

- > Hepatitis C section of the HFA web site – www.haemophilia.org.au
- > Hepatitis Councils - contact details at www.hepatitisaustralia.com
- > If you have any questions about services or support, contact your Haemophilia Centre, state/territory Haemophilia Foundation or HFA.


Many thanks to the people who took part in focus groups and the state/territory Haemophilia Foundations, health professionals and community agencies who were involved in the consultation. H

HEPATITIS C RETREATMENT NEWS

Suzanne O'Callaghan

Earlier this year, HFA advocated to the Pharmaceutical Benefits Advisory Committee of the Australian government for access to subsidised retreatment for those people who have previously had unsuccessful hepatitis C treatment. Some people with bleeding disorders have been able to receive subsidised retreatment through other schemes or clinical trials, but others have been excluded. It is pleasing that from 1 December 2008, pegylated interferon alfa-2b/ribavirin will be reimbursed on the Pharmaceutical Benefits Scheme (PBS) for retreating hepatitis C in people who have had unsuccessful treatment.

At this stage, one treatment course has been registered in Australia and listed on the PBS for retreatment. This is a 48-week standard course of PEGATRON (pegylated interferon alfa-2b/ribavirin), based on the results of a very large international study.

If you are considering retreatment, it is important to consult your hepatitis specialist to discuss whether a course of retreatment might be suitable for you, what options there are and the likelihood of it being successful, based on your current health and previous experience with treatment. 



HIV futures six
Making positive lives count

The HIV Futures survey is about all aspects of living with HIV. Make sure your experience counts. Complete the online survey or ask your local HIV/AIDS organisation for a hardcopy.

www.hivfutures.org.au

Australian Research Centre in Sex, Health and Society, La Trobe University

HIV FUTURES 6:

Making Positive Lives Count

HIV Futures 6 is the sixth national survey of Australians living with HIV/AIDS.

The survey is out now and will be available until January 15 2009.

It can be filled out and submitted online by going to www.hivfutures.org.au.

Paper copies are available from Haemophilia Social Workers/Counsellors or by calling 1800 064 398 or emailing hivfutures@latrobe.edu.au. There is an envelope attached to the survey booklet so that you can return the survey anonymously and free of charge.

The survey is about all aspects of living with HIV. It is a valuable source of information on the needs of people who are HIV positive for community organisations, like HFA, hospitals and other service providers, doctors and government.

The HIV Futures surveys have been conducted every 2 years since 1997 by the Australian Research Centre in Sex, Health and Society, La Trobe University. About 1000 people living with HIV/AIDS respond each time, including people with bleeding disorders. 

NATIONAL HAEMOPHILIA FOUNDATION RAFFLE

The raffle was drawn, Friday 24 October 2008 at 1624 High St Glen Iris VIC at 4pm (EST). All winners have been notified and the prizes have been delivered.

Results

1st Prize – Overnight accommodation for two people in a Travelodge Hotel of choice (Sydney, Melbourne, Perth, Brisbane, Darwin, Rockhampton and Newcastle) valued at \$250 plus \$100 Shopping Centre Voucher (RRP \$350)

Package kindly donated by Travelodge Hotels

WINNER: C.Foran No: 2778

2nd Prize – Signed Andrew Gaze frame from Sydney Olympics 2000 (54/500) (RRP \$295)

WINNER: M.Sullivan No: 1671

3rd Prize - Natio Hamper valued at \$100 and \$50 i-subscribe voucher (RRP \$150)

Hamper pack kindly donated by Natio and voucher kindly donated by i-subscribe

WINNER: F.Crook No: 0209

4th Prize – 2 dozen Topma Golf balls (RRP \$72)

WINNER: A.Foran No: 2780



THE VISION AND LEADERSHIP AWARDS

What would make a difference in your life? What have you wanted to do, if only you had some help to get started?

The Haemophilia Foundation Australia Vision and Leadership Awards enable men and women affected by haemophilia and related bleeding disorders to achieve new goals and explore new opportunities!

It's an opportunity to undertake education or do a project or program to improve your personal skills or career options, or to learn new skills to lead or participate in the bleeding disorders community. It might be a conference or study tour, a vocational course, a computer course, or a leadership project. The possibilities are endless and this is just the chance for you to act on the goal that inspires you and make your vision a reality.

Up to 5 Awards of \$2,000 each are available to:

- o Young men and women aged 15-25 who have a bleeding disorder or who are affected by a bleeding disorder
- o Adults aged 26 years and over (men or women) with a bleeding disorder or who are affected by a bleeding disorder

Application forms will be available from 16 January 2009 from the HFA office or HFA website. Call 1800 807 173 or visit www.haemophilia.org.au

The Vision and Leadership Awards are supported by a grant from Wyeth Australia. 

THAI - AUSTRALIA TWINNING

Sharon Caris



The twinning partnership between Haemophilia Foundation Australia (HFA), the Thai Patient's Club (TPC) and National Hemophilia Foundation of Thailand (NHFT) was further strengthened by a visit to Australia by two representatives of the Thai Patient's Club 13-21 September.

The twinning between the Thais and Australians is supported by grants from the World Federation of Hemophilia (WFH). In April 2007, Australian representatives joined with Thai volunteers to run a training workshop for 40-50 patients and/or their relatives in Bangkok which focused on developing networking and outreach skills.

Mr Nawin Pajakgo and Mr Narong Yamnual came to Australia in September for a series of meetings and activities with representatives of the Australian bleeding disorders community. Unfortunately, the plan for three additional TPC representatives to join the Thai delegation had to be cancelled due to visa and other administrative difficulties.

Mr Pajakgo and Mr Yamnual are both fathers of boys with haemophilia and have taken on leadership roles with the patient organisation in Thailand.

Mr Pajakgo lives in the north east of Thailand with his family. He actively works to find families with children affected by bleeding disorders and refers them for care and treatment. Many of these people live in isolated areas and have not had access to treatment or involvement with other families affected by bleeding disorders. They are encouraged to become involved in the support and networking activities undertaken by TPC.

Mr Yamnual lives just outside Bangkok with his family and works in Bangkok. He is involved with a network of volunteers who work with TPC in Bangkok and around the country.

The main purpose of the recent visit was for the TPC representatives to learn more about patient organisation activities in Australia, to share ideas and learn from each other.

Our Thai guests were met at the Brisbane airport by Haemophilia Foundation Queensland (HFQ) representatives and stayed with members of the bleeding disorders community. They attended the HFQ Annual General Meeting where they met could meet families, ask questions and learn about haemophilia treatment for children in Australia. They participated in a Global Feast function and made an excellent presentation about care and treatment in Thailand, and the activities of Thai Patient's Club.

The visitors moved on to Melbourne where Mr Pajakgo and Mr Yamnual visited HFA to discuss the role of the national patient organisation and talk with staff about their roles, and how HFA participates with government and other stakeholders in the development of services and care for people with bleeding disorders. The Melbourne visit also included a meeting with Dr Chris Barnes, Director and the comprehensive care team at the Royal Children's Hospital and was followed with a tour of patient treatment areas and the emergency department of the hospital.

A highlight of the visit to HFA was a presentation by our visitors about services, treatment and care in Thailand at a Global Feast lunch attended by Ann Roberts (Haemophilia Foundation Victoria President and HFA Board member) and HFV staff, and staff from the Royal Children's Hospital.

TPC volunteers are actively involved in camps and workshops in Thailand and an update about several camps and workshops held for families affected by bleeding disorders provided a great insight to the Australians. The active outreach work

in rural and regional areas of Thailand has increased patient numbers on the patient registry and an ever increasing network of volunteers is developing in key parts of the country.

The visit continued on to South Australia from Melbourne and included visits to the haemophilia treatment centre at the Royal Adelaide Hospital and attendance at the Haemophilia Foundation South Australia Family Camp and National Youth Leadership Weekend held south of Adelaide at Wirrina Cove.

The South Australian families and the youth who were in attendance from all around Australia enjoyed the opportunity to talk with Mr Pajakgo and Mr Yamnual about haemophilia care and treatment in Thailand, the role of volunteers and to share their experiences and socialise and learn from each other about their personal experiences in an informal environment. The Australians were able to understand and appreciate first hand the differences about treatment access between Thailand and Australia, and shared a resolve to improve treatment and care access to more people around the world.

The visit was a great success in all respects and a wonderful learning experience for those who met Mr Pajakgo and Mr Yamnual. Their feedback since returning to Thailand is that they were able to take back ideas which can be put into effect in Thailand. HFA, the Thai Patient's Club and the National Haemophilia Foundation of Thailand are currently making plans for further work together as part of the valuable twinning partnership.

For more information about WFH Twinning visit the WFH web site at www.wfh.org

TRAVEL TIPS

Megan Walsh

Travel for business or pleasure has become a part of our lives. For people with bleeding disorders improvement in treatment products have made things easier, especially with the newer, smaller, and more concentrated dose vials.

Here are a few tips to help make your travel a success.

Interstate Travel

It is a good idea if you intend to travel interstate to let your haemophilia centre know. It may be helpful to advise the centre in the state where you will be travelling, just in case you run into problems. Your treatment centre staff can assist with this.

Take your treatment product with you. Product is distributed differently in different states. Most haemophilia centres would require you to present to the centre for any product to be issued to you, even if you wanted to top up your prophylaxis stock.

Always carry your emergency treatment card issued by your centre which states what type of bleeding disorder you have and which product you are treated with.

As some of the smaller haemophilia centres have different hours of operation, it is a good idea to check in advance with the centre in the state where you are travelling so you know when health professionals are available and how to access treatment, if you need assistance. For example, you should check whether you would need to go directly to the haemophilia centre, or to a day treatment area or the emergency department of the hospital.

Carry sufficient amounts of your treatment product with you for your stay. Remember that some haemophilia centres may not stock the full range of products, or carry the full range of vial sizes.

Ask your centre to provide a letter stating you will be carrying needles and syringes with your treatment

and that you must carry your product on board the plane in the cabin section as your product is temperature sensitive. If your luggage is lost the product will not be replaced. It is also recommended that you carry a medical treatment letter stating the product you are treated with and recommended doses for emergencies, especially if you are traveling in more remote places.

Carry your product in a cooler bag. Even though the newer products can be stored at room temperature, once they are taken out of 2-8° C their expiry dates drop to between 3-6 months depending on which product you use. Always ensure you use the remaining product first when you return home.

Overseas Travel

Planning is critical! Make sure you give your treatment centre plenty of notice, especially if you are planning to be away for a long time. There is quite a bit of work to be done to organise this part of your trip.

Telephone the consulate of the country where you will be travelling to and check if they have any special requirements, for carrying product/equipment and medication through their border control. Permits are required to take prescription pain killers into some countries, such as Thailand. Some countries require specific documentation to carry your treatment product into that country. Remember this may also include stopovers.

If you require regular on demand treatment it is recommended that you take treatment product with you on your trip. You should at least have enough with you to give yourself 12-24 hours' cover to get to a country where you can access adequate medical treatment. If you are on prophylaxis, you should take all of your required treatment with you or for longer trips or organize for more to be delivered to you overseas.

It is important to note that your treatment product may not be

available in the country in which you are travelling. There may be a range of different plasma derived and recombinant factor products available.

If you have infrequent bleeds, talk to your treatment centre staff about whether to take product with you. Unused treatment products cannot be returned.

For Travel Overseas For Up To Six Months

The National Blood Authority currently allows haemophilia centres to provide treatment product to patients for travel overseas for up to six months and requires that all of the issued product is carried by the patient in the cabin section of the plane. It should be carried in a cooler bag.

The National Blood Authority has indicated that product which is lost or damaged will not be replaced. Please make sure you do not carry product in checked luggage where it can be exposed to extremes of temperature or lost, stolen or broken.

Some airlines have a medical allowance to carry a larger quantity of medication on board the aircraft, so it is a good idea to ring around to check their requirements, especially if you will be carrying six months worth of product with you. Your treatment product must be carried in a cooler bag with small ice bricks. This is to keep the product under 25 degrees. As this will not maintain the product between 2-8 degrees the expiry date is shortened. Check with your airline about how to carry your ice packs (ice bricks may need to be under 100mls and remember that gel packs may not be allowed due to security requirements, you should check with your airline and DOTARS - see below). Be careful where the cooler bag is placed in overhead bins as the reading lights can warm the product significantly.

People who are traveling for 6 months or less who want to receive delivery of product at overseas destinations must make such

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arrangements with the National Blood Authority via their treatment centres.

For Delivery Of Product Overseas And/Or Traveling For Periods Longer Than 6 Months

People who are traveling for longer than 6 months who wish to either take product with them or have it delivered overseas are required to make such arrangements with the National Blood Authority via their treatment centres. The arrangements are complex, and may take time to put in place.

Special arrangements usually need to be made to import and export plasma derived clotting factors and different countries have different requirements and restrictions (see below). Some suppliers of treatment products in Australia have advised they can deliver product to patients to some selected overseas locations where the product is registered, and often can only deliver to an overseas haemophilia centre. You may incur some costs for delivery or import tax. You may only be able to receive the local registered product under this arrangement and although it will be the same product it may be labeled differently or it may have a slightly different reconstitution device, for example. You must give plenty of notice for this option and you will still need to carry some product with you on departure from Australia to cover you until your delivery arrives.

Travel Insurance

You must have travel/medical insurance and your cover should allow a medical evacuation in case of emergency. Some insurance companies will cover product cost. Be mindful some countries do not have access to any treatment products at all, and other countries will only be able to offer you products made from fresh blood products manufactured with varying quality and safety standards.

The Australian government has reciprocal healthcare arrangements with UK, Republic of Ireland, Malta, Italy, Norway, Sweden, Finland, the Netherlands and New Zealand. Australian travelers will be entitled to receive health care free of charge in these countries. Treatment is generally for emergencies only, but not for prophylaxis. See www.medicareaustralia.gov.au and

www.smartraveller.com.au for further information about access to health care in these countries especially if you have other medical and health requirements in addition to your bleeding disorder. A current Medicare card and Passport is required for treatment. It is essential to check the countries you are visiting carefully, as some countries also require a medical document which needs to be completed by your treating doctor prior to departure in order for you to access treatment.

The Australian Department of Transport and Regional Services (DOTARS) implemented new aviation security requirements for carry-on baggage at international airports in March 2007, including new rules for taking liquids, aerosols and gels (see web site www.dotars.gov.au) Medical products and devices are exempt, however you must carry appropriate documentation. It is essential that you carry letters describing your product, the active ingredients, its presentation and how many vials you are carrying. The letters must state that the product is for your personal use and that the vials must not be opened when they are being checked by security officials. The product must be carried in its original packaging and you should declare the product at security points and customs.

You are advised to consider having all your documentation letters translated if you are travelling to non English speaking countries.

If you are traveling on cruise ships or booking budget type accommodation you should check whether you will have a refrigerator in your room to store your product and make arrangements for a refrigerator to be provided in your room. This will be particularly critical if you are visiting tropical countries.

If you are travelling with plasma products produced in Australia (such as plasma derived factor VIII Biostate® or plasma derived factor IX MonoFix®) you will require an export permit to take the product out of the country. Your centre will help you to arrange this with the ARCBS and to ensure you have appropriate documents from the Therapeutic Goods Administration if required (see web site www.tga.gov.au).

Immunisations are necessary for some destinations and you should check well ahead of time with your doctor. Usually these need to be administered subcutaneously, however you should check with your haemophilia centre for their recommendations. If you have HIV, always check with your infectious diseases specialist as to what vaccinations are recommended and note there are some vaccinations you will need to be careful with.


If you do not usually make up your product, you should learn how to reconstitute it before you leave home! This can be helpful especially in places where the medical staff are unfamiliar with your treatment product.

If you are travelling to places with limited access to safe health care it is a good idea if a partner or your travelling companion learns to access your veins and give your treatment in case of emergency.

If you cannot access your own veins and you are on regular treatment you will have to contact overseas treatment centres to investigate whether you can access such treatment assistance and whether there will be costs for this. Be aware that your travel insurance may not cover this. For details of haemophilia treatment centres around the world see the WFH Passport at www.wfh.org, ask at your haemophilia centre or contact Haemophilia Foundation Australia on freecall 1800 807 173.

Be prepared, even if you have not had a bleed for years and remember you will probably be more active than you normally are when travelling, especially as you may be dragging heavy cases and lifting things onto an ever increasing number of airport screening belts! We have had patients who have been bumped by a taxi, grazed by an out of control motorbike, walked into a towball on safari or tripped and fallen under a rickshaw and seen shoulder/elbow bleeds from heavy cases. Accidents do happen and you should be well prepared.

Remember, if you return home with treatment product always use this product first.

And..... last of all, have a great holiday 

6TH AUSTRALASIAN VIRAL HEPATITIS CONFERENCE

Suzanne O'Callaghan

Brisbane is a lovely place to visit in October and I was lucky enough to attend the Australasian Viral Hepatitis Conference at the Brisbane Convention and Exhibition Centre during 20 – 22 October this year. The Conference venue was close to South Bank and the Brisbane River so walking to and from the conference gave me lots of opportunities to enjoy the morning sunshine, warm evenings, the tropical gardens at South Bank and all the interesting activities happening along the river.

The Conference was in two parts: a smaller meeting with participants in the Viral Hepatitis Conference on Monday and Tuesday and a very large combined meeting on Wednesday when we were joined by other gastroenterology teams taking part in the Australian Liver Association Workshop. The exhibition hall included the trade display and the research posters and was a great place to be enthused by new ideas and talk to the people who knew most about them. On the first two days it was small, cosy and focussed, and a lot of the stands belonged to hepatitis and research organisations, but on Wednesday the display was enormous – many more pharmaceutical companies put up stands. The medical education and professional organisations had a large stand and were very interested in HFA's work on hepatitis C.

HFA needs assessment

On Monday afternoon I gave a presentation about HFA's hepatitis C needs assessment, the feedback and HFA's response. This seemed to raise some interest as I noticed that most of the 100 copies of the Needs Assessment Report summary I put on the information table disappeared!

Education, information and support

I was very keen to hear Jacqui Richmond, a very active Victorian nurse educator and researcher, give the results of Hepatitis Australia's information, education and support needs assessment relating to people with hepatitis C. This involved a 7.30am start, very early by Melbourne standards, but well worth it. Findings were very interesting:

- > Information: more than half of people with hepatitis C preferred print information; others preferred information on the internet, by phone or in chat rooms.

They would like to see more research information on Australian web sites.

- > Support: most preferred face-to-face support, but some preferred phone or internet, particularly if they didn't want to disclose their identity. There was some debate about the value of having drop-in style support groups during hepatitis clinics, while people are waiting to see their specialist.

New treatments

In the combined meeting on Wednesday there was a lot of discussion about treatment for hepatitis C and the need for many more people to be treated. Public health researchers pointed out that it was cheaper for government in the long run to treat more people now so that they didn't have problems with liver disease later.

What about people who have genotype 1 or have not had successful treatment? Professor Henry Chan from the Chinese University of Hong Kong gave an informative overview of new treatments for these groups. In particular, he focussed on two new types of hepatitis C drugs, the

protease inhibitors telaprevir and boceprevir, which are currently being tested separately in international clinical trials.

- > Telaprevir (Tibotec) and boceprevir (Schering-Plough) are both used in combination with pegylated interferon and ribavirin.
- > Both so far have shown a substantial increase in the number of people with genotype 1 who have successful treatment compared to those who have standard pegylated interferon/ribavirin treatment.

These trials are also

- monitoring side effects, which include gastroenterological problems, rash and anaemia with telaprevir and anaemia with boceprevir
- testing different lengths of treatment and when to start the protease inhibitor part of the treatment.

Final results will not be available until the clinical trials are finished in 2010.

There were many other stimulating presentations on subjects such as mental well-being, hepatitis B and health promotion activities. It's exciting to have the chance to see what colleagues are doing in these areas and leaves me with plenty of food for thought for my work at HFA! **H**

CALENDAR

Haemophilia Conference 2009

Brisbane 8-11 October 2009

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The Haemophilia Foundation Australia office will be closed over the Christmas/New Year period from Thursday 25 December and will re-open on Monday 5 January 2009. If any assistance is required contact Sharon Caris 0410 419 914.



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Haemophilia Foundation Australia acknowledges the funding and assistance received from the Commonwealth Department of Health and Ageing which makes this publication possible.