

National Haemophilia

Haemophilia Foundation Australia

www.haemophilia.org.au

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2006

HFVA Family Camp	HFNSW Family Camp
Keith Hill Research Project	HFT Family Weekend
HFSA Family Camp	Youth Training Weekend
Australian and New Zealand Physiotherapy Haemophilia Group	Mark Skinner and Miklos Fulop WFH visit to ACT
Australian Haemophilia Nurses' Group	13th National Haemophilia Conference - Tai Chi Workshop
Global Feast	13th National Haemophilia Conference - Remembrance Service
Haemophilia Awareness Week Launch	WFH Congress, Vancouver
HFQ Camp	
HFV Camp	
World Haemophilia Day Afternoon Tea	

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ACCESS TO RECOMBINANT FACTOR VIII AND RECOMBINANT FACTOR IX IN AUSTRALIA

New contracts between suppliers and the National Blood Authority (NBA) for the supply of recombinant and certain plasma products took effect from 1 July 2006. These contracts cover treatment products that are not produced in Australia, but are required for people with haemophilia and other rare clotting disorders. Plasma derived factor VIII and plasma derived factor IX is manufactured in Australia by CSL Bioplasma from blood donated to the Australian Red Cross Blood Service.

The new contracts for the imported recombinant products mean that people with haemophilia A have more treatment product options. This is good news! HFA has advocated to governments that patients and their clinicians should have a real choice of the world's best practice products that are available so they can make a full and informed choice about their treatment. The new contracts mean that many patients believe they now have access to better products in terms of formulation or convenience. In addition to this benefit it is also important to have a range of


products available to guard against any shortages should a supplier not be able to meet NBA orders because of future production or delivery problems. So we are in a better position now in terms of supply security as well.

There are now three recombinant factor VIII (rFVIII) products available for the treatment of haemophilia A to choose from in Australia (Advate®, a third generation rFVIII and Recombinate®, a first generation rFVIII - both manufactured by Baxter; and ReFacto® a second generation rFVIII product manufactured by Wyeth). Wyeth is the only manufacturer worldwide of recombinant factor IX BeneFIX®, for the treatment of factor IX deficiency. Recombinant factor VIIa, NovoSeven®, manufactured by Novo Nordisk, is used in Australia for the treatment of inhibitors to factor VIII and factor IX. Novo Nordisk is the sole manufacturer of recombinant VIIa.

As the NBA now purchases treatment products for use throughout Australia under a cost sharing arrangement with State/Territory governments under the National Blood Agreement,

all products can be supplied. I believe there should no longer be any barrier to patients using their treatment product of choice.

I am aware that some haemophilia centres do not yet offer all options and I believe they should. All patients around the country should have access to the best products for their treatment, and should have the chance to discuss the differences between the products and why each may be more or less suitable.

If you have not already been in contact with your haemophilia centre about your treatment product options I encourage you to do so, to ensure you are using the best product for your needs. 

Gavin Finkelstein is the President of Haemophilia Foundation Australia.



Gavin Finkelstein

FROM THE PRESIDENT

Gavin Finkelstein

I recently presented my Annual Report outlining our achievements for the 2005-2006 year to members and provide extracts of this report below. During the year HFA focused on its four key priority areas:

Advocacy and Representation
Services and Care
Education and Community
Awareness
Research

HFA activities are supported through two Australian Government Department of Health and Ageing grants and donations from individuals, service clubs and corporate supporters. We are grateful for the support of the Department of Health and Ageing for these grants to support our secretariat and some of our objectives and our valuable donors who have assisted HFA with financial donations or non financial forms of support or other expertise. The government funding does not cover the cost of all administration expenses, however, and we need to generate further funds to cover the gap.

We met all reporting requirements during the previous year and held the Annual General Meeting and Council Meeting on 2-3 October 2005. An election of office bearers was held to fill vacant positions on the Executive Board. Council Delegates attended a facilitated workshop on governance during the 2005 Council Meeting. Three face-to-face meetings of the Executive Board in Melbourne, and two teleconferences, were held during the year.

Our Sustaining Patrons' Program was renamed the Corporate Partners' Program during the year to more appropriately reflect our

relationships with the generous donors who participate in this program. HFA established Memorandums of Understandings with each of its Corporate Partners during the year to guide these partnerships and ensure transparency and accountability. HFA has full discretion over the use of all donations. The only directed grants accepted are from trusts and foundations for specific purposes such as camps, workshops and other education programs conducted by State/Territory Foundations around the country.

HFA has worked hard to establish and maintain strong relationships with supporters and stakeholders based upon sound ethical principles and transparency which will withstand public scrutiny. This is supported by internal policies and guidelines to guide our decision making.

HFA is appreciative of the support received from staff and volunteers of State/Territory member Foundations, many of whom have readily donated their time and expertise to assist HFA develop its activities and programs for the bleeding disorders community. It has become increasingly difficult for Foundations to undertake their activities with a diminishing number of volunteers and heavy reliance upon a few, however HFA will continue to work with its member Foundations to develop strategies to make our organisations sustainable, effective and responsive to the needs of our community.

HFA is clearly faced by many significant challenges. We need to rise to the challenges of the needs of our community – this includes our young people, people who are ageing and facing difficulties with joint damage, pain and disability,

and the changing needs of people with blood borne viruses.

We have been able to maintain our efforts in advocacy and representation and our commitment to education and research, and we now have good representation in the processes for ensuring adequate supply of safe and effective treatment products for our community. We have worked strongly with governments and other stakeholders to achieve a good standard of care and treatment for Australians with bleeding disorders.

However there are urgent areas of need where we have not had a significant impact. In particular, we have not been able to adequately meet the needs of some of our community affected by hepatitis C.

The Executive Board has decided to appoint a Policy Officer to help HFA with its strategic planning to meet the health, psychosocial and financial needs of the bleeding disorders community in relation to hepatitis C and other blood borne viruses. The policy officer will also work on other policy issues for our members, including issues such as medical complications of treatment (eg inhibitors), issues for our young people, those who are ageing, the needs of women affected by bleeding disorders, and those with von Willebrand disorder and other rare bleeding disorders.

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It is important that we continue to identify the needs of our community in this way, and develop strategies to meet these needs. We need to anticipate major policy issues which will affect our treatment product safety and supply and we will initiate dialogue as we move forward into 2007.

WORKING WITH OTHERS

HFA has received an increasing number of requests to participate in consultations and support the development of a range of policies which may affect our members. This is an important role for HFA and we aim to respond in a timely manner to requests from government departments and community organisations for representatives and/or information and community views. In particular HFA made several submissions to the National Blood Authority and other areas of government, government review committees, specialist health professionals' organisations and industry throughout the year on treatment product supply and safety issues and consumer health issues.

HFA also liaises with other community organisations and industry organisations on issues of community interest affecting our members including Australian Haemophilia Centre Directors' Organisation (AHCDO), Australian Federation of AIDS Organisations (AFAO), National Association of People Living With HIV/AIDS (NAPWA), Australian Hepatitis Council (AHC), Australasian Society for HIV Medicine (ASHM), Consumers' Health Forum of Australia (CHF) and Medicines Australia (MA).

EDUCATION

Education activities focused on the education of the bleeding disorders community through the national conference, further development of the youth leadership and mentoring program, and the production of education materials and regular newsletters.

We funded several people with bleeding disorders and/or their relatives, staff and health professionals to attend the XXVII WFH Congress in Vancouver in May 2006. This meeting is recognised by all stakeholders as a leading congress for the global bleeding disorders community, and attendance inspires health professionals and community members alike.

The HFA Youth Committee worked strongly and enthusiastically with teleconferences, meetings and conference attendance during the year. The Youth Committee developed a successful youth stream in the main conference program at the national conference in Melbourne. Paul Bonner, Chairman of the Youth Committee, was invited to make a presentation about evolution of the HFA Youth Leadership and Mentoring Program at the Vancouver Congress.

HFA is currently undertaking a review of its printed material, and published quarterly newsletters (*National Haemophilia* and *H.Link*) and other education materials during the year. Website hits and uptake of our extranet facility by health professionals' groups for internal communication and information has increased.

COMMUNITY AWARENESS

We seek to raise awareness about the needs of the bleeding disorders community in Australia and overseas through the national Haemophilia Awareness Week campaign in October, public speaking engagements at service clubs, media interviews and community education campaigns.

World Haemophilia Day was celebrated on 17 April 2006 with a presentation in Sydney on 19 April 2006 by Prof Alison Street on the achievements and challenges for the global haemophilia community.

SERVICES AND CARE

HFA maintained its strong commitment to special projects such as peer support, carers' support,

education, youth development, camps and workshops around the country. These programs are run by State/Territory Foundations for their members in their local community.


We supported the Australian Haemophilia Nurses' Group, Australian and New Zealand Physiotherapy Haemophilia Group and Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group to run during the year. These groups participated strongly in the national conference program.

RESEARCH

\$88,086.45 was allocated towards parts of new and ongoing research projects during the year spanning study topics including: hepatitis C genotype - social and ethical dimensions of genetic testing; balance, strength and related falls risk factors in people with bleeding disorders; thrombin generation (role of hyperfibrinolysis); and clinical predictors of outcome of head injury in children with haemophilia.

INTERNATIONAL DEVELOPMENT

HFA works closely with the World Federation of Hemophilia (WFH) and was delighted that President, Mark Skinner, visited Australia in August 2005 and participated in a round of meetings with government officials and haemophilia community representatives.

Rob Christie, a former HFA President, serves the WFH as Vice President Finance, and Prof Alison Street, Director of the Ronald Sawers Haemophilia Centre in Melbourne, chairs the WFH Medical Committee. Ms Maureen Spilsbury, Senior Social Worker at Queensland Haemophilia Centre, chairs the WFH Psychosocial Committee. Each of these people, and many others, serve the international bleeding disorders community in a voluntary capacity and generously contribute to the improvement of the care of people with bleeding disorders throughout the world, particularly in parts of the world where there is little or no treatment. 

HFA COUNCIL

HFA is governed by a Council of Delegates who are nominated by State/Territory Foundations. Council elects an Executive Board from its number. Current Council Delegates are:

Bill Atkinson, HFNSW

David Bell, HFWA

Rob Christie, HFSA,
HFA Executive Board Member

Gavin Finkelstein, HFWA,
HFA President

Judi Fisher, HFV,
HFA Co-opted Executive
Board Member

Peter Fogarty, HFQ,
HFA Executive Board Member

Beth Large, HFQ

Peter Mathews,
HFNSW and HFA Vice President

Janet Quaggin, HFT

Ann Roberts, HFV,
HFA Treasurer

Chris Wensing, HFACT

Sharyn Wishart, HFSA

SUCCESSFUL DINNER MEETING IN ACT

Almost 40 HFACT members and friends attended a dinner meeting at the Hotel Kurrajong in Canberra in September. Presentations were given by Dr Phillip Crispin (on behalf of Dr Michael Pidcock, haematologist), Simon McMenemy, Chris Wensing and Sharon Caris (HFA Executive Director) on their attendance at the XXVII International Congress of the World Federation of Hemophilia in Vancouver in May 2006.

Dr Crispin's presentation highlighted biotechnical advances, possibly leading to the development of a longer lasting factor VIII. This provides some hope for people with bleeding disorders living in countries without a prophylaxis program.

Messages that Chris Wensing emphasised were:

The continued importance of prophylaxis to avoid or reduce the incidence of major bleeding episodes.

The importance of exercise in prevention of joint damage through strengthening of muscles and joints.

Where joint damage has occurred, surgery may provide a suitable remedy for reducing pain and improving the joints.

The significant differences between countries in the quantity and quality of treatment options for haemophilia.

Simon McMenemy provided some light entertainment with a very personal story of his Congress experience.

Sharon Caris described a presentation at the Congress by Dr Bruce Evatt, WFH, on "The natural evolution of haemophilia care: developing and sustaining comprehensive care globally".



L-R Chris Wensing, Dr Michael Pidcock and Simon McMenemy at the Vancouver Congress

HEPATITIS C PROJECT

Suzanne O'Callaghan



Over the next few months I will be focusing on getting in touch with the bleeding disorders community affected by hepatitis C and finding out what their current needs and priorities are.

I recently joined HFA to take up the new position as Policy Officer. I will be doing a range of policy and project work. An important role is to assist HFA in understanding the needs of the bleeding disorders community affected by hepatitis C and to develop and carry out a plan to deal with these needs.

For some years I managed the Resource Centre at Fairfield Infectious Diseases Hospital in Melbourne and then took up the role as Co-ordinator of the Access Information Centre at The Alfred in Melbourne, which provided information to the Victorian community on HIV, viral hepatitis and

sexually transmissible infections. Most recently I have been employed in the Respecting Patient Choices Program, which helps people to make decisions about their future health care. The Program was based at the Austin Hospital in Melbourne and worked with aged care hostels, nursing homes and palliative care services in Melbourne and also lead hospitals around Australia, so I had the opportunity to get to know first-hand some of the issues for health services as far apart as Hobart and Townsville.

This role is a great opportunity for me to work with the bleeding disorders community around issues that the community has identified as important. I have long been aware that hepatitis C can affect people's lives in a variety of ways and the difficulties for people when they do not have the information they need.

Over the next few months I will be focusing on getting in touch with the bleeding disorders community affected by hepatitis C and finding out what their current needs and priorities are. HFA Council Delegates from the States and Territories have already been involved in a discussion about the

plan at the HFA Council Meeting in October, and I will be working more intensively with the State and Territory Foundations on this. An Advisory Group of experts is also being set up to advise HFA on this project. I am looking forward to having the chance to work more closely with the bleeding disorders community to get the community's perspective on issues, including visits to some States and Territories.

If you have any thoughts about hepatitis C, this is a good time to voice them. Stay in touch with your State/Territory Foundation to hear how to be involved: the plan is to look at the best ways to communicate with the bleeding disorders community (eg informal discussion, focus group), then your Foundation will be able to let you know what options there are for you to have your say. **H**

PLASMA FRACTIONATION REVIEW

Under the Australia-United States Free Trade Agreement, the Australian Government committed to undertake a review of its arrangements for the supply of plasma fractionation services for plasma collected in Australia. The review was to focus on the provision of plasma fractionation services following the collection of plasma donated in Australia, on a voluntary basis, to meet Australian demand for plasma derived products. A Review Committee, chaired by Mr Philip Flood AO, was set up and submissions were heard during 2006. The Review process was scheduled to be completed by 1 January 2007 with a report to be sent to the Federal Minister for Health, the Hon Tony Abbott MHR.

At the time of printing the Review report had not been released, however HFA will advise members of recommendations from the Review when they are publicly available. H

DAWN THORP HAEMOPHILIA NURSES' TRAVEL GRANT

The Dawn Thorp Haemophilia Nurses' Travel Grant was established in 2004 by CSL Bioplasma to support continuous improvement in haemophilia nursing care in Australia and New Zealand. The Travel Grant is valued at AUD\$8,000 and may be shared by one or more applicants to attend international haemophilia related conferences or other education activities.

CSL Bioplasma is soon to announce a funding round. Details will be distributed to members of the Australian Haemophilia Nurses' Group, however further information is available from Michael.Grant@csl.com.au at CSL Bioplasma. H

DAWN THORP

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

ACCESS TO MENTAL HEALTHCARE

Leonie Mudge

If you or a family member has a bleeding disorder life can present more than the usual range of challenges. There may be times when you would like to seek out some formal means of emotional support, either directly for yourself or to help you support someone close to you more effectively. Some examples of things you may seek help for are problems in getting a good night's sleep, depression or anxiety, concerns about dependence on alcohol, or medication, to name just a few.

In each State/Territory the Haemophilia Treatment Centres have counselling or social work support where people with bleeding disorders can access qualified staff for emotional support. These counsellors are knowledgeable about bleeding disorders, cost nothing to access and work in with the other members of the treatment team. It is possible to see them in person, or seek support over the telephone. Some centres also have links to psychologists and psychiatrists who may also be available for psychological support.

However, our community is widespread and for some it may not be practical to travel to seek help within the hospital. From 1 November 2006 new Medicare initiatives were introduced to support GPs to undertake early interventions for their patients with concerns of a psychological nature. GPs have new Medicare items to provide referral pathways to clinical psychologists and other allied health mental health service providers, who are appropriately trained to provide care such as cognitive behaviour therapy, relaxation strategies and interpersonal therapy.

Eligible patients need to be referred to a psychologist, or other health professionals, by their GP, or other doctor such as psychiatrist or paediatrician to obtain the Medicare rebate. The practitioner they are referred to needs to be registered with a Medicare Provider Number.

If you are already seeing a psychologist and they have a Medicare Provider Number, you will need to obtain a referral to them from an appropriate medical practitioner to obtain the rebate.


After the first six sessions your referring doctor will assess your progress. You can generally receive up to 12 individual sessions in a calendar year, or up to 12 group therapy sessions where such services are available and seen as appropriate.

The cost to you will vary depending on whether the psychologist bulk bills or charges over the schedule

fee. It is a good idea to check this out with the practitioner before commencing treatment. If the psychologist charges the schedule fee or above and does not bulk bill then the settlement of the account is your responsibility. You may claim a rebate by lodging a claim through Medicare. Any of your out-of-pocket expenses will count towards the Medicare Safety Net. If you have private health insurance ancillary cover, you may use this method of payment instead of Medicare.

Further information is available from:

Australian Government Department of Health and Ageing:
www.health.gov.au

The Australian Psychological Society:
www.psychology.org.au 

There may be times when you would like to seek out some formal means of emotional support, either directly for yourself or to help you support someone close to you more effectively.

HYDROTHERAPY VS AQUATIC PHYSIOTHERAPY – WHAT’S THE DIFFERENCE?

Gwen Sampson

According to the Collins Dictionary, ‘hydrotherapy’ means ‘the treatment of disease by the external application of water’. The term ‘hydrotherapy’ is derived from the Greek words ‘hydor’ meaning water, and ‘therapeia’ meaning healing. When water was first used for healing purposes is not clear, although it is known that Hippocrates (c 460-375 BC) used hot and cold water (contrast baths) as part of treatment of disease. The Romans used water for recreation and curative purposes and the remains of Roman Baths can be seen in UK and Europe. Little more was heard on this subject until the 17th century when Sir John Floyer, an English physician, published papers on the subject and opened a clinic. Scientific investigation was undertaken in Europe in the 1830’s and a physiological basis was established for ‘hydrotherapy’. Like many other forms of treatment, the use of ‘hydrotherapy’ was treated with suspicion, but it gradually became a recognised form of treatment.

WHAT IS ‘HYDROTHERAPY’?

It is a term that is used widely to include spas, aquarobics, flotation tanks, specialist beauty treatments and even colonic washouts! However, it is generally used to describe exercise therapy in warm water. Hydrotherapy pools are specially designed for rehabilitation and are kept at a temperature of usually between 32-34°C. Heated pools are not specifically designed for hydrotherapy and not as warm, eg up to 28°C. However, it is still possible to exercise using the unique properties of water.

The therapeutic effects of exercise in warm water are many. The warm water helps to relieve pain and induce relaxation; the same effects can be gained from applying a warm compress, but the advantage of the pool is that heat is maintained throughout the exercise leading to less muscle fatigue. The buoyancy of the water supports the body and counter-balances much of the effect of gravity. As a result, the pressure on joints is reduced and greater freedom of movement is permitted. Graded exercise can be achieved by using buoyancy firstly to assist movement, then as a support and finally as a resistance. Further modification can be achieved by using floats or changing speed, thereby creating turbulence which makes the exercise more difficult.

WHAT IS ‘AQUATIC PHYSIOTHERAPY’?

The Australian Physiotherapy Association has defined the specific practice of physiotherapy in water as ‘aquatic physiotherapy’. The physiotherapist performs a comprehensive assessment and uses clinical reasoning skills to develop a treatment program specifically for the person. Regular re-assessment is undertaken and outcome measures recorded in accordance with evidence-based practice.

The aims of aquatic physiotherapy include rehabilitation of the individual, which may require mobilising stiff joints and/or strengthening weak muscles. It can assist in preventing injury, eg strengthening muscles around a joint to reduce the risk of trauma, to prevent deterioration, eg balance, and falls prevention. It can be used alone or in conjunction with other physiotherapy and rehabilitation practices.

WHICH IS BEST FOR ME?

If you are looking to maintain and/or upgrade body strength, flexibility, conditioning and general fitness, then a water exercise program run by exercise professionals may be ideal for you. Most public pools and health clubs provide various levels of aqua fitness activities ranging from ‘Ai Chi’ (Tai Chi in water), aquarobics, water workout, water callisthenics and deep water running, not to mention swimming!

However if you have joints or muscles that have been affected by bleeds, or you want to reduce the risk of injury to specific joints, or even if you want to increase the strength and/or stability of certain areas, please see your haemophilia physiotherapist. He/she can ensure that you obtain the optimum result by prescribing the correct exercises, and through regular review, can progress or modify the exercises appropriately. A program of suitable exercises can also be taught so that you can do them independently. It is important that you keep in regular touch with your haemophilia physiotherapist so that the program can be tailored to your condition.

Remember, your haemophilia physio is always happy to give you advice on the most suitable form of ‘water exercise’ for you. **H**

HAEMOPHILIA AWARENESS WEEK 2006

Natashia Coco

"Busting the Myths" was the theme for 2006 Haemophilia Awareness Week. The week was most successful with 14 print articles and 5 radio spots. Added to this were 12 events and information booths around the States/Territories.

A highlight was a radio spot on ABC Radio National ~ Life Matters program featuring Robert McCabe and Neil Boal. Robert and Neil told their personal stories and busted the myths!!

The week was launched by our patron, Sir Ninian Stephen, and the guest speakers were Neil Boal and Dr Chris Barnes. Over 30 people listened to Neil speak about living with haemophilia and Dr Barnes described current and new haemophilia treatments. H



Busting the myths, bust haemophilia

Roberts, of Moggill, became the first Queensland to receive the first available treatment, cryoprecipitate. Until then he had had more blood transfusions than he could count, a broken hip and both his knees and shoulder replaced.

"In those days we never dreamed of a cure," Mr Roberts said. "All of a sudden my life turned around."

Mr Roberts said before available treatment, he frequently had internal bleeding into joints and muscles. He would often wake up with his knees swollen from blood and unable to walk for months. He now treats the illness with home injections. Visit www.haemophilia.org.au.

Relief ... Erl Roberts.

This week the Haemophilia Foundation of Australia hopes to educate the community and bust a few myths, as part of Haemophilia Awareness Week. Peanuts aside, in 1964 Mr

A bloody good life

Haemophilia facts

THIS week is Haemophilia Awareness Week and it's time to bust a few myths about the blood disorder, organisers say.

The Haemophilia Foundation Australia said the week aimed to educate the community about the disease, which - with the right treatment - was not as life-threatening as many people believed.

Foundation president Gavin Finkelstein said haemophilia is an incurable bleeding disorder caused by the absence or deficiency of essential blood-clotting factors that affected about 1800 boys and babies every year.

But with blood transfusion treatments, the disease was rare, he said.

"Being diagnosed with haemophilia is not a death sentence. It does people with the condition need to be wrapped in cotton wool," Mr Finkelstein said.

"Today, with safe and effective treatment, people with haemophilia work, travel, play

sport and live a normal life." He said the symptoms were usually internal bleeds affecting joints and muscles that were usually caused by injury or trauma.

But they could also occur spontaneously and become life-threatening without medical treatment.

"Treatment is with an infusion of the required clotting factor extracted from blood donations," he said. "Children with haemophilia are taught early to manage regular treatments at home to prevent long-term damage to joints and organs."

Mr Finkelstein said haemophilia affected about one in 10,000 male births globally. Most of these cases were hereditary, but one-third of families affected had no previous history of the disorder.

Haemophilia Awareness Week is from October 8 to 14. For more details, go to www.haemophilia.org.au.



SHENTON Park university student Robert McCabe is living proof that many people can live full lives with serious medical conditions. The 22-year-old, who is in his final year of law at Notre Dame University, lives with medically diagnosed severe haemophilia (an hereditary blood coagulation disorder).

Despite not being able to play Australian Rules football, Mr McCabe said he copes well with the condition.

"I can still do a lot of things," he said. "I like surfing. I probably do not get to do it as much as I would like but that's just more of a time thing."

"The surfing and swimming actually strengthens my joints."

Haemophilia is a disorder in which one of the blood's essential clotting factors, usually Factor 8, is deficient.

There are two main types of haemophilia, Haemophilia A (most common) and Haemophilia B.

The disease almost exclusively affects men but is passed on through female carriers of the defective gene.

While a family history of the disease is common, it is estimated that between one quarter and one third of all occurrences appear in families with no previous history. While haemophilia is a life-long condition, Mr McCabe said part of managing it is weighing up the risk of a 'bleed'.

Most bleeds happen in joints such as the knees and elbows.

"If I want to do something that seems to be a bit risky, I just weigh it (the



Doesn't stop childish fun



Neil uses his experience to raise haemophilia awareness

by Emma Ballingall

Warragul resident Neil Doal is dedicated to improving the lives of Australians living with haemophilia, an incurable bleeding disorder which has affected his life since the age of two.

Neil stepped forward to tell his incredible life story in the hope of raising awareness of haemophilia and its complications in the community during this week's Haemophilia Awareness Week themed "Busting the Myths".

It has not only been haemophilia and its symptoms that have affected Neil's health. He contracted HIV at the age of 22 through an unsafe batch of blood products used to treat his haemophilia, and later contracted hepatitis C through the same means.

"It's ironic that something used to save your life could also threaten it," he has told.

After his battle with HIV and hepatitis C for many years, he told his story whilst lobbying for better and safer treatments. He said the support he has received since he has received since has been fantastic. He said the best part has been the response, or lack of response, from most people he has told.

Haemophilia, caused by the absence or deficiency of the essential blood clotting factors, affects only one in 6000 to 10,000 male births globally including 1800 Australians. One third of people diagnosed with haemophilia have no prior history of the condition.

The symptoms are inter-vening bleeds affecting joints and muscles that are usually caused by injury or trauma. They can also occur spontaneously and without treatment.

"Being diagnosed with haemophilia is not a death sentence. It's not a condition that you need to be wrapped in cotton wool," said Gavin Finkelstein, HFA president and co-founder of the safe and effective treatment.

Neil has also been reported as being one of the genetic disorders most likely to be cured. However, Neil said it will never be totally eradicated.

Neil is currently experiencing good health, though he still experiences pain daily. He has chronic arthritis in both ankles and his right elbow as a result from bleeding in his joints from a young age. He also underwent a total knee replacement at the age of 40.

As a result of haemophilia, Neil is unable to work as a mechanic because treatment often kept him away from the workplace. However, he said all his previous employers were fantastic and very supportive.

He said being unable to work due to haemophilia can open up other illnesses like depression due to constant pain and financial issues.

Neil is currently on top of his HIV and is still responding well to treatment. This is the first year that his daily tablet dosage has been less than 20.

Over the past 12 years Neil has undertaken his health

through the hardships that Neil and those of his generation have suffered. In Neil's childhood, he was unable to play the socially accepted sports of football and cricket and couldn't travel far from the local hospital in case of a bleed which would result in a trip to hospital.

Haemophilia can now be managed through regular self-treatments at home or while travelling, the treatments can prevent long term damage to joints and organs, and advancements in safety equipment and treatments allow youngsters to play most sports.

"It's really opened the door for people to go out and see the world," said Neil.

Haemophilia has also been reported as being one of the genetic disorders most likely to be cured. However, Neil said it will never be totally eradicated.

Neil is currently experiencing good health, though he still experiences pain daily. He has chronic arthritis in both ankles and his right elbow as a result from bleeding in his joints from a young age. He also underwent a total knee replacement at the age of 40.

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Neil is currently on top of his HIV and is still responding well to treatment. This is the first year that his daily tablet dosage has been less than 20.

Over the past 12 years Neil has undertaken his health

could reappear in future. He is feeling much better now he is not constantly tired, lethargic and nauseous.

What do you know about haemophilia?

To raise awareness of haemophilia in the local community, an information session will be held on Monday, October 23 at 7pm in the Scope Building, 12 George Street, Warragul.

The guest speaker on the night will be Royal Children's Hospital haemophilia nurse Janine Furnledge who will talk about haemophilia from a family perspective.

This is a great opportunity to increase awareness of and learn about the current management and treatment, first aid, genetic information and other background.

Supper will be provided by making a gold coin donation.

To RSVP or for further information please contact 0438 212 122.

NEWS

Blood disease no

By LINDSAY MCPHEE

WHEN Claire Fitzgerald's son Kade was diagnosed with haemophilia just before his third birthday, the Mt Hawthorn mother was heartbroken.

Haemophilia is an incurable bleeding disorder caused by a lack of blood clotting factors, although with treatment, most with the condition lead normal lives.

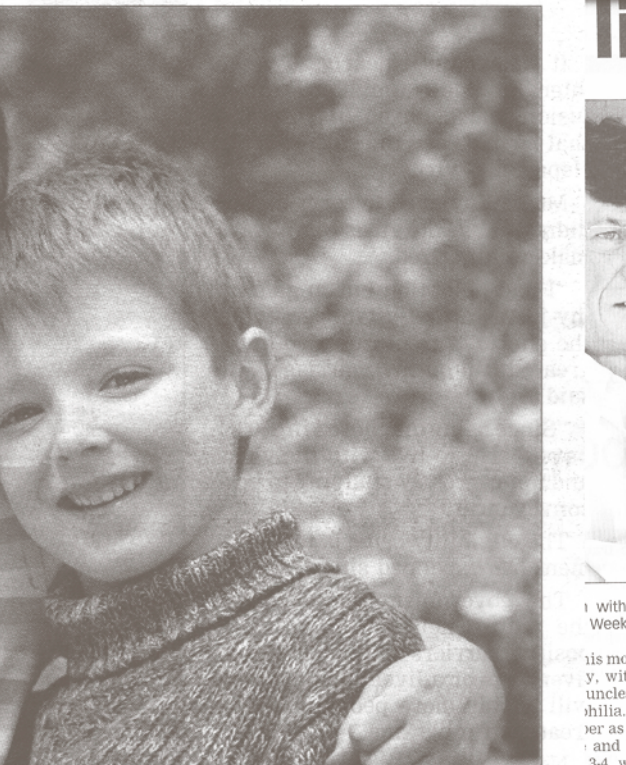
"He was starting to walk and had the odd bruise, but they became more frequent," Ms Fitzgerald said. "He developed haematomas on his ankles and whenever he took a knock to the mouth, the bleeding would take ages to stop."

Several frustrating visits to GPs followed with no answers.



Haemophilia

bruises or spots. Ms Fitzgerald said she thought 'oh my haemophilia, he's dead', but it's nothing just takes long. "Initially, I was



Home with his sister Amy

Normal life ... Strathpine disability support worker and hemophiliac Craig Bardsley does not let his illness affect his life.

Leading by example

By HADLEY TOWELL

STRATHPINE'S Craig Bardsley has not allowed a rare and incurable bleeding disorder to stop him from being a support worker for people with disabilities and mental illnesses.

The 24-year-old hemophiliac is a volunteer youth committee member for Haemophilia Foundation Australia (HFA).

"I really enjoy helping people

Today, with safe and effective treatment, people with hemophilia work, travel, play sport and live a normal life.

and encouraging them to do things they wouldn't normally do because of their illness," he said.

Mr Bardsley, who has a family history of hemophilia, said he

coped very well managing his own illness and did not allow it to stop him from helping others.

HFA president Gavin Finkelstein said being diagnosed with hemophilia should not be seen as a death sentence.

"Today, with safe and effective treatment, people with hemophilia work, travel, play sport and live a normal life," he said.

Visit www.haemophilia.org.au for further information.

Life



With life ... Mike Holloway at the launch of Week.

his mother's side, with three of his uncles also having haemophilia.

As a kid I fell and I was bed-ridden for 3-4 weeks," Mr Holloway said.

He said in his early days he relied on Panadol and ice to soothe the pain in joints and muscles that could simply have been caused by a simple bump or knock through the doorway.

Mr Holloway said there were no real treatments for

You come to live with it and there's worse things in life that are more restrictive.

From page 22

"Now, thankfully, there's numerous blood or lab generated products to treat us but there's still no cure," he said.

Mr Holloway uses Recombinant factor VIII which is made from cells (rather than human plasma) which have been modified so that they produce factor VIII.

Mr Holloway has given up table tennis due to arthritic pain in his elbow.

I got through it all and went home for immediate treatment," Mr Holloway said. "You come to live with it and there's worse things in life that are more restrictive."

Mr Holloway is also a member of 22 years of the Haemophilia Foundation Australia (HFA) which is educating the community and busting a few myths about the rare bleeding disorder during Haemophilia Awareness Week October 8-15.

HAEMOPHILIA Busting the myths

Haemophilia Foundation Australia National Haemophilia Awareness Week 2006 8-14 October

Myth Busters

- Q: How common is haemophilia?
- A: Haemophilia affects approximately one in 6-10,000 males.
- Q: Who gets haemophilia?
- A: Haemophilia is found in all races and all socio-economic groups.
- Q: Are there different types of haemophilia?
- A: Yes. Each "type" refers to the lack of a specific clotting factor.
- Q: Don't people with haemophilia bleed to death?
- A: It is a common myth that people with bleeding disorder will bleed to death if they are cut or scratched. People with haemophilia can find their cuts bleed a little longer than others - but under most conditions they will bleed to death! Actually, internal bleeding is the biggest concern for people with haemophilia.
- Q: Is haemophilia a royal disease?
- A: Haemophilia is not a family disease. Haemophilia is a genetic disease sometimes referred to as the royal disease because several members of the Royal Family were affected by it in the 1800s. In fact, Queen Victoria of

to educate... myths about... d the notion... themselves... death... that they... wear protect... us, which are... it: it is a roy... was a curter... occur in a... ation or a chan...

The following article was submitted by the Australian Haemophilia Nurses' Group. For further information about the group, please contact either of the Co-Chairs – Megan Walsh megan.walsh@alfred.org.au or Helen Starosta rhhpaedonc@dhhs.tas.gov.au.

MEETING OF THE AUSTRALIAN HAEMOPHILIA NURSES' GROUP

The Australian Haemophilia Nurses' Group meeting was held at the HFA office in Melbourne on 7-8 September 2006. The meeting was very well attended with 18 nurses representing Haemophilia Centres from seven Australian states as well as Auckland, New Zealand.

A representative from each centre gave an overview of the structure of their centre and new initiatives or highlights over the preceding year. With many nurses attending for the first time this session was an excellent opportunity to hear about similarities and differences between centres and to discuss varied approaches to common issues.

Megan Walsh described the Alfred Hospital's (Melbourne) approach to the introduction of alternative recombinant Factor VIII products. A display of each product with accompanying consumer information is available in the Alfred Haemophilia Centre waiting area. Some centres have conducted information sessions and others discuss the new products at clinic visits. Many people with haemophilia are choosing to swap to products that deliver their dose in more convenient packaging and volumes.

Nurses who attended the World Federation of Haemophilia Conference in Vancouver earlier this year reported back to the group about their experiences and particular areas of interest including haemophilia resources, transition of haemophilia patients from paediatric to adult centres and communicating information about haemophilia to school and kindergarten teachers.

Presentations were made by invited guest speakers. Dr Paul Denborough, Head of Child and Adolescent Mental Health at the

Alfred Hospital spoke about helping families and adolescents with chronic illness. Dr Stephen Opat, haematologist at the Alfred Hospital, gave an excellent overview of von Willebrand Disorder. John Burns and Geoff Barker from the National Blood Authority (NBA) discussed the role and function of the NBA and administration of the new deed involving supply of recombinant clotting factor concentrates.

Anne Jackson described a recent initiative at Women's and Children's Hospital, Adelaide, that focused on improving information for young adults with haemophilia. One of the outcomes of the initiative was the production of a leaflet for young people living with chronic illness written by an adolescent with haemophilia. This leaflet is entitled "Living with a chronic health problem" and is available on line at http://www.headroom.net.au/lounge/pdf/chronic_text.pdf

Haemophilia Foundation Australia launched an extranet site within the HFA website providing nurses with a forum to post and respond to questions and to share documents and publications within the group.

Acknowledgement and thank you to the following members of the group for their hard work and contribution:

Megan Walsh, Alfred Hospital, for her extensive contribution as a member of the NBA Tender Evaluation Committee. Megan will continue as the adult representative/Co-Chair of the Australian Haemophilia Nurses' Group.

Anne Jackson has completed a two year term as paediatric representative/co chair.

Beryl Zeissink, Royal Brisbane, has stepped down as the nurse

representative on the Haemophilia Foundation Research Committee after many years in the role.

Fiona Rennison, Royal Prince Alfred Hospital, Sydney, continues as the Australasian representative for the World Federation of Hemophilia Nurses.

Welcome to those elected to new positions:

Helen Starosta, Royal Hobart Hospital, new paediatric Co-Chair.

Salena Griffin, Royal Children's Hospital, Brisbane, is now the nurse representative on the Haemophilia Foundation Research Committee.

Fiona Rennison and **Anne Jackson** nominated to provide paediatric and adult representation on the 14th Australian & New Zealand Haemophilia Conference Program Committee (Canberra, 2007).

Thank you to HFA for supporting haemophilia nurses throughout Australia and New Zealand, and providing this opportunity to get together. 

YOUTH LEADERSHIP TRAINING WEEKEND - 12-15 OCTOBER 2006, LAUNCESTON, TASMANIA

Paul Bonner

The Youth Leadership Training weekend was a great success with 21 young people from around Australia attending. A diverse range of people attended with different backgrounds from the bleeding disorders youth community, who all found the weekend to be beneficial.

Workshop sessions on Leadership Skills Development, Public Speaking, Being Active, Taking Care of Yourself, Discrimination and Insurance, were followed by recreation activities which included horse riding and fly fishing. Natasha Coco, HFA Development Manager developed the training program and facilitated most of the weekend.

The weekend stimulated many conversations about haemophilia and von Willebrand disorder and problems associated with it such as, treatment, complications of treatment including hepatitis C, dealing with health professionals, and lifestyle issues such as personal development, travel, sport and recreation. These discussions brought the group together and gave participants a chance to

contribute and learn more about issues they were unfamiliar with or had not considered. Opportunities like this help people to build confidence and communication skills.

It was also important to have input from people with expertise on health issues and relationships and other relevant topics. Penny McCarthy (haemophilia nurse) and Brendan Egan (haemophilia physiotherapist), both from haemophilia centres in Melbourne, and Sharon Caris from HFA added their expertise.

I facilitated the Leadership session. This was the first time that I have done this sort of presentation and feedback was positive. All of the sessions were very informative and covered a wide range of topics that were relevant to the group.

The Youth Camp was held at the same time as the Haemophilia Foundation Tasmania (HFT) Family Camp. Being involved with families was good as it gave everyone the opportunity to meet and get to know each other. For some of the parents with young children, it was even an opportunity for them to learn more about issues for children with bleeding disorders as they grow older.

At a combined session with the youth delegates and the HFT members I gave an overview of the

HFA Youth Committee - how it was started, what we have done, what we are doing, and then added more about what we had achieved over the weekend. I think this was well received as on Sunday I was approached by one of the parents from HFT about how the Youth Committee could help in mentoring and networking with the youth of HFT which I feel was a positive step.

The weekend was successful for the following reasons -

New friendships were made

Existing friendships were reaffirmed

People gained knowledge and skills

People had the opportunity to push their personal limits in a safe environment

Interest in being involved in future activities was shown

Interest in becoming involved with HFA and state foundations was shown

HFA support to the Youth Committee is valuable. If these weekends and the national conferences continue to prove successful, these things could become quite big, which is great for HFA, the state Foundations, and the haemophilia community as a whole. H



WHAT IS THE WFH TWINNING PROGRAM?

Sharon Caris

The World Federation of Hemophilia (WFH) Twinning Program has developed to improve haemophilia care and treatment around the world over many years and now supports 48 twins in 51 countries.

The Hemophilia Organisation Twinning (HOT) Program links haemophilia organisations in developed and developing countries to share knowledge in areas such as patient education, outreach, fundraising, and all aspects of operating a successful haemophilia organisation. Twinning is a positive two-way experience that motivates staff and volunteers, attracts youth involvement, and enables both sides to learn from each other.

The Hemophilia Treatment Centre Twinning (HTC) program pairs treatment centres in developing countries with those in more economically developed countries to help increase the levels of diagnosis and medical attention for people with haemophilia.

In 2005-2006, several of the new twinning partnerships have extended the program into new territories with the inclusion of Cape Verde-Coimbra (Portugal); Guatemala-Colombia; Honduras-Georgia (USA); Tunisia-Quebec (Canada); South Africa-Canada; Shiraz (Iran)-Milan (Italy); Oran/Sidibelabbas (Algeria)-Strasbourg (France); Dharwad (India)-Detroit (USA); Armenia-United Kingdom; San Salvador (El Salvador)-Houston (USA); and Vientiane (Laos)-Brest (France).

The WFH's Global Alliance for Progress (GAP) in Hemophilia project is another component of the WFH initiatives to bring communities together to improve care and treatment. WFH helps GAP countries to develop new national programs for hemophilia care, training, and education. To date, five governments have signed formal agreements with the WFH to increase resources for hemophilia care and the purchase of treatment products in their countries.

In the past three years, over 5,000 patients with hemophilia have been identified through GAP and more than 4,100 haemophilia health care professionals, patients, and families have received training or education.

HFA VISIT TO THAILAND IN NOVEMBER 2006

Gavin Finkelstein (President) and Sharon Caris (Executive Director) represented Haemophilia Foundation Australia at meetings with the National Hemophilia Foundation of Thailand in Bangkok, Thailand, 16-19 November 2006. The visit was planned after a meeting between representatives of each organisation at the Vancouver Congress in May 2006 to discuss the possibility a twinning partnership. The Australian representatives were accompanied by Robert Leung, WFH Program Officer for the Asia Pacific Region.

Thailand is one of the countries participating in the WFH Global Alliance for Progress (GAP) in Hemophilia project and the National Hemophilia Foundation of Thailand was keen to develop its organisation

to strengthen patient participation and its capacity to represent the haemophilia community in Thailand, through the Thai Patients Club.

At the November visit to Thailand, Gavin Finkelstein and Sharon Caris visited the International Hemophilia Training Centre at Ramathibodi Hospital and met with Prof Rajata Rajatanavin, Dean of the Faculty of Medicine and other hospital administrators and health professionals who provide care and treatment to the haemophilia community. Further visits to the Phramongkutklao Hospital and the National Blood Center provided a further understanding of health care services, and haemophilia treatment in Thailand. At a meeting with representatives at the National Health Security Office (NHSO) exciting new initiatives for the allocation of services and care to the haemophilia community were described, including a tour of a busy call centre which services health professionals and patients around the country.

The meeting of the Thai Patients Club was attended by approximately 40 members and was a wonderful opportunity for the Australians to meet members of the community. Many individuals and their families had travelled long distances from the Provinces to attend the Sunday meeting.

At the conclusion of the full meeting schedule and informal discussions, both the Thai Patients Club and HFA were ready to develop an Action

Plan to submit to WFH for formal approval of the proposed twinning partnership. There was agreement from both sides that a formalised twinning relationship would create opportunities for the Thai Patients Club and HFA to share ideas and experiences and learn new skills.

The successful visit was coordinated by hosts Dr Partrapor Isarangkura, Director of the IHTC and President of the National Hemophilia Foundation of Thailand, Dr Monthon Suwannuraks, Department of Dentistry of Ramathibodi Hospital and Ms Srisupha Kaewprapan and Mr Alongkorn Lomaphun, of the Thai Patients Club. A social visit with the hosts and members of the patient community to the ancient site of Ayuthaya provided a wonderful cultural experience and opportunity for more informal communication. HFA representatives were made very welcome by the haemophilia community in Thailand. **H**



MEN AND WOMEN LIVING HETEROSEXUALLY WITH HIV

Leonie Mudge

The research study 'Men and Women Living Heterosexually with HIV: the StraightPoz Study' conducted by the National Centre in HIV Social Research, University of NSW, and the Heterosexual HIV/AIDS Service, Sydney South West Area Health Service, NSW Health, was launched on the 29 November by Dr Roger Garsia, Chair of the NSW Ministerial Advisory Committee on HIV/AIDS and Sexual Health Strategy. Whilst none of the 31 individuals interviewed for this study had haemophilia, the report dealt very sensitively with a myriad of issues relevant to men with haemophilia/HCV and HIV and their families, such as relationships, disclosure and the effects of stigma and secrecy. Dr Garsia is the immunologist who sees several haemophilia patients at the Royal Prince Alfred Hospital (RPAH) in Sydney. In his launch of the study, he paid tribute to the initial group of patients with haemophilia and HIV who he treated at a clinic at RPAH from 1984. He commented that many in the initial group were still living very productive lives, thanks to the new combination therapies introduced from 1996.

I have attempted to summarise some of the insights from the study below.

Whilst many participants described a desire to get on with life, HIV positivity was an ongoing process of negotiation. In this process four modes were prominent:

Adjustment: the most common mode involved a strong emphasis on 'normality', maintaining a positive attitude and not dwelling on it.

Disengagement: partly a result of HIV receding into the background in the absence of any concrete symptoms or daily reminders such as medications. This mode did make participants and couples potentially vulnerable, especially if they disengaged from services.

Constraint: life was dominated by a daily struggle with illness, medications, regular hospital visits, secrecy, isolation and poverty. Alternatively HIV was experienced as a loss of control over life choices.

Defiance: participants refused to let HIV define their life and identity, and were determined not to give in mentally and emotionally.

Participants described the two areas of life in which HIV came most prominently into play, being in disclosure and relationships. Direct experiences of HIV related discrimination were relatively uncommon. They generally kept their HIV status secret and did not expose themselves to potential discrimination.

SECRECY AND DISCLOSURE

Many participants created over time an 'invisible micro ghetto'. This was typically made up of immediate family and/or close friends, but also included primary health workers and other sources of support. Members of the micro ghetto did not all know each other, but were likely to know of each other. Most participants had disclosed only to a chosen few and often only after considerable deliberation and agonising. Reasons for secrecy included fear of rejection, but predominantly concern about the ability of others

to cope with the information and not wanting to worry or burden loved ones, particularly young children and elderly relatives. There was a sense that by confiding in people, they would unfairly force others into secrecy as well. A few had had a bad initial experience from disclosure and resolved never to disclose again.

Several participants emphasised the importance of telling a few well chosen and trusted people. This was seen as important in terms of having someone to talk to, but also to have someone affirm 'that you are still you, and that you are OK'. Disclosure emerged as an ongoing and complex process repeatedly up for negotiation. There were many stories of having to take on the role of supporter, rather than supported. They might feel compelled to withhold information or 'smooth things over' so as not to upset loved ones. Some described a silencing about HIV in their families that arose out of uneasiness or disinterest – an awkward spectre that could be washed away by not acknowledging it.

Some recognised the need for others to talk to somebody, to have an outlet and tried to factor that in when disclosing, negotiating with the person to whom they disclosed who that 'somebody' should be.

Amongst couples, disclosure could be a source of tension. Negative partners often wanted to disclose to more people than did the positive partner, eg one partner said it was hard to explain things to people about not working, not having children, being in hospital – but the positive partner did not want people to pity him.

Social isolation was both a coping mechanism and a consequence of secrecy.

NEGOTIATING INTIMATE RELATIONSHIPS

Participants struggled with the dilemma of whether or not to tell straight away and risk being rejected and also risk gossip, or whether to wait and see if the relationship developed into something more serious and then disclose, in which case rejection could hit harder because of greater emotional investment. If they waited to disclose the partner might get angry about not being told earlier, or they might feel emotionally deceived, opening up irreparable issues of distrust. Some participants emphasised the importance of carefully preparing for disclosure, ensuring that the time and space were safe and appropriate. They made sure they had plenty of HIV related information at hand. They took on the role of educator because the partner might react with a range of emotions or questions and be in need of emotional support.

Many partners emphasised the importance of information and communication in the process of coming to terms with their partner's status. Being invited into the emotional world of their partners was seen as imperative, as was their sense of being legitimate participants in 'living with HIV'.

The report distinguished between 'sero-sharing' couples, and 'sero-silent' couples. In sero-sharing relationships both partners were

engaged in the everyday emotional and practical management of HIV in various ways. In sero-silent couples HIV was much more in the background, and was more common in couples who had not endured illness. Couples who were sexually active were mostly relatively well informed about safer sexual practices. However they used a variety of strategies to manage the tension between sexual risk and sexual desire. Participants were also aware of post-exposure prophylaxis (PEP) although only one couple had used it after an incident when a condom broke.

Positive partner's fear of infecting a negative partner was a much more common theme in the interviews than negative partner's fear of becoming infected. It is possible that this was played down by negative partners out of bravado or a sense of loyalty to their partners.

About regular partner testing, an uncertain serostatus sometimes compelled even partners who were not sexually active to have regular HIV tests.

About reproductive risks, the yearning to have children was more complicated for positive men and negative female partners. Some were exploring reproductive technology such as sperm washing.

The full report can be viewed at: <http://nchsr.arts.unsw.edu.au/pdf/reports/Straightpoz.pdf>

Being invited into the emotional world of their partners was seen as imperative, as was their sense of being legitimate participants in 'living with HIV'

Global Feast 2006



Natashia Coco

Haemophilia Foundation Australia joined other international Haemophilia Foundations - New Zealand, Ireland, United Kingdom, Portugal, Iran, Argentina and Netherlands for Global Feast 2006.

To mark this special event, Haemophilia Foundation Australia organised a sausage sizzle in Melbourne City Square on Friday 6 October 2006. City workers donated \$463.70 towards Global Feast.

Other events hosted around the world were in the UK where a Global Name that Tune night was held, Buenos Aires held a Cocktail Party, Montréal held a Thanksgiving lunch, Tehran hosted a Business Dinner and New Zealand organised a lunch! 



HFT FAMILY WEEKEND

The Haemophilia Foundation Tasmania (HFT) Family Weekend in Launceston on 14-15 October has been pronounced a terrific success by all of the 36 people who attended.

Saturday afternoon kicked off with Dr James Daly (haematologist) and Helen Starosta (haemophilia nurse), both from the Royal Hobart Hospital (RHH), holding an information session on the 'Hobart Treatment Centre'. The session prompted a lively discussion which continued during 'Secrets Men's Business' in the Resort's Bar and at the Forum held with Gavin Finkelstein (HFA President) and Sharon Caris (HFA Executive Director) immediately before dinner. Several issues facing those with bleeding disorders in Tasmania were identified and key areas requiring action were highlighted.

Twelve children aged 2 to 17 attended the weekend and enjoyed a very lively fitball session with Jan Menzies (physiotherapist RHH) on Saturday afternoon and joined members of the Youth Training Weekend for various activities on Sunday morning. Four Tasmanians also participated in the Youth Training Weekend which by all accounts was also a huge success.

On Saturday night we joined members of the Youth Training Group for a gourmet BBQ dinner at the Country Club Resort. A set-top box, kindly donated by weekend participant Ian Lim, was raffled during the night raising \$200 for our funds. It was won by Andrew Richardson, HFT member.

"I just wanted to say thank you very much for the wonderful weekend. We all had an absolute ball and have made some new friends..."

'Secret Women's Business' on Sunday morning was a wonderful opportunity for all the women to get together, share stories, experiences, hopes and fears. Contact details were exchanged and support networks built. Women from the south of the State have decided to get together on a regular basis for friendship and support. Two women from the North and North-West would like to have similar groups, but unfortunately no other families from their areas attended the weekend.

The weekend ended with a leisurely buffet lunch shared with new friends. A thank you letter received a couple of days later summed up the weekend.

"I just wanted to say thank you very much for the wonderful weekend. We all had an absolute ball and have made some new friends. The boys haven't stopped talking about the weekend, the other kids, the parents and of course the villas and casino. I can honestly say that haemophilia isn't as scary now that we have support from other families as well. It was an excellent weekend. Thank you."

Thank you to Haemophilia Foundation Australia for funding and supporting this event. **H**

Photos:[Top to bottom]
Andrew Richardson with Thomas Lim
Saturday Night Dinner
Fitball Session



HEALTH, HAPPINESS AND HEPATITIS C

“I think the most positive thing is that I’m more aware of my body and the benefits of staying at home and mellowing out a bit.”

Maintaining your physical health will help you cope with the symptoms and illness of hepatitis C. Some of the ways to maintain good health include:

- eating a healthy diet
- reducing alcohol consumption
- getting adequate rest
- avoiding or managing stress
- giving up smoking
- regular exercise

Avoiding substances that are harmful to the liver, such as alcohol, is strongly advised. It can be hard adopting new health promoting behaviours straight away – such as reducing alcohol intake. Taking small steps to reduce the amount of alcohol consumed can help the body deal better with the virus.

While there is no direct connection between hepatitis C and cigarette smoking, reducing or quitting smoking cigarettes can also improve a person’s overall health.

Getting vaccinated against other hepatitis viruses is also suggested to avoid further damage to the liver. A doctor can provide information about vaccinations against hepatitis

A and hepatitis B. Talking with a doctor about the impact of other prescription and over-the-counter drugs is also recommended. Some medicines can be harmful to the liver if taken for a long period of time or in high doses.

While there can be benefits in taking alternative and complementary therapies for hepatitis C, some health supplements and dietary vitamins can also cause problems in the liver. Check with your doctor, naturopath or herbalist about any medicines or supplements taken. This will ensure you are getting the best possible care without further harming your liver.

FEELINGS AND FEARS

The feelings and emotions that come with living with hepatitis C infection can add long-term stress to an individual, their family and their community. Thoughts about whether you will be able to continue to work and have financial independence, or the realities of reduced energy levels are issues that people with hepatitis C may have to face.

Being diagnosed with hepatitis C can feel like the end of the world. People react differently to the news, but everyone is affected emotionally one way or another.

You may feel overwhelmed with the amount of information you have been given, or frustrated by a lack of information.

You could also feel angry, confused or depressed. Questions you would perhaps have asked the doctor about the virus or about treatment may have escaped you.

Finding out about your illness may have a numbing effect – where you don’t know how you feel or you may not feel anything at all.

Depression can also be a concern for people with hepatitis C. Sometimes it results from changes in a person’s body caused directly by the virus, while at other times it may be a side-effect of treatment. However it occurs, it is a feeling that should be talked about immediately with a trusted doctor or other health professional.

A fear of death can accompany a diagnosis of hepatitis C. The fear of losing control over your life can be a concern for some people and this can lead to a sense of urgency or panic. Talking to your doctor about the details of liver disease and asking for the facts can be reassuring, as most people with hepatitis C will not die from the infection.

People with hepatitis C may develop a fear of infecting others, which can be an incredible burden on their self-esteem. This fear can lead to isolation from family, friends, partners and society.

SUPPORT GROUPS

Support groups can help you address some of your feelings and fears. Getting support makes you realise you are not alone and can teach new approaches to living with hepatitis C.

Speaking to other people with hepatitis C can make a difference because they will understand some of the feelings. Speaking to a social worker/counsellor can also be helpful. Family members are also welcome to get involved in support groups – this can help the family understand what you are going through. **H**

“I stopped thinking I was a hypochondriac when I met others going through the same thing.”



HEP

The 14th Australian and New Zealand Haemophilia Conference

is to be held at Hyatt Canberra from Thursday 4 October – Sunday 7 October 2007.

Our biennial national 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.

The 2007 conference will include a clinical and psychosocial program, exhibition, concurrent youth program, interactive workshops and a social program.

The multidisciplinary program committee has representatives from all clinical disciplines and community representatives from both Australia and New Zealand for the first time, and is chaired by Dr Scott Dunkley of Royal Prince Alfred Hospital in Sydney.

The program will include presentations on the treatment and care of children and adults with bleeding disorders, those who are ageing, new treatments for people with blood borne viruses, issues in research, and models for psychosocial support and wellness. Sessions will include hot topics in the local and international community, emerging issues for treatment and care, treatment product safety, supply and sustainability, and data and information management.

The theme for the 2007 conference *bleeding disorders ~ achieving success to last a lifetime* has been chosen to reflect the needs of people with bleeding disorders over their lifespan. There will be topics of interest to people with haemophilia, von Willebrand disorder and other rare disorders.

The Canberra location for the conference provides a great opportunity for people to combine the conference with other meetings, or a holiday.

WHO SHOULD COME?

People with haemophilia, von Willebrand disorder or other bleeding disorders and their parents and siblings

Young people – a Youth Stream will be integrated into the program with topics of interest to youth

Health professionals – doctors, nurses, physiotherapists and social workers

Treatment product producers and suppliers

Policy makers and government officials

Haemophilia Foundation volunteers and staff

FAMILIES

Our conference is family friendly and will be helpful for young families as well as people who have lived for many years with bleeding disorders.

YOUTH

Come along and enjoy friendship and fun, and the new opportunities for learning and peer support.

HEALTH PROFESSIONALS

Share information and knowledge and learn about new developments.

SPONSORSHIP

If your organisation wishes to participate in this exciting education event contact HFA to discuss an attractive sponsorship package.


EXHIBITION AREA

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

SUBMIT AN ABSTRACT

A call for Abstracts will be published on the HFA website soon. Register your interest so that we can send you details.

REGISTRATION OF INTEREST

To register your interest and to receive regular updates, email your contact details to hfaust@haemophilia.org.au or call 1800 807 173. 

2007

The 2007 conference will include a clinical and psychosocial program, exhibition, concurrent youth program, interactive workshops and a social program.

Our website will be regularly updated. Registration forms will be available in early 2007 and program details will be published in mid 2007.

Haemophilia Foundation Australia

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

bleeding disorders ~ achieving success to last a lifetime

www.haemophilia.org.au



HAEMOPHILIA FOUNDATION AUSTRALIA

Calendar

4th IAS Conference on HIV Pathogenesis, Treatment and Prevention

Sydney 22-25 July 2007
email info@ias2007.org
web www.ias2007.org

14th National Haemophilia Conference

Canberra 4-7 October 2007
ph 03 9885 7800
fax 03 9885 1800
email hfaust@haemophilia.org.au



XXVIII International Congress of the World Federation of Hemophilia
Istanbul, Turkey, 1-5 June 2008
web www.wfh.org

Corporate Partners

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

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

We are pleased to welcome a new Corporate Partner, Novo Nordisk Pharmaceuticals Pty Ltd.

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CSL Bioplasma
Biotherapies for Life™



Wyeth



Season's Greetings and Best Wishes for the Coming Year

On behalf of the Haemophilia Foundation Australia Council and Staff we wish you a safe and happy festive season.

We thank you for your support during the year and look forward to our work together in 2007.

Sharon Caris

Sharon Caris
Executive Director

Gavin Finkelstein

Gavin Finkelstein
President



HAEMOPHILIA FOUNDATION AUSTRALIA

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